

PARCS Project Final Report – October 2014



Chest
Heart &
Stroke
Scotland



The PARCS project

Person-centred Activities for people with Respiratory, Cardiac and Stroke conditions

Final Report

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INTRODUCTION

In Scotland, people are living longer than ever before. It is the ambition of the Scottish Government and of health charities to ensure that those lives are as healthy as possible, while recognising that more people are living with one or more conditions that impact on their health and quality of life. Services must move with the times and people's circumstances; new ways must be found to reach those in need while keeping costs as low as possible.

It was against this backdrop that, in March 2012, the Scottish Government Health Department invited the partner charities to explore how more and improved generic exercise opportunities could be offered to people with long-term conditions throughout Scotland, in an integrated way. This initiative was driven by the knowledge that keeping active after a diagnosis of a cardiovascular or respiratory condition contributes importantly to both continued good health and continued well-being.

Chest Heart and Stroke Scotland (CHSS), British Lung Foundation (BLF) Scotland and British Heart Foundation (BHF) Scotland, as charities representing large numbers of people who could benefit from exercise, agreed to jointly deliver a project which would point the way ahead, having analysed current provision and ascertained how to enhance services.

This report details the work of that project and is companion to the resource pack which will be produced by the end of 2014, aimed at service planners and managers and service delivery staff, enabling them to provide the highest quality service in their area.

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The PARCS project is testament to the dedication and passion of many people working in partnership for and with communities throughout Scotland.

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SECTION A

RECOMMENDATIONS OF THE PARCS PROJECT

Alignment with Scottish Government policy objectives and improvement programmes

Background

A substantial body of evidence supports the efficacy of physical activity and exercise for people with cardiovascular, respiratory and other conditions in enhancing physical and mental recovery, health and wellbeing, and cognitive function.

These recommendations build on the work undertaken by the partnership of Chest Heart & Stroke Scotland, British Heart Foundation Scotland and British Lung Foundation Scotland, at the request of and with funding provided by the Scottish Government Health Department (SGHD), to identify the extent of generic (multi-condition) exercise-based activities for people in Scotland with cardiovascular disease, respiratory and other long-term conditions; analyse critical success factors and key barriers to engagement, and deliver a strategy to enhance these activities.

The recommendations are based on:

- a comprehensive scoping exercise and extensive consultations with service providers from all parts of Scotland
- a review of provision elsewhere in the UK
- a detailed engagement with service users and non-participants through a commissioned evaluation project.

Scottish Government health policies

The proposals are fully in line with the Quality Strategy emphasis on activity which is person-centred, safe and effective, and with a particular emphasis on collaborative working. They meet precisely the aspiration in the 2020 Vision towards *“integrated health and social care, a focus on prevention, anticipation and supported self-management”*. They address key challenges identified in the Route Map including inequalities and multimorbidity, and support key elements of success such as partnership working, promoting independence, and effective use of resources. Appendix 1 of Section A evidences their alignment with the 3-Step Improvement Framework for Scotland’s public services.

Health Improvement Plans

In terms of the Heart Disease Improvement Plan, the recommendations meet the HD Management and Rehabilitation priority to support patients to live longer, healthier and independent lives, and contribute to other priorities including prevention of coronary heart disease, enhancing mental health, support for people with heart failure, and patient engagement.

Within the Stroke Improvement Plan, they meet the Supporting Self-management and Living with Stroke priority to improve wellbeing and quality of life for people affected by stroke, and contribute to other priorities including secondary prevention and transition to the community.

The proposals also align with the 2014 Multimorbidity Strategy, and with the planned cardiac rehabilitation improvement programme; in particular with the role of the proposed cardiac rehabilitation clinical champion in facilitating self-management programmes for people with heart disease. In terms of physical activity, they support the objectives set out in *Let’s make Scotland more active: a strategy for physical health* (Scottish Government, 2003) and the

Recommendation 1: National service framework

As part of its strategic approach to the prevention and management of cardiovascular, respiratory and other long-term conditions, SGHD should adopt the proposed national service framework for community-based physical activity, and promote this to NHS Boards, Local Authorities, and Health and Social Care Partnerships:

- the adoption of the proposed framework (see Figure 1 below) on a national basis will help address inequalities in current service provision, including inequities in services offered by condition and locality, socio-economic circumstances and ethnicity
- referral to the proposed service framework is designed to facilitate integration with health-based rehabilitation services, including the proposed redesign of cardiac rehabilitation, exercise after stroke and pulmonary rehabilitation services
- referral pathways should also interface with primary care and self-referral routes, ensuring equitable access for all patients
- discharge from the proposed model aligns with and supports current work in tackling multimorbidity and promoting self-management.

Recommendation 2: Local service delivery

The proposed national service framework should to be implemented equitably across Scotland reflecting the diversity of demography, health status and established service infrastructure, but ideally should incorporate the following key elements:

- a person-centred focus based on generic rather than condition-specific approaches, recognising the significance of multimorbidity and long-term conditions
- collaboration and partnership working: effective models of service delivery have been identified for city, urban, rural and remote/islands areas
- a single point of referral to programmes within each Health and Social Care Partnership area
- incorporation of peer and professional support, addressing mental as well as physical health and wellbeing
- telehealth and other innovative approaches, where relevant, to ensure the widest possible accessibility to services.

Recommendation 3: Resources

The following resources should be deployed to facilitate local delivery of the service framework:

- potential use of the Integrated Care Fund to help resource local service improvements
- the PARCS Resource Pack, which offers a range of resource materials to help establish the business case for local services, and deliver and manage services once established (see Figure 2 below)
- a PARCS implementation co-ordinator, to be employed for a two-year period to facilitate local service development through promoting the sharing of good practice, networking and 'buddying' initiatives; working in co-ordination with key staff from the Joint Improvement Team, Multimorbidity Strategy, and the proposed cardiac rehabilitation clinical champion

- to stimulate and kick-start this process, the partner charities and SGHD should arrange a national learning event, to be held after April 2015, to bring together the multi-agency and multi-disciplinary stakeholders involved.

Recommendation 4: Tackling inequalities

Community-based physical activity services should be as widely accessible and inclusive as possible, with a clear person-centred approach and capacity to take services to the person where required:

- services need to be adapted to the needs of all potential beneficiaries, taking account of health status and mobility, socio-economic circumstances, employment status, transport issues, ethnic and cultural diversity
- models of good practice have been identified which demonstrate innovative and replicable approaches to promote inclusion
- linkages should be established with related activities (e.g. the Alliance ALISS programme) to maximise opportunities to 'signpost' access to services, particularly for traditionally difficult-to-reach groups
- the PARCS Resource Pack offers guidance and support to service providers to engage service users and maximise take-up of services offered.

Recommendation 5: Instructor training

A standardised national approach should be adopted for specialist instructor training in Scotland, with one or more academic institutions invited to develop a generic course, integrating and expanding the range of condition-specific courses now offered:

- the sub-group of the PARCS Reference Group which was established to explore this issue should be re-convened and tasked with developing a specification for the proposed course
- this should take into account existing provision of training and levels of qualification, potential registration requirements, quality assurance and cost-effectiveness
- the proposed course(s) should be endorsed by SGHD, and Scottish academic institutions should then be invited to tender for course development and delivery; ideally training should be available on a regional basis.

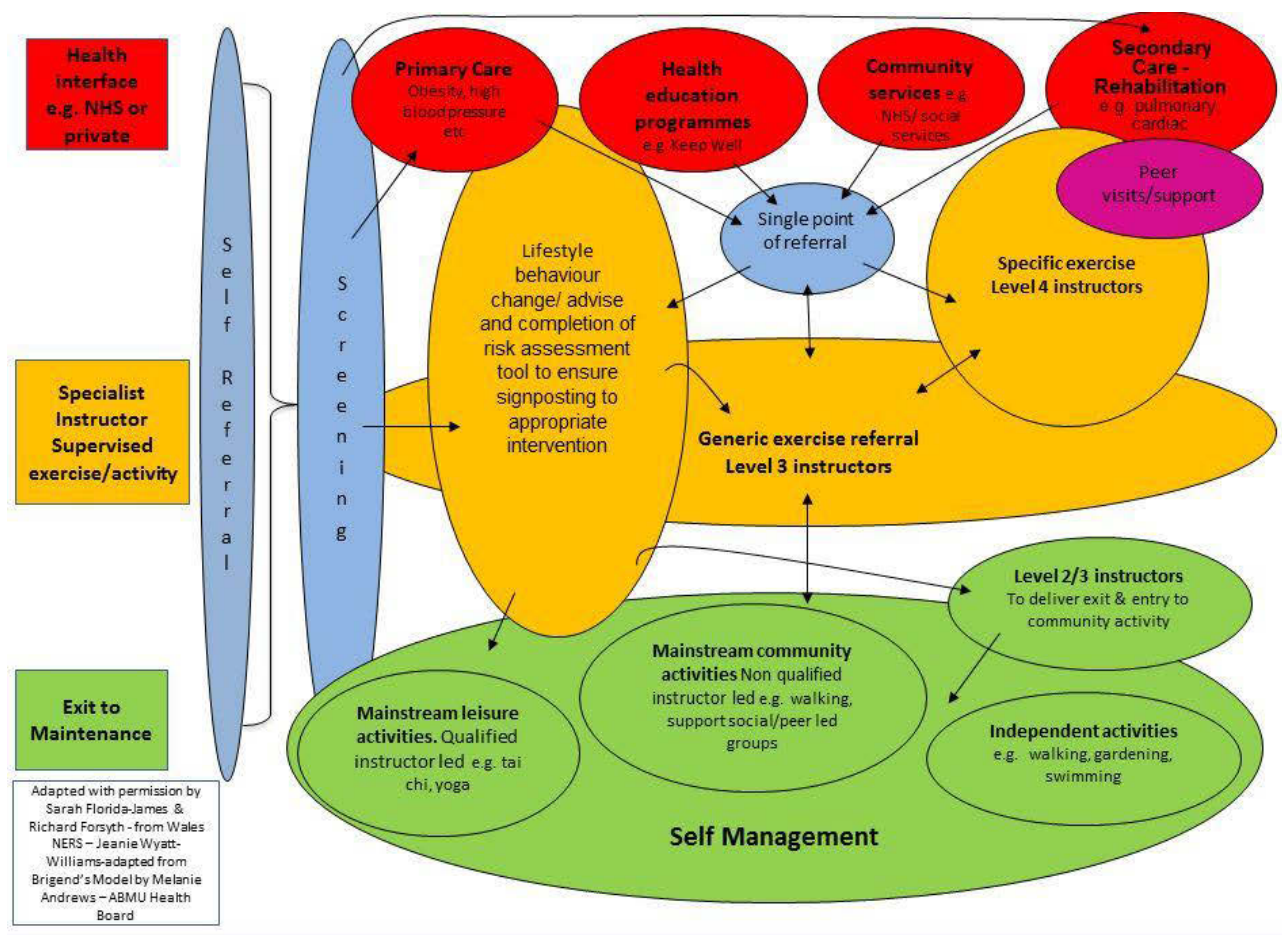
Recommendation 6: Audit and evaluation

A standardised national approach should be taken to data collection, audit, health evaluation and cost-benefit analysis:

- a working group should be established of service managers, health researchers, health economists and ISD to identify an appropriate national dataset, taking into account work in related areas such as cardiac rehabilitation
- issues to be addressed should include: standardisation of outcome data and logistics of data collection by multi-disciplinary and multi-agency staff; ethics, data protection and patient confidentiality; licensing, data ownership, and data linkage (CHI, SCI)
- securing the potential for long-term follow-up is a pre-requisite of any meaningful evaluation of both health and economic benefit, which should also incorporate measures of patient experience
- as services mature, methodologies which facilitate continuous quality improvement through small cycles of change and use of patient-reported outcome measures (PROMs) should be encouraged
- SGHD should consider funding for this exercise.

Figure 1

Proposed national framework for the transition from health to community based activity in the prevention and management of chronic conditions



Basis for the proposed national framework

The proposed framework for Scotland is based on the framework for exercise referral currently in place in Wales, the National Exercise Referral Schemes (NERS). This provides:

- a national approach to training specialist instructors across a variety of conditions
- a standardised single local point of referral, with one national and 22 regional co-ordinators
- standardised pathways and interventions which link with rehabilitation
- a multifaceted model of delivery (including professional and peer support)
- defined exit strategies.

The proposed framework defines the transition from health to community-based physical fitness and activity, rather than operating solely in an exercise referral context. It aligns with the strategic drivers of shift of care to the community, and the integration of health and social care. The framework retains the focus in the Welsh model on a national duty of care for patients/service users and established professional minimum standards, qualifications and training pathways.

Description of the framework

The framework provides a multi-intervention approach, including professional and peer support.

Health Interface tier (red)

Ideally there should be multiple entry points into services:

Health interface: this includes NHS services or private provider equivalent.

All sectors should be addressing lifestyle factors including physical activity either as strategies for primary prevention (screening and identification of individuals at risk) or secondary prevention (for those with established disease).

Primary care: For example, GPs and specialist nurses working largely in the community. In relation to long term conditions (LTC), the regular reviews often scheduled with primary care should be used as opportunities to discuss lifestyle issues including physical activity.

Health Education programmes: such as 'Keep Well'; largely involved in primary prevention.

Community services: both NHS and social services in line with health and social care integration.

Secondary care: involved in the treatment and management of those with ill health including those having falls and LTC, e.g. pulmonary conditions. This includes rehabilitation such as cardiac rehabilitation (CR), stroke rehabilitation/exercise after stroke and pulmonary rehabilitation (PR).

Specialist Instructor Supervised Exercise/Activity tier (amber)

Lifestyle behaviour change/advice and completion of risk assessment tool to ensure signposting to appropriate intervention:

It is helpful to have discussions with service users to support behaviour change and ensure potential risks are addressed. This is an area of particular importance for those with LTC considering undertaking exercise/physical activity, and can be approached in different ways dependent on regional infrastructure. This would ideally be started by HCPs within the health interface tier and be evident throughout the tiers. Some regions offer specific support in relation to this, e.g. lifestyle advisors within primary care and instructors within leisure services offering one-to-one support for behavioural change. This can range from one-off support and referral/signposting to regular follow up throughout a longer period, such as three to twelve months.

Specialist exercise instructors

Approaches to delivery include:

- specialist level 4 instructors working alongside HCPs to deliver rehabilitation programmes, such as cardiac and pulmonary rehabilitation.
- specialist level 3 and 4 instructors delivering physical activity/exercise maintenance classes employed by different providers (e.g. leisure, third sector, private sector) or self-employed, to deliver classes in various community venues.

The Exit to Maintenance tier (green)

This tier encompasses the principles of self management and offers a person-centred approach to delivery including menu-based options:

- Mainstream leisure activities – a wide range of organised physical activities, e.g. yoga, tai chi
- Community activities, e.g. walking, and non-physical activities including social and peer support groups, cultural activities
- Individual activities, e.g. walking, gardening and swimming.

Quality assurance and duty of care within this tier

It is important those referring into these options clarify the differences in insurance and quality assurance, and personal responsibility between the qualified instructor and non-instructor led options, in relation to the standards of supervision and exercise delivery.

Qualified instructor led options: The qualified instructor led options would be delivered by instructors with the specialist skills, knowledge and expertise detailed in the section above. This could include mainstream L2/3 instructors or continuing at specialist L4 instructor dependent on the assessed need of the individual and the service offered in the regions, e.g. some regions offer a specialist L4 instructor (not time-limited).

Non-qualified instructor led: This could include a variety of peer-, volunteer- or carer-led activity. Peers/volunteers could have often undergone training to deliver an activity, e.g. Paths for All Walk leader training, or completed a specific course, e.g. seated exercise, to deliver the respective activity. This is not always the case.

Guidance for service users: All options listed in this tier would ideally include guidance for service users with LTC when they are choosing a group, which may include a disclaimer. This guidance could include:

- a checklist for the person exercising which offers practical guidance when choosing a group
- appropriate details of the group, e.g. whether this is peer or qualified instructor led.

Pathways within the framework

It is intended that there is fluidity and flexibility within the individual's pathway to respond to service user need. In cases of change in condition, for example, this is represented by the double-headed arrows. The pathway is also intended to facilitate ongoing communication between all stakeholders.

Figure 2

PARCS Resource Pack (cover)



PARCS Resource Pack (template page)

Creative service design		INTRODUCTION
<p>There are a number of successful rehabilitation and exercise services that already exist across Scotland which may provide inspiration for those currently developing new delivery models. The examples on the next few pages demonstrate some of the ways in which services have been creatively designed to successfully meet the needs of their users.</p>		PARTICIPANT PATHWAY 4.
<p>USING TECHNOLOGY TO EXTEND THE REACH OF EXERCISE SERVICES The e-Pulmonary Rehab Project</p> <p>The service COPD patients can struggle to access exercise services: just travelling to a session can be exhausting. This project provides COPD patients with a tablet computer pre-loaded with exercises for them to complete at home. The results are relayed back to a physiotherapist who monitors their progress.</p> <p>Evidence of success The project reports improved self-management, and a reduction in unnecessary hospital admissions.</p> <p>Further details [weblink] [email contact]</p>		MODELS OF GOOD PRACTICE 12.
 <p>"Example quote... on the next few pages demonstrate some of the ways in which services have been creative designed to successfully meet the needs."</p> <p>Shirley Clayton XXXXXX XXXXXX</p>		CRITICAL SUCCESS FACTORS 16.
		INNOVATIONS 20.
		ECONOMIC EVALUATION 26.
		BUSINESS CASE TOOLKIT 30.
		INSTRUCTOR TRAINING DOCUMENT 31.
		DRAFT REFERRAL FORMS 35.
		POTENTIAL SCREENING 38.
		LITERATURE REVIEW 39.

Appendix 1

Alignment with The 3-Step Improvement Framework for Scotland's public services (Scottish Government, 2013)

Step 1 – Seven points to ‘change the world’

- **A vision:**
Every person in Scotland who can benefit has access to an exercise/physical activity programme tailored to their individual needs.
- **A story:**
Parts of Scotland already have excellent programmes and there are lessons to be learned from elsewhere in the UK, and most importantly from service users. We need to spread good practice across the country and extend the programme equitably to cover all relevant conditions and all communities.
- **A set of actions:**
 - Working with NHS, Local Authority, Health & Social Care partnerships, Leisure Services, third sector and other partners to identify and overcome barriers to successful local implementation of the strategy
 - Securing early implementation in priority areas
 - Promoting collaboration between local agencies to ensure the spread of good practice
 - Ensuring services are as inclusive as possible, including through promoting telecare, home-based and community approaches, and addressing the needs of people in remote and rural areas, BME communities and disadvantaged areas
 - Working nationally with academic partners to implement a new generic exercise training qualification
 - Working towards establishment of a national audit of activity to help evaluate the effectiveness of the programme.
- **A clear framework for improvement:**
The project sits centrally within the policy framework established by the Quality Strategy and the Route Map to the 2020 Vision. The integration of health and social care through local H&SC Partnerships offers an empowering statutory structure through which its objectives can be delivered. The multi-agency, multi-disciplinary Reference Group established to ‘steer’ the project provides a supportive guidance framework to facilitate delivery. The comprehensive baseline of current service provision (PARCS 1) and the planned national audit will provide a framework for evaluation.
- **A strategy to engage and empower the workforce:**
The PARCS project manager has established a network of health professional and service management contacts throughout Scotland who are enthusiastic about developing their own services locally and collaborating with others to secure broader service improvement. The workforce will be further empowered through implementation of the recommendation in the PARCS 1 Report to rationalise and modernise exercise training.

- **An understanding of how the change will work locally (everywhere):**
Over the last two years, the PARCS project manager has developed an unrivalled knowledge of the range of exercise / physical activity-based services for people with long term conditions across Scotland, the critical success factors and barriers to engagement which influence take-up of services, and the management and governance structures within which they operate. The wider Reference Group (see point below) includes representation from throughout the country and from the range of stakeholders involved.
- **A guiding coalition:**
We already have an established coalition of stakeholders, including health professionals, service managers, third sector organisations, academics, patients and carers who have provided the guidance for the first phase of the project. This Reference Group will continue to offer its experience and expertise to help steer the next phase of work.

Step 2 – Creating the conditions

The PARCS implementation improvement plan meets the criteria set out in Step 2:

- There is a clear, agreed aim, i.e. implementation of the proposed national service framework in line with local needs and circumstances
- Phase 1 of the PARCS project has generated a comprehensive dataset of current provision and local priorities for improvement
- Local change ‘champions’ have been identified who can facilitate improvement in the methods and structures most appropriate for local circumstances
- PARCS phase 1 provides a comprehensive baseline of existing services, while the proposals in phase 2 for standardised audit and evaluation will enable progress to be measured and reported
- PARCS phase 1 provides models of service delivery in different areas (city, urban, rural, remote/islands) which can provide guidance on deployment of staff and financial resources to secure improvement
- The improvement programme will be implemented throughout Scotland.

Step 3 – Making the improvement – aim big – start small

The implementation plan for PARCS is fully compatible with the ‘Act, Plan, Do, Study’ methodology.



The PARCS project

Person-centred Activities for people with Respiratory, Cardiac and Stroke conditions

SECTION B

EXECUTIVE SUMMARIES

- 1. Scoping exercise of current activity in Scotland**
- 2. Review of comparable activity in the rest of the UK**
- 3. Qualitative evaluation report commissioned from Brightpurpose**

1: Scoping exercise of current activity in Scotland

EXECUTIVE SUMMARY

Background

There is strong evidence of the benefits of physical activity (PA) for those with long term conditions (LTC), including cardiac, respiratory and stroke conditions and the effectiveness of rehabilitation. There is evidence from systematic reviews that exercise after stroke improves function; supervised PA/exercise maintenance (EM) after rehabilitation, for chronic obstructive pulmonary disease (COPD), is effective at increasing PA and in the short and medium term improving exercise capacity, and evidence that maintaining PA is beneficial for those with cardiac conditions. However, individuals with these conditions do not achieve PA targets and evidence suggests that after rehabilitation, PA/exercise is not maintained. Qualitative research evidences multiple benefits, barriers and enablers. Optimal PA/EM interventions are likely to include PA/exercise, with self-management and behaviour change supported by professionals and peers.

PARCS Advisory Groups

- 1) PARCS Advisory Group consisted of representation from: Managed Clinical Networks' (MCN) managers, clinical leads: healthcare professionals (HCPs) and MCN Lead Clinician, Leisure Services, NHS Health Scotland, the three charities: Chest Heart & Stroke Scotland (CHSS), British Heart Foundation (BHF) Scotland and British Lung Foundation (BLF) Scotland, and an academic institution (professorial lead). This group advised throughout the lifespan of the project.
- 2) PARCS Advisory Sub Group – this consisted of similar representation with another key academic related to the national body in relation to instructor qualifications and training. This group reached consensus on the recommendations for a framework for delivery and instructor training which was endorsed by the wider PARCS Group.
- 3) Service User Advisory Group, representing all three conditions, cardiac, respiratory and stroke, and differing geographical regions. This group was consulted on issues from a service user perspective.

Scoping

The PARCS scoping evaluated the current service delivery of PA/EM in Scotland, in the community for LTC, focusing on cardiac, respiratory and stroke conditions. The full list of objectives, methods and outcomes/results can be found in Appendix 1 of section C. One key output was the production of overview profiles of current service delivery for the 14 Health Board regions of Scotland.

Methods

The production of the 14 overview profiles involved engaging with multiple stakeholders via surveys to MCNs (n=14), HCPs (n= 274), GPs (n=146), service users (n=221), service providers (mainly leisure) (n= 40), and meetings with a cross section of stakeholders (n=63).

Results

Service delivery, pathways, funding approaches and data collection varied across and often within the 14 Health Board regions. Key issues were:

- service delivery: approaches and systems of delivery and specialist instructor training
- pathways: effective referral and a single point of referral
- economics/impact: including lack of or inconsistent data collection, collation and service/role collating this, and varied approaches to funding. Impact from a service user perspective of attending exercise groups, included achieving physical activity targets, improvement in their condition(s), and benefits of social support/interaction, motivation to exercise, remaining more active and 74% (n=165) reported no admissions to hospitals in the last year. Partnership and collaborative working (incorporating professional and peer support) were evidenced as most effective for service delivery.

Conclusion

Recommendations were made after wider consultation with the PARCS Advisory Groups and Sub Groups and management groups that were based on the findings of all strands of the CHSS, BHF and BLF PARCS partnership project (See Appendix 9). These relate to key issues and include:

- 1) a framework for service delivery
- 2) local service delivery (incorporating key elements: a person centred, multimorbidity/LTC and partnership approach, single point of referral, peer and professional support, innovations and telehealth
- 3) resources to facilitate implementation
- 4) tackling inequalities
- 5) a standardised approach to specialist instructor training
- 6) a standardised approach to audit, evaluation/data collection, to maximise impact and resources

2. Review of comparable activity in the rest of the UK

EXECUTIVE SUMMARY

(a) England and Northern Ireland

Background

During the period of scoping, the NHS in England was undergoing a significant period of transition and restructure. In light of the commissioning process, NHS services had been opened up to competition from providers that meet NHS standards on price, quality and safety. As a result, there was a natural trepidation from services to be transparent and share detailed information on service provision.

As a result of this, community based exercise maintenance services were under increased scrutiny, funding of such projects/programmes was often short term with services asked to morph into a new method of delivery, aligning to an increased number of the local health and wellbeing outcomes/performance indicators.

The report provides an in-depth review of programmes in three counties, highlighting the variance in service provision, inclusion criteria, data collection, outcomes, key successes and challenges.

Although this did not mirror the current NHS climate in Northern Ireland, it was apparent that many services were similarly undergoing redesign. New partnerships had been launched to embrace health and social care integration. The focus of this report was on the Belfast 'Healthwise' programme.

Scoping

Four areas were identified for the purpose of this report. These were Belfast, Brighton, Nottingham (Broxtowe) and Sunderland. The four areas were representative of varying health indicators (risk factor prevalence), long term condition prevalence, socio-economic status and programme/service delivery. The report evidence base was collated both by desk review and direct programme engagement.

Key findings/issues

- Significant variation in programme delivery and remit (both nationally and locally)
- Programmes receive time-limited funding – commissioning process
- Staff retention issues due to short fixed term contracts
- Programmes redesigned to secure funding, not local need
- Participant may receive short term intervention – segmented pathway to supported self-management
- Programme may exclude participants with a long term condition
- Lack of equitable access to programmes for cardiac, stroke and respiratory patients

- Data collected often not aligned to programme aims
- Multiple pathways/referral routes create a barrier for the referrer
- Partnerships vary locally – services/programmes may operate in ‘silo’
- Services in competition with private/third sector partners
- Lack of consistency in instructor training/qualifications.

Conclusion

Due to the nature and duration of the funding, the programmes reviewed struggled to embed themselves as a ‘constant’ in the pathway of supported self-management for participants with a long term condition. The catalyst for service redesign may be to secure additional funding rather than being driven by the need of the local community or in striving for equity of access. Variance in programme provision was expected nationally; however, this was also prevalent at a local authority level where multiple parallel services appeared to operate in silo, making the referral process arduous both for the referrer and participant. Lack of programme continuity and partnership involvement/support may be attributable to reduced levels of participant engagement, adherence and opportunity to long term supported self-management.

(b) Wales

Background

The National Exercise Referral Scheme (NERS) for Wales was developed to standardise exercise referral opportunities for participants across all 22 local authorities. Funded by the Welsh Government and now managed by Public Health Wales, the initial aim of NERS was primary prevention, targeting the inactive population 'at risk' of developing a long term condition. Post 2009, the programme was extended to support participants with a long term condition (LTC), offering two distinct but inter related components: primary and secondary prevention, providing tiered support from point of referral (health interface; primary care, clinical rehabilitation) to mainstream leisure and community activities (self-management).

Scoping

In addition to reviewing the programme on a national basis, four areas (Cardiff, Carmarthenshire, Powys and Vale of Glamorgan) were identified to compare service provision and programme delivery across urban, semi-rural and rural populations. This ranged from 98.3% urban in Cardiff to 13.5% in Powys, representative of the demographic variance across Scotland. The report evidence base was collated both by desk review and programme engagement (national co-ordinator and four regional co-ordinators).

Key findings

- Programme management – national co-ordinator and 22 regional co-ordinators – central point of contact/referral
- Nine standardised national referral pathways (1 primary prevention and 8 LTC including cardiac, stroke and respiratory)
- Standardised data collection tools and methods nationwide
- Instructors qualified and trained to REPS level 4 – national framework for instructor training
- Established partnerships with primary care, secondary care and third sector
- National programme appears flexible to local demographics
- Partnership funding – long term vision
- Participant perceived seamless transition from clinical care to community provision.

Conclusion

Although initially created as a national model of standardised primary prevention (via exercise referral), the programme has evolved to now focus on offering tiered support to participants with a long term condition, establishing clear and recognised referral pathways and processes on a national plane, as well as remaining engaged with the community on a local level. The programme overall is sensitive to local need, condition prevalence, budget and demographics and adapts accordingly.

3. Qualitative evaluation report commissioned from Brightpurpose

EXECUTIVE SUMMARY

During the winter of 2013-14, we carried out a qualitative evaluation with people with cardiac, respiratory and stroke conditions, about their experiences of exercise maintenance. We spoke with people who participate in exercise maintenance activities and those who do not, to find out their experiences of and attitudes towards exercise maintenance and the key factors influencing whether they participated or not.

The key findings of the evaluation were as follows.

The current pathways

Where the pathway from treatment to rehabilitation and onward into exercise maintenance is coherent and seamless, there is a much greater likelihood of sustained engagement in exercise maintenance and/or independent exercise. Some pathways would fit this description, especially those for cardiac and pulmonary patients which are becoming increasingly coherent. However the pathway for stroke patients is variable, fragmented and inconsistent.

Even the pathways which are coherent and seamless are system-centred, rather than person-centred. They require the patient to proceed through a linear process at a consistent pace. For those unable or unwilling to do so, it is difficult to remain on the pathway. Once off the pathway, it is difficult to get back onto it.

Touch points with certain healthcare professionals can have a big influence on a patient's decision to engage with physical activity. These are:

- physiotherapists – during initial therapy sessions whilst still in hospital and during rehabilitation sessions in the community
- clinical nurse specialists – whilst still in hospital
- practice nurses – during routine appointments and chronic disease management clinics

However, negative messages about physical activity from other healthcare professionals can sometimes negate the value of these touch points. The entire multi-disciplinary team needs to promote consistent positive messages about the importance of being physically active to patients, albeit to different levels of depth.

Understanding more about why people engage or not with exercise maintenance

The report examines in detail the main factors influencing engagement with exercise maintenance. We present the highlights below.

Motivations – why do people participate in exercise maintenance?

People are motivated to exercise after diagnosis/treatment because they are convinced of the benefits (usually influenced by a healthcare professional) and want to 'get back to normal'. They see exercising as a way to regain function and independence. Spouses' and partners' influence should not be underestimated either.

People are attracted to exercise maintenance services, as opposed to independent exercise, for the tailoring, supervision and perceived safety it offers, especially if they are new to exercising. They are also drawn to the social aspects of a group class – our evaluation shows that this social aspect is incredibly important in both attracting and retaining people.

Once they are exercising the combined benefits of enjoyment, feeling the physical benefit and social support are the principal factors encouraging people to continue. In addition, class attendance becomes a habit or a routine.

Enablers – how do we make it easy for people to participate in exercise maintenance?

A variety of local, accessible and affordable services, offered at a range of times and on different days is essential. The process of referral and entry to the class is also important: people are more likely to participate if they perceive that they have been referred by a healthcare professional, and if there's been a seamless transition from treatment and/or rehabilitation into exercise maintenance. When exercise maintenance is the next obvious step, people are more likely to take it.

The qualities of the instructor also make a difference. They need to:

- be friendly and approachable
- take time to get to assess new joiners and advise on the right class and/or exercise modifications
- make the classes a lot of fun

Barriers – what stops people participating in exercise maintenance?

Practical issues such as transport, accessibility and cost can be very powerful barriers. These are particularly challenging for people with mobility problems and people on low incomes, although they are not the only people affected. Dark nights in the winter, and general bad weather also act as barriers.

Alongside these practical barriers are the very real psychological barriers of fear and confidence: fear of being the new person in an established group, fear that exercising might be dangerous for their condition, lack of confidence that they will be able to manage the exercises.

Some people have multiple comorbidities which can deter them from taking exercise. Interestingly though, the people we met with comorbidities who did exercise reported feeling generally better after exercise – for example, less joint pain.

Why do people stop participating in exercise maintenance?

Some people stop attending exercise maintenance for a very positive reason: they decide to exercise independently, often progressing to more challenging exercise as they become fitter.

However, other less positive factors can also lead to disengagement. Habit and routine are very important motivators to continue exercise maintenance, so when these are broken for any reason they can be difficult to re-establish. The most common reasons we heard for these broken habits were illness and/or exacerbation of an existing condition. Once the routine is broken, we heard that the psychological barriers to initial participation come back into play. People lose confidence and therefore are fearful of starting again.

Improving provision to enable and maximise engagement

The findings of this evaluation provide some very helpful insights into how provision could be improved to maximise engagement.

Further development of seamless pathways

More work is required to develop a seamless pathway for all conditions, that introduces the concept of physical activity as early as possible in the patient's journey, reinforces positive messages about physical activity at all opportunities and facilitates a seamless transition between each stage of the pathway to minimise disengagement.

The stroke pathway is the one requiring most attention, but the pathways for cardiac and respiratory conditions both need further development too.

Follow-up and safety nets

Whilst the pathway for transitioning into exercise maintenance is a linear one, human beings don't always follow logical and linear paths. They will have different needs and motivations, and will be at different stages of readiness. Therefore the processes supporting the pathway need to become more person-centred:

- if people are not willing or able to engage with the pathway at the first time of offering, there need to be processes to make it easy to engage at a later date
- if people disengage, for reasons other than progression to independent exercise, there need to be processes for following up these people and making it easy for them to re-engage at the right time

Harness the influence of healthcare professionals

Healthcare professionals are very influential upon patients' attitudes about exercise and willingness to engage with exercise maintenance. Therefore all healthcare professionals involved in the patients' journey need to understand the benefits of physical activity, and play their part in encouraging patients and reinforcing their colleagues' positive messages about exercise maintenance.

The role of the third sector

Support groups and other voluntary organisations are in some cases already providing exercise maintenance and/or helping their members access exercise maintenance (for example through providing transport for people with mobility problems). Other groups have an appetite to do so too, but finance is a barrier. These established and trusted groups present a huge opportunity to reach more people with exercise maintenance; our findings indicate that people who would not go to a separate exercise class would participate in exercise maintenance if it was part of their support group meeting.



The PARCS project

Person-centred Activities for people with Respiratory, Cardiac and Stroke conditions

SECTION D

Review of comparable activity elsewhere in the UK

- 1. England and Northern Ireland**
- 2. Wales (National Exercise Referral Scheme)**

The PARCS Project

**Person-centred Activities for people with Respiratory, Cardiac and
Stroke conditions**

SECTION D

Review of comparable activity elsewhere in the UK

1. England and Northern Ireland

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Figure 1- NICHS – Stroke Service User Pathway

Figure 2- Bassetlaw Council – Patient-focused service integration model

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Figure 4- Brighton Generic Service Referral Form

1. Introduction

A scoping exercise of comparable activity across England and Northern Ireland was undertaken between June 2013 and July 2014 to support the development of the overarching PARCS project recommendations.

For the purpose of this report, the following four areas were identified and reviewed: Belfast, Sunderland, Nottingham (Broxtowe) and Brighton. The four areas are representative of varying health indicators (risk factor prevalence), long term condition prevalence, socio-economic status and method of programme delivery. Mirroring the similar scale of variance currently experienced across Scotland provides a more valid and transferable insight.

Detail on each programme was sourced and collated both by desk review and direct programme engagement. The programme review focuses and reports on the following key themes: service provision, inclusion criteria, referral processes, data collection/audit and evaluation, programme funding, staff training/qualifications, key challenges and successes. Additional detail is reported (where applicable) on future service developments, areas of innovation and third sector involvement.

Local and national health policies, frameworks and delivery plans have been cited throughout the report to highlight programme integration, need and, where applicable, impact.

National / Regional Overview

2.1 NATIONAL / DISTRICT PROFILE¹

Country / Area	Total Population	Urban	Rural
North East England	2,596,886	81.6	18.4
Sunderland	275,506		
East Midlands	4,533,222	73.3	26.7
Nottingham	305,680		
South East England	8,634,750	79.6	20.4
Brighton	273,369		
Northern Ireland	1,814,000 ²	63	37³
Belfast (HSCT)	348,204 ⁴		

Figures from the 2011 Census reveal that 8.6% of Sunderland residents deem their health to be bad or very bad, compared to 5.3% in Brighton⁵

In urban areas, the proportion who described their health in general as poor or very poor was almost double (11%) the rate in rural areas (6%)⁶

2.2 HEALTH INDICATORS⁷

Area	% who currently smoke	% who have BMI > 30 (Obese)	% who have had a MI / angina	% who have had a stroke	% who have high blood pressure	% who have high cholesterol
UK	20.6	21.1	1.3	0.8	18.7	26.7
North East England	24.6	22.7	1.6	0.8	19.9	26.2
Sunderland	27.3	23.2	1.7	0.9	19.9	25.5
East Midlands	20.2	21.8	1.5	0.7	19.7	27.1
Broxtowe (Nottingham)	17.9	21.7	1.5	0.7	20.5	27.8
South East England	18.2	20.2	1.2	0.6	18.3	27.3
Brighton	21.6	16.3	1.0	0.5	15.6	24.9
Northern Ireland	21.8	23.0	1.5	0.7	19.5	26.8
Belfast	28.7	23.1	1.5	0.8	18.8	24.9

Inequities in health are avoidable differences in the opportunity to be healthy, and in the risk of illness and premature death which can arise from an unfair distribution of services, resources or power.⁸

¹ England & Wales Census (2011) – Office for National Statistics; - <http://www.ons.gov.uk/ons/rel/census/2011-census/>

² Ireland & Northern Ireland Census 2011 – p9

³ Family Resources Survey – Urban Rural Report 2010/11 – NISRA p2

⁴ Northern Ireland Statistics & Research Agency (NISRA) - <http://www.ninis2.nisra.gov.uk/public/AreaProfileReportViewer.aspx>

⁵ England & Wales Census (2011) – Office for National Statistics; - <http://www.ons.gov.uk/ons/rel/census/2011-census/>

⁶ Health Survey Northern Ireland 2012/2013 – Public health and information research branch, p2

⁷ Acorn (2014) – England and Northern Ireland – Wellbeing Reports – BHF Business Unit (April 2014)

⁸ Putting a health inequalities focus on the Northern Ireland cardiovascular service framework, Health impact assessment, NI Cardiovascular Framework, p15

2.3 STRUCTURED CLINICAL REHABILITATION

2.3.1 CARDIAC⁹

	England	North East	East Midlands	South East	Northern Ireland
Number of Cardiac Rehabilitation Programmes	271	23	23	23	15
Cardiac Rehabilitation Referral Population	122,030 <i>MI 72,774 PCI 35,036 CABG 14,230</i>	8,142 <i>MI 4,945 PCI 2,231 CABG 966</i>	9,665 <i>MI 5,719 PCI 2,957 CABG 989</i>	9,153 <i>MI 5,530 PCI 2,490 CABG 1,133</i>	5,128 <i>MI 2,221 PCI 2,309 CABG 598</i>
Patients Receiving Cardiac Rehabilitation	53,568 <i>MI 33,317 PCI 10,236 CABG 10,015</i>	4,727 <i>MI 3,132 PCI 749 CABG 846</i>	3,909 <i>MI 2,820 PCI 617 CABG 472</i>	4,899 <i>MI 2,792 PCI 1,123 CABG 984</i>	1,942 <i>MI 1,109 PCI 428 CABG 405</i>
% Uptake of Cardiac Rehabilitation	44% <i>MI 46% PCI 29% CABG 70%</i>	58% <i>MI 63% PCI 34% CABG 88%</i>	40% <i>MI 49% PCI 21% CABG 48%</i>	54% <i>MI 50% PCI 45% CABG 87%</i>	38% <i>MI 50% PCI 19% CABG 68%</i>

“The coordinated sum of activities* required to influence favourably the underlying cause of cardiovascular disease, as well as to provide the best possible physical, mental and social conditions, so that the patients may, by their own efforts, preserve or resume optimal functioning in their community and through improved health behaviour, slow or reverse progression of disease”¹⁰

*The BACPR's seven core components for cardiovascular disease prevention and rehabilitation constitute the coordinated sum of activities.

2.3.2 STROKE

	England	Northern Ireland
Estimated Strokes per annum ¹¹	107,300	4,000
Living with the effects of Stroke ¹²	1,083,180	120,000
Stroke Mortality ¹³	40,567 (Female 24,743 / Male 15,824)	1,239 (Female 750 / Male 489)
Patients not receiving a single joint assessment post hospital care ¹⁴	39%	24%
Patients and carers reported problems caused by either poor or non-existent co-working between health and social care providers ¹⁵	48%	59%

⁹ The National Audit of Cardiac Rehabilitation – Annual Statistical Report (2013) 2011-12 Data Set

¹⁰ The BACPR Standards and Core Components for Cardiovascular Disease Prevention and Rehabilitation 2012 (2nd Edition) p2

¹¹ Stroke Association Available at www.stroke.org.uk/news/stroke-facts-and-statistics-your-area

¹² Stroke Association Available at www.stroke.org.uk/news/stroke-facts-and-statistics-your-area

¹³ British Heart Foundation Coronary Heart Disease Statistics 2012, p 20

¹⁴ The Daily Life Survey, Stroke Association, 2011 (patient sample n= 2,050)

¹⁵ Struggling to Recover, Stroke Association, Spring 2012 – reference The Daily Life Survey, 2011

“For people with stroke, who are continuing an exercise programme independently, physiotherapists should supply any necessary information about interventions and adaptations so that where the person is using an exercise provider; the provider can ensure their programme is safe and tailored to their needs and goals”¹⁶

2.3.3 PULMONARY

“Respiratory disease affects one in five people in the UK. It is responsible for around one million hospital admissions and is the third biggest cause of death in the UK”¹⁷

“Around three million people in the UK are estimated to be living with chronic obstructive pulmonary disease (COPD), 2.2 million of whom are undiagnosed”¹⁸

Year	UK Mortality Rates 2001 – 2010 ¹⁹	
	Diseases of the circulatory system per 100,000	Diseases of the respiratory system per 100,000
2001	257.38	78.10
2010	164.19	67.50
% Change - decrease	36.21%	13.57%

Pulmonary rehabilitation audit - Mapping of pulmonary rehabilitation services in England and Wales is currently taking place (**Completion date December 2014**). **Up to June 27th 2014 – approx. 150 pulmonary rehabilitation services had been mapped** (Report is due to be published Feb 2016)²⁰

Seymour, JM et al showed that providing pulmonary rehabilitation after discharge from hospital can reduce readmissions within three months from a third to just 7% of patients.²¹

“People completing pulmonary rehabilitation are provided with an individualised structured, written plan for on-going exercise maintenance”²²

¹⁶ NICE Guideline (CG162) – Stroke Rehabilitation; Long-term rehabilitation after stroke – published June 2013

¹⁷ Report on Enquiry into respiratory deaths, AAPG on respiratory health, p5

¹⁸ Prevalence, diagnosis and relation to tobacco dependence of chronic obstructive pulmonary disease in a nationally representative population sample, Shahab et al, Thorax 2006: 1043-1047.

¹⁹ Report on Enquiry into respiratory deaths, AAPG on respiratory health, p12

²⁰ National COPD Audit programme; Pulmonary Rehabilitation work stream - <https://www.rcplondon.ac.uk/projects/pulmonary-rehabilitation-workstream>

²¹ Outpatient pulmonary rehabilitation following acute exacerbations of COPD. Seymour JM et al. Thorax 2010 May;65(5):423-8

²² Quality Standards for Pulmonary Rehabilitation in adults, BTS, May 2014 – standard 7

3. Exercise Maintenance – Northern Ireland (Belfast)

3.1 Northern Ireland – Contextual Overview

In 2008 the Health Promotion Agency (HPA) commissioned a mapping of all exercise referral services in Northern Ireland. Some of the key points will be noted below and throughout this section. Although this document is now six years old, many of the recommendations presented are still pertinent to the service provision currently being delivered. This research was based on a survey of 370 GP practices (202 responses), 63 Leisure Centre managers (43 responses) and focus groups with regional physical activity co-ordinators.

- The majority (89%) of GP practices promote physical activity during consultations²³.
- However time restraints within the consultation and lack of awareness of service provision were cited as barriers to conveying this message²⁴.

In April 2011, a new initiative was launched – the Active Belfast partnership – with the initial aim of improving levels of participation in health enhancing physical activity. The partnership includes representation from the Public Health Agency, Belfast Health and Social Care Trust and Belfast City Council. To raise awareness of the work being undertaken and have a collective recognition, a city wide logo was created to badge both new and existing programmes.

The Active Belfast strategy has five key objectives: People, Places, Participation, Partnership and Promote – set against the three themes of Active Living, Active Leisure and Active Travel (Active Ageing is currently being developed).

For the purpose of this section of the report, focus will be on the delivery arm of the integrated health and physical activity pathway – „Healthwise” programme.

3.1.1 Programme Background

- **Initial programme focus was primary prevention; to support referred clients currently not meeting the physical activity guidelines who were ‘at risk’ of developing a chronic condition.**
- **Currently the programme is delivered via two pathways:**
 - **Healthwise referral** – 12 week programme offered to all sedentary participants referred via their GP or healthcare professional
 - **Cardiac Phase IV referral** - 12 week programme (with option of additional 12 week maintenance programme) for participants directly referred from cardiac rehabilitation (phase III).

²³ Mapping physical activity referral schemes in Northern Ireland (2008) – Perceptive Insight Market Research prepared for HPA. P8

²⁴ Mapping physical activity referral schemes in Northern Ireland (2008) – Perceptive Insight Market Research prepared for HPA. P9

3.2 Healthwise Referral

3.2.1 Programme Inclusion Criteria:

- Sedentary individual, not currently participating in regular physical activity
- Motivated to complete a 12 week programme of moderate intensity physical activity.
- MUST be considered capable of undertaking physical activity as course of treatment.
- **Suffer from/or at risk of:**
 - Mild - moderate hypertension > 140/90mmhg but < 180/100mm/hg
 - Controlled diabetes or a strong family history
 - Heart disease or risk factors associated with coronary heart disease
 - Anxiety / Stress / Depression
 - Overweight or obese (body mass index (BMI)>25)
 - Asthma, bronchitis or chronic obstructive pulmonary disease (COPD)
 - Osteoporosis
 - Being treated for or having a previous diagnosis of breast cancer
 - Other* (must specify).

*Stroke and TIA participants would be referred into the standard Healthwise programme.

Programme Exclusion Criteria:

- Undertakes regular physical activity
- Uncontrolled hypertension
- Poorly controlled epilepsy
- Unstable angina
- Uncontrolled diabetes
- Cardiomyopathy, unless recommended by a cardiologist
- Severe disease or disability that impairs ability to take part in physical activity
- Less than 12 weeks since a cardiac event
- Under the age of 16
- Within 12 weeks of a cardiac event
- Systemically unwell due to infection or side effects of medical treatment. Must see a medical practitioner prior to clearance for inclusion.

3.2.2 Service provision

- **Programme offered at 9 leisure facilities/healthy living centres across Belfast**
- **Participant 1-1 assessment (see data collection) at Baseline, 6 weeks and 12 week stage**
- **Personalised participant goal and physical activity plan**
- **Access to a variety of independent and group based exercise activities**
- **Minimum of three supervised gym sessions (if applicable)**
- **12 weeks 'free' access to leisure facility (follow on membership can be purchased at a subsidised rate)**
- **Feedback provided to referring healthcare professional upon discharge (see data collection).**

3.3 Phase IV Cardiac Rehabilitation

3.3.1 Programme Inclusion Criteria²⁵ (in line with BACPR guidelines)

- Post Myocardial Infarction
- Acute Coronary Syndrome
- Post revascularisation – Following Coronary Artery Bypass Grafting/Following PCI
- Post-transplant (as deemed appropriate)
- Post valve replacement (as deemed appropriate)
- Stable angina.
- All of these conditions must be clinically stable prior to referral and:
 - Participants must be able to achieve 30 minutes of continuous physical activity without symptoms (cardiac chest pain/discomfort, severe breathlessness, dizziness or palpitations) before being referred
- Participants must have been clinically stable and well in themselves for a minimum of two weeks prior to referral
- Participants must be a minimum of eight weeks from their event or surgery and should have completed a Phase III Cardiac Rehabilitation Programme in order to assess suitability for exercise.

Programme exclusion / refer back to healthcare professional

- Existence of unstable angina (defined as any or all of the following: -
 - Angina occurring at rest
 - New event of angina within the past four weeks
 - Angina occurring more easily on less effort
 - Angina that does not respond so easily to GTN, or fails to respond at all
- Uncontrolled blood pressure where systolic is > 180 mmHg and/or diastolic >100mmHg
- BP drop > 20 mm/Hg demonstrated during Exercise Tolerance Testing
- Resting pulse rate of greater than 100 beats per minute
- Uncontrolled arterial or ventricular arrhythmia
- Unstable or acute heart failure
- Unstable diabetes
- Patient with severe co-morbidity which prevents safe or effective exercise (as assessed by cardiac rehabilitation nurse/physiotherapist)
- Patients with severe psychiatric illness who may endanger themselves or others
- Acute febrile or systemic illness
- Orthopaedic limitations which would prohibit exercise.

3.3.2 Service Provision

- **Programme is offered in 4 leisure centres across Belfast**
- **Participant 1-1 assessment (see data collection) at Baseline, 6 weeks and 12 week stage**
- **Personalised participant goal and physical activity plan**
- **Access to a BACPR qualified instructor circuit based class**

²⁵ Cardiac Rehabilitation Guidelines (2010-2011) – Phase IV Eastern Area, p 6-7

- 12 weeks free access to the classes, with an option for additional 12 weeks continuation class (follow on membership can be purchased at a subsidised rate)
- Feedback provided to referring healthcare professional discharge (see data collection).

3.4 Referral Processes

- 1 standardised referral form for cardiac rehabilitation participants (BACPR template)
- 1 „generic“ exercise referral form for Healthwise programme

	Primary Care	Secondary care	Social Services	Voluntary/ Third Sector	Health Education/ Programmes	Other
Sectors referring to Healthwise & phase IV	Yes	Yes	No	No	No	No

3.5 Audit/Evaluation

DATA	Not collected	Leisure services	CHP	Academic institution	NHS	Other
Referral source data		✓				
Condition breakdown of referrals	✓					
Follow on data		✓				
Cost effectiveness						✓ ²⁶
Drop outs positive or negative		✓				
Person centred data		✓				

3.5.1 Data Collection

SERVICE DATA COLLECTED	Service Total
Total number of referrals	✓
HCST distribution	✓
GP Practice/Referrer	✓
Referral uptake	✓
Adherence	✓
Drop outs	✓

²⁶ Capturing and quantifying social and economics outcomes for Belfast - Commissioned health and social wellbeing programmes, May 2014

PARTICIPANT DATA COLLECTED	Data Collection - Stage			
	Referral	Baseline	6 Weeks	12 Weeks
Gender	✓			
Age	✓			
Demographics	✓			
Ethnicity	✓			
Socioeconomic data	✓			
BMI*	✓	✓	✓	✓
Blood pressure/RHR*	✓	✓	✓	✓
Reason for Referral*	✓			
Past medical history	✓			
Goal Setting*		✓	✓	✓
% Body Fat*		✓	✓	✓
Strength*		✓	✓	✓
Feel Good Index*		✓	✓	✓
Smoking Status*		✓	✓	✓
Flexibility*		✓	✓	✓

***The data collected at baseline, 6 weeks and 12 weeks is collated and forwarded to the referrer. In addition within this reporting mechanism data on number of sessions attended, future exercise plans and personal comments are also included.**

From the 2008 mapping report the incidence of exercise referral schemes providing feedback to the GP/referrer varies; with only 36% of schemes providing this on a regular basis. 18% of schemes claim that the information is not requested by the GP²⁷.

From April 2013 – March 2014 Healthwise received approximately 2200 referrals and over 600 cardiac phase IV referrals. Over 150 cardiac patients are participating in the phase IV and continuation programmes every week.

²⁷ Mapping physical activity referral schemes in Northern Ireland (2008) – Perceptive Insight Market Research prepared for HPA. P28

3.5.2 Social Return on Investment (SROI)

To assess and demonstrate the financial value of the outcomes of the „Healthwise“ programme, the Social Return on Investment methodology was applied.

In addition to the quantitative data collected by the programme at baseline, 6 and 12 weeks, a participant focus group was held to provide a qualitative perspective on the participant journey.

The physical activity services provided through the referral programme generates a social value of approximately **£1:£7** over a five year period. This is based on a Total Present Value (overall social value identified) of £484,697 created against an input of £69,000 over the extrapolated 5 year period, due to the impact being experienced by stakeholders beyond the period the service is delivered.²⁸

3.5.3 Key Recommendations from Active Belfast Commissioned Evaluation²⁹

- **Implementation of the four dimensional model – framework development, measurement, quantifying and communicating impact.**
- **Detailed review of its internal data collection processes.**
- **Explore the possibility of an IT management information system for analysing and collating data.**
- **Consideration should be given to the support required to enable Active Belfast staff to implement these recommendations, in terms of time commitment, skills development and financial resources.**

3.6 Funding

- Programme is funded by the Public Health Agency.
- Operating costs of £69,000 were recorded for the Healthwise programme (financial year 2012/13 at Andersonstown Leisure Centre (one of nine venues)³⁰
- **Programme co-ordinator funded for 3 years, Healthwise staff are on a 12 month rolling contract**
-

“The point was made that, for some, there was a continual process of applying for funding which was distracting from the overall implementation of the scheme. In addition, even where the scheme had been set up and was working well, the next application for funding would have to meet other criteria and therefore it was difficult to continue with the scheme in its current format.”³¹

²⁸ Healthwise Physical Activity Scheme, SROI Pilot Exercise, Gauge NI p 6

²⁹ Capturing and quantifying social and economics outcomes for Belfast - Commissioned health and social wellbeing programmes, May 2014

³⁰ Capturing and quantifying social and economics outcomes for Belfast - Commissioned health and social wellbeing programmes, May 2014 p99

³¹ Mapping physical activity referral schemes in Northern Ireland (2008) – Perceptive Insight Market Research prepared for HPA. P36

3.7 Staffing – Training & Qualifications

- One Programme Co-ordinator
- All Heathwise staff trained to REPS level 2 gym instructor and REPS level 3 Exercise Referral Qualification
- All staff involved in the delivery of Cardiac IV are qualified BACPR level 4.

3.8 Key Successes

- Central programme co-ordinator
 - “Where there is a dedicated central resource for organising referrals the scheme appears to be working better and is more effective. They appear to be more pro-active in informing GPs about the scheme, approaching clients, screening them for their suitability for the scheme, monitoring their progress and in achieving more positive outcomes in terms of keeping clients on the scheme”³².
- Programme accessibility – offered in 9 venues across the HCST
- Established referral pathway and inclusion/exclusion criteria
- Multi agency approach – Active Belfast Partnership
- Positive Social Return on Investment evaluation
- Third sector support groups utilise leisure facilities to meet (integration)

3.9 Key Challenges

- Short term staff funding
- Parallel pathways for Healthwise and Phase IV referrals
- Various schemes / local service provision pilots across Northern Ireland
- Stroke and Respiratory participants offered generic prevention referral service
- Co-ordinating internal and external data collection mechanisms – aligning programme outcomes and performance indicators.

3.10 Participant Satisfaction / Evidence of impact

Outcomes identified both at a „beneficiary“ (increased activity, health and well-being) and „community“ (reduced social isolation) level;

Level of Activity

“Do more at home. Simple things like getting upstairs or carrying something, I feel stronger. Before I hadn’t left home for over a year.”

Social Engagement

“The best things are meeting people; it’s a good laugh and I am enjoying the (fitness and weight) machines”

³² Mapping physical activity referral schemes in Northern Ireland (2008) – Perceptive Insight Market Research prepared for HPA. P37

71% of participants surveyed noted an increase in confidence levels with 92% citing they were more aware of the services available to them.³³

3.11 Future Service Development

- Programme extension piloted a cancer specific pathway – „Small Steady Steps” – positive evaluation.
- Currently developing framework for a similar respiratory pilot – dedicated specialist member of staff – 36 week programme post pulmonary rehabilitation
- Scoping and developing regional plans to support a proposal for a national service provision framework.

3.12 Innovations

There are many innovative pieces of work being undertaken in Belfast and across Northern Ireland, one example of which was the ‘Healthy Hearts in the West’ project;

- Community assets based approach to tackle the underlying risk factors for CVD in West Belfast
- Two-year pilot involving community, voluntary, statutory and private sectors
- Six key objectives identified³⁴
 - Raise awareness about the risk factors contributing to heart disease.
 - Raise awareness about how to achieve a healthy lifestyle through local programmes.
 - Strengthen partnerships between community, statutory, voluntary and private sectors to improve heart health.
 - Improve access to preventative, diagnostic, treatment and rehabilitation services.
 - Promote self-management for those with cardiovascular disease.
 - Create care pathways that enable delivery of integrated services for cardiovascular disease.

One work strand of this project was to offer cardiac rehabilitation in the community and integrate services;

- Delivering phase III cardiac rehab in a community setting elicited a 25% increase in uptake³⁵
- Cardiac nurses were able to directly refer participants to the counsellor and complimentary therapist within the same facility
- Community phase IV classes were also offered within the same facility

³³ Healthwise Physical Activity Scheme, SROI Pilot Exercise, Gauge NI p 9

³⁴ Healthy Hearts in the West Initiative – phase 1 – Evaluation Report (Sept 2013), Public Health Agency and Belfast Local Commissioning group.

³⁵ Healthy Hearts in the West – Two Years in a Nutshell – celebration report p 25

3.13 Third sector involvement

- Active Belfast engage with third sector organisations via steering groups to develop new condition management pathways (e.g. cancer and pulmonary).

Generic Support Groups

- Three Northern Ireland Chest, Heart & Stroke (NICHHS) groups for chest, heart and stroke patients

Respiratory Support Groups

- 21 Northern Ireland Chest, Heart & Stroke (NICHHS) groups
 - five located within Belfast HCST
- Four British Lung Foundation – Breathe Easy Groups in Northern Ireland

Providing: social support, education – self management, healthy lifestyle, links to alternative services, promote continued rehabilitation and campaigning on service provision/redesign.

Cardiac Support Networks

- 22 NICHHS support networks in Northern Ireland
 - four located within Belfast HCST

Stroke Support Schemes

- 21 NICHHS groups nationwide
 - two located within Belfast HCST
- Eight young stroke support groups nationwide
 - two located within Belfast HCST

The Young Stroke Groups have been specifically designed to meet the needs of the younger stroke survivor. The service aims to provide specialised, community based support to improve the recovery of younger survivors of stroke or Transient Ischaemic Attack (TIA).³⁶

Innovation

Moving on Programme³⁷

- Developed in partnership with Southern HCST stroke team
- Six week physiotherapist led community based programme
- Education and exercise based post rehabilitation enablement programme³⁸ - aimed to rebuild participants' lives and confidence

³⁶ Northern Ireland Chest, Heart and Stroke – stroke support services - <http://www.nichs.org.uk/571/young-stroke-schemes>

³⁷ Northern Ireland Chest, Heart and Stroke – Moving On - <http://www.nichs.org.uk/863/moving-on>

³⁸ Appendix Figure 1 – NICHHS service user pathway

4. Exercise Maintenance – England (Sunderland, Nottingham & Brighton)

4.1 England: Contextual Overview

Throughout the scoping activity for this report (June 2013-July 2014), the NHS in England was undergoing a major period of transition and restructure. From April 2013, the core structure of the NHS evolved, with many of the primary care trusts (PCTs) and strategic health authorities (SHAs) being abolished and new organisations such as clinical commissioning groups (CCGs) taking their place.

In addition, local authorities had taken on responsibility for the budgets for public health resulting in a far bigger role to play in terms of service integration. Specifically, health and wellbeing boards have duties to oversee and encourage a more cohesive approach of working between commissioners of services across health, social care and public health.

Boards themselves recognise that that they need to change gear, building on the investment in their development during the shadow year to establish a firm grip on local issues and make a real difference to services and outcome.³⁹

Unfortunately due to this „shifting sands” situation in relation to core services, care pathways and community based service provision, difficulties were encountered to create an evidence base from each core component across the patient journey.

In light of the commissioning process, NHS services have been opened up to competition from providers that meet NHS standards on price, quality and safety as a result there was a natural trepidation from services to be transparent and share detailed information on; rehabilitation pathways, service provision and local evaluation. Moreover, as a consequence of the restructuring process job roles and responsibilities had been amended, staff had new remits, overseeing multi-morbidities thus gaining an insight to historical and current provision was challenging.

As a direct consequence, community based exercise maintenance services were under increased scrutiny, funding of such projects/programmes was short term with services asked to morph into a new method of delivery, aligning to an increased number of the local health and wellbeing outcomes/performance indicators. The programmes/projects detailed throughout this report represents a snap shot of activity – due to the nature of the funding process, few services could predict existence (and in what form) more than 12 months in advance.

Three areas were identified for the purpose of this scoping activity. These were Sunderland, Nottingham (Broxtowe) and Brighton. The three areas were representative of varying health indicators (risk factor prevalence), long term condition prevalence, socio-economic status and programme/service delivery. Providing a review of activity similar to the varying demographics encountered across Scotland. The report evidence base was collated both by desk review and direct programme engagement.

³⁹ Health and Wellbeing boards – One year on. Kings Fund, Ideas that change healthcare, Oct 2013 p2

4.2 Sunderland Exercise Referral and Weight Management

4.2.1 Programme Background

- Commissioned in November 2008
- Exercise referral (ER) component provides opportunities for exercise professionals to play an important role in disease prevention and health promotion, in partnership with medical practitioners and allied health professionals
- Programme aims include⁴⁰ –
 - To provide opportunities for people with underlying medical conditions to become more active.
 - To provide access to safe and effective exercise in a supervised environment.
 - To elicit the co-operation of health care professionals in referring to the programme and to make them aware of the benefits of exercise for certain conditions.
 - To network with community based leisure operations to provide maximum opportunities for patients referred to engage in appropriate physical activity.
- Developed as part of 5 tier obesity agenda
 - Tier 1 - mainstream activity
 - **Tier 2 – Community intervention***
 - **Tier 3 -Specialist Community intervention***
 - Tier 4 – General hospital based rehabilitation (BMI 40+)
 - Tier 5 – Specialist hospital services BMI> 50

*(Exercise referral and weight management scheme)

4.2.2 Programme Inclusion Criteria

- Adults (16 years plus) with a BMI ≥ 28 with no co-morbidities
- Adults (16 years plus) with a BMI ≥ 28 with one or more of the co-morbidities listed below:
 - Osteoporosis
 - Arthritis or joint problems
 - Anxiety, depression or stress
 - Asthma/bronchitis/emphysema/COPD
 - Angina
 - Heart Attack
 - CABG/PCI (completed Phase III)
 - Mild to moderate heart failure
 - Suffered from or are recovering from stroke
 - Claudication
 - Balance problems as a result of Parkinson's Disease, MS etc
 - Awaiting or recovering from surgery (not cardiac)
 - Non acute severe mental illness
 - Family history of heart disease
 - Cholesterol levels consistently over 5 total cholesterol
 - Hypertension (<100 diastolic) for cardiac patients

⁴⁰ SUNDERLAND EXERCISE REFERRAL AND WEIGHT MANAGEMENT PROGRAMME ANNUAL REPORT (April 2011 to March 2012), p2

- Hypertension (<110 for general population)
- All types of diabetes
- Impaired glucose tolerance (IGT)
- Hyperlipidaemia
- Inflammatory bowel disease
- Food intolerances or allergies
- Renal/Liver problems
- Other dietary related problems i.e. Coeliac disease
 - Hyperglycaemia – HbA1C level<10 at last 15 months
 - Stable insulin dépendant diabètes (Type 1)
 - Non stable dépendant diabètes (Type 2)
- **Participants with a BMI <28 with one or more of the co-morbidities listed above can be referred to the Exercise Referral component only**

Programme Exclusion Criteria

- People who have previously been referred
- People who are already exercising on a regular basis
- People under the age of 16 years (see LAF programme)
- People who are not motivated to make lifestyle changes
- People whose mental health or ability to learn would not allow them to participate in the programme
- Those showing symptoms or traits considered absolute contraindications* to exercise i.e. Unstable angina, Unstable to acute heart failure, Specific cardiac problems
- Active myocarditis

*adhering to BACPR exercise contraindications

4.2.3 Service Provision

- Programme offered in 9 sites across Sunderland
- Combination of leisure centres, wellness centres and community venues
- 15 week participant centred programme including baseline consultation, exit assessment and 6 & 12 month follow up contact (see data collection)
- Personalised participant goal and physical activity plan
- 15 week subsidised access to leisure facilities – fitness suite, classes and independent activities
- Exit assessment feedback provided to referring healthcare professional (see data collection)

4.3 Referral Processes

- 1 standardised referral form used for both exercise referral and weight management programmes
 - Additional section to be completed by referrer for participants with CVD / respiratory conditions.

	Primary Care	Secondary care	Social Services	Voluntary/ Third Sector	Health Education/ Programmes	Other
Sectors referring to Exercise / Weight Man	Yes	Yes	No	No	No	Yes*

*community pharmacists – as part of the NHS health check pilot

Self-referral is available for the weight management component only.

29.3% of people with COPD and Medical Research Council (MRC) Dyspnoea scale ≥ 3 were referred to a pulmonary rehabilitation programme. (target referral rate of 22.3% 2013/14)⁴¹

4.4 Audit/Evaluation

DATA	Not collected	Leisure services	CHP	Academic institution	NHS	Other
Referral source data		✓				
Condition breakdown of referrals		✓				
Follow on data		✓				
Cost effectiveness	✓					
Drop outs positive or negative		✓				
Person centred data		✓				

- **From Apr 2011 – Mar 2012 – 3112 were received**
 - **Of which 2084 (67.0%) booked an initial assessment**
 - **Of which 1957 (93.9%) attended the initial assessment**
- **Adherence – of the 1957 participants attending the initial assessment – 858 (43.8%) completed the 15 weeks, with a further 214 (10.9%) becoming independently active prior to the 15 week assessment.**
- **Across all facilities and activities – 56,617 attendances were recorded.**

⁴¹ NHS Sunderland Clinical Commissioning Group (CCG) Annual Report and Accounts 2013/14, p21

Condition specific data (of the 3112 referrals)

- 335 (10.8%) had cardiac conditions (Angina, MI, CABG & CHF)
- 137 (4.4%) had respiratory problems (excluding asthma)
- 71 (2.3%) had a previous stroke

4.5 Data Collection

PARTICIPANT DATA COLLECTED	Data Collection - Stage				
	Referral	Baseline	15 Weeks	6 Months	12 Months
Gender	✓				
Age	✓				
Demographics	✓				
Ethnicity	✓				
Socioeconomic data	✓				
BMI*	✓	✓	✓		
Waist Circumference*	✓	✓	✓		
Blood pressure/RHR*	✓				
Reason for Referral	✓				
Past medical history		✓	✓		
Goal Setting*		✓	✓	✓	✓
% Body Fat*		✓	✓		
Strength*		✓	✓		
GHQ-12*		✓	✓	✓	✓
Smoking Status*		✓	✓	✓	✓
Peak Flow*		✓	✓		

*The data collected at baseline and 15 weeks is collated and forwarded to the referrer.

4.6 Funding

- **The programme is jointly funded by the NHS and joint local authority**

4.7 Staff – training and qualifications

- 1 WTE Programme team leader
- 10 WTE exercise referral consultants
 - **Minimum qualifications REPS Level 3 advanced gym instructor and REPS Level 3 Exercise referral qualification**
 - **All staff also REPS Level 4 Obesity and diabetes management trained**
 - **Staff directly supporting cardiac/high risk referrals – BACPR level 4 qualified**
- 2 WTE programme administrators

4.8 Key Successes

- Central programme co-ordinator
- Programme accessibility – assessments offered in 9 venues across the city – leisure, wellbeing centres and community venues
- Established referral pathway and inclusion/exclusion criteria
- Multi agency approach – overarching steering group includes health, leisure and rehabilitation leads.
- 100% of GP practices in Sunderland refer to the service
- Administrative support to assist with communication plans and data collection/analysis
- One standardised referral form for both services
- Direct link with cardiac and pulmonary rehabilitation and community stroke physiotherapists
- Strong links with voluntary sector – cardiac support groups meet within leisure facility – service signposts to support groups

4.9 Key Challenges

- Delivery staff on a 12 month rolling contract
- Exercise referral scheme badged with weight management service
- Time limited intervention (15 weeks)
- Performance indicators heavily biased towards weight loss/maintenance
- Staff funding split by NHS and joint local authority – each funder requests staff specific statistics
- Limited activity options for participants with reduced functional capacity
- Service variance – different schemes operate across the north east – can be confusing for the referrer

4.10 Participant Satisfaction / Evidence of Impact

- At the 6 and 12 month follow up stage – 80% felt their health and well-being had improved.

“This service is great for people with a health condition who would benefit from a more active lifestyle. It offers personalised exercise advice and guidance by an experienced team of health and fitness professionals resulting in an activity programme which is safe and appropriate for the individual.”⁴²

Practice Manager

- **63% of participants had maintained their levels of physical activity at the 12 month stage.**

“This programme has changed my life for the better, and everyone with any health complications should be given the opportunity to try this”

Male participant, 64

4.11 Future Service Developments

- Improve links with pulmonary rehabilitation and explore feasibility to train staff in level 4 certificate Exercise Training for Chronic Respiratory Disease.
- Amend the assessment protocol and personalise the consultation time to meet the needs of the participant
- Develop and launch pilot stroke programme
- Data collection: aligning performance indicators to participant goals (reduce bias towards weight loss/maintenance)
- Explore the opportunity of a generic rehabilitation class, based on participant's level of functional capacity – project shadowing GGC model

4.12 Third Sector Involvement

- **Service recognition**
 - The Sunderland Stroke Community Rehab team were awarded most improved stroke service 2011 by the Stroke Association. Helping to reduce average length inpatient length of stay from 30.3 days to 12.5 days. Moreover establishing a seven day service for early supported discharge and community service⁴³.
- **British Lung Foundation – 1 group based in Sunderland**
 - **Meets monthly – facilitated by members offering a network of support, education and advice, links to patient services, activities and social excursions.**

⁴² SUNDERLAND EXERCISE REFERRAL AND WEIGHT MANAGEMENT PROGRAMME ANNUAL REPORT (April 2011 to March 2012), p34

⁴³ Stroke Association website - <http://www.stroke.org.uk/involved/most-improved-stroke-service-sunderland-community-rehab-team>

- **British Heart Foundation affiliated cardiac support groups**
 - **12 based in the North-East, 2 located in Sunderland**

“Run by former heart patients for the support of heart patients and their carers”

- Founded in 1993 by six heart patients (currently 179 members on their database)
- In addition to social support activities, the cardiac support group runs 6 exercise sessions per week. Each session is led by two IV BACPR instructors
- Format: standard multi station circuit class
- Direct exit strategy from phase III, BACPR referral form template adopted
- Established peer support links with phase III, support group members attend phase III sessions monthly to promote service
- Exercise sessions cost £2 – annual group membership is £2
- Average class attendance is 20 members
- Sessions offered in local leisure centres – good links with exercise referral scheme – cross signposting (if applicable)
- 75% active members are female
- Additional activities include group walks (April – October) and monthly social gatherings
- Key challenges;
 - Raising funds to maintain level of service (entirely self-funded)
 - Keeping participant costs to a minimum
 - Appearing an attractive option for younger cardiac patients
 - Recruiting volunteers to become trustees / board members

“I am certain it does me good and helps keep the heart healthy. Everyone who attends enjoys the exercise as well as the social aspect of meeting friends once or twice a week, especially as a lot of our members live alone”

Sunderland Cardiac Group, Service User

- **Stroke Association Support Groups**
 - Offer community integration services – return to work and peer support sessions
 - Family care support services – patient / carer transport, benefit support information
 - No exercise session delivery, work closely with local health trainers and signpost accordingly. Keen not to duplicate services

5.1 Nottingham Exercise Maintenance Services – (Broxtowe)

5.1.1 Programme Background

- **Broxtowe is one of seven borough/county councils in Nottinghamshire – each of which has its own independent exercise maintenance service and protocol**
- Exercise maintenance services in Broxtowe are delivered in partnership with Broxtowe Borough Council and NHS Nottinghamshire County
- Post 2010 the service sits under the sports development department of Broxtowe Borough Council
- Exercise maintenance is delivered via three core services;
 - Exercise Referral Scheme
 - Cardiac Rehabilitation (Heartbeats)
 - Strokeability sessions (time limited funding 2 x 12 week blocks)
- Current service protocol due to be re-commissioned post August 2014
 - Initial funding period only extended by 5 months (Apr-Aug 14)
- Exercise Referral aim;
 - Help people to improve their health by becoming more active. Exercise Referral is available to people who suffer from or are at risk of certain diseases that would benefit from physical activity.
- Cardiac Rehabilitation (Heartbeats);
 - Is a network of exercise sessions throughout Broxtowe, suitable for people with diagnosed heart problems who would like to be more active.
- Strokeability Sessions;
 - Programme specifically designed for people who have had a stroke encouraging them to become more active.

5.1.2 Programme Inclusion Criteria (Exercise Referral)

- **Over the age of 16, currently active and have at least one of the following;**
 - Family history of heart disease
 - High cholesterol levels (consistently above 5.2 total cholesterol)
 - Obesity/Overweight (BMI >27)
 - Hypertension (140/90 to 179/99 mmHg)
 - Waist circumference measurement above: Male: 102cm (40 inches) Female: 88cm (35 inches)
 - Treated Type 1 or 2 Diabetes Mellitus
 - Controlled Asthma
 - Mild to moderate rheumatoid arthritis or osteoarthritis
 - Mild to moderate COPD
 - Mild to moderate depression, stress or anxiety.
- **Exclusion Criteria**
 - Angina pectoris
 - Uncontrolled hypertension (regular readings over 180/100)
 - Severe Peripheral vascular disease
 - Paroxysmal arrhythmias

- Recent cardiac event (e.g. MI or Cardiac Surgery) but no current angina
- Poorly controlled or brittle insulin dependent diabetes (type 1, or 2 on insulin)
- Severe or poorly controlled asthma
- Severe chronic pulmonary disease
- Chronic muscle, joint or bone conditions that greatly impede mobility or require physiotherapist treatment
- Unstable or severe mental health state
- Patients who in the Healthcare Professionals opinion are not medically fit to undertake an exercise programme, due to other conditions.

- **Cardiac Rehabilitation Inclusion Criteria (Heartbeats)**

- Myocardial Infarction
- Percutaneous Coronary Intervention
- Coronary Artery Bypass Grafting
- Aortic or Mitral Valve Replacement or repair
- Stable Angina
- Heart Transplant
- Heart Failure
- Cardiomyopathy
- Arrhythmia and or implantable devices

Patients must also be:

- Clinically stable prior to the event
- Motivated to attend the sessions
- Able to exercise independently and safely

Exclusion Criteria

- Those showing symptoms or traits considered absolute contraindications* to exercise i.e. unstable angina, unstable to acute heart failure, specific cardiac problems

*adhering to BACPR exercise contraindications

5.2 Service Provision

Exercise Referral Scheme

- Programme offered in 3 leisure centre venues across the borough
- 12 weeks subsidised access to a wide variety of leisure activities
- 12 week participant centred programme including baseline consultation and exit assessment (see data collection)
- Personalised participant goal and physical activity plan
- Additional activities available via the sports development team

Cardiac Rehabilitation (Heartbeats)

- Programme offered in 3 leisure centre venues across the borough
- 6 sessions in total offered weekly
- 3 supervised gym sessions / 3 circuit based classes
- Each session duration – 90 minutes
- Initial 1-1 assessment undertaken prior to exercise participation
- On-going assessment by qualified instructor of participant readiness to attend mainstream activities (after a minimum of 8 attendances)
- Access to Heartbeats programme up to a maximum of 6 months
- Subsidised access during this period

Strokeability Sessions

- Not currently being offered in Broxtowe but available in two of the other Nottinghamshire boroughs*.
- When operational the programme consisted of a time limited 12 week programme of one session per week (60 mins) followed by an education session
- Sessions were open to both the participant and their carer

*Ashfield and Newark boroughs offer Strokeability sessions on a continual basis, each area has a different criteria and cost structure. Cost is generally reduced for the first 10 weeks then increases thereafter.

5.3 Referral Processes

- 1 standardised referral form for cardiac rehabilitation participants (BACPR template)
- 1 „generic“ exercise referral form for programme

	Primary Care	Secondary care	Social Services	Voluntary/ Third Sector	Health Education/ Programmes	Other
Sectors referring to Exercise Referral & Heartbeats	Yes	Yes	Yes*	No	No	No

*Adult and Social care services can refer into the exercise referral scheme only.

A neighboring exercise referral service in Bassetlaw produced a patient focused model for exercise on referral – ‘People who can make it happen!’⁴⁴

⁴⁴ Bassetlaw District Council – Exercise Referral Guide – model depicted in Appendices – figure2

5.4 Audit/Evaluation

DATA	Not collected	Leisure services	CHP	Academic institution	NHS	Other
Referral source data		✓				
Condition breakdown of referrals		✓*				
Follow on data		✓				
Cost effectiveness	✓					
Drop outs positive or negative		✓				
Person centred data		✓				

***only a selected number (9) of conditions / reasons for referral can be identified**

Exercise Referral Scheme

- **Target of 500 referrals per annum**
- From Apr 2012 – Mar 2013 – 492 referrals were received
 - Of which 346 (70.3%) started the programme
 - 82.9% of referrals were from primary care with only 6.5% coming directly from a rehabilitation service (not specified)
- Adherence – of the 346 participants starting the programme – 154 (44.5%) completed the 12 weeks.

Heartbeats Cardiac Rehabilitation

- From Apr 2012 – Mar 2013 – 80 new referrals were received
- Due to the flexible nature of the service – adherence is difficult to quantify

“Key ambitions for the people of Nottinghamshire – a good start, living well, coping well and working together” ⁴⁵

Two of the key operating priorities in relation to the above are:

- support people with long-term conditions
- support older people to be independent, safe and well

⁴⁵ Our strategy for health and wellbeing in Nottinghamshire, 2014-2017, Nottinghamshire County Council p3

5.5 Data Collection

PARTICIPANT DATA COLLECTED	Data Collection - Stage		
	Referral	Baseline	12 Weeks
Gender	✓		
Age	✓		
Demographics	✓		
Ethnicity	✓		
Socioeconomic data	✓		
Referral Source	✓		
BMI	✓	✓	✓
Blood pressure/RHR	✓	✓	✓
Reason for Referral	✓		
Past medical history	✓		
Goal Setting*		✓	✓
Stage of Change		✓	✓
Physical Activity (category)		✓	✓
EQ-5D		✓	✓

Quarterly and annual reports detailing the above data fields are submitted by the service to the commissioning manager for review.

5.6 Funding

- The service is currently jointly funded by NHS and Joint Local Authority (up to August 2014)
- During the period of scoping Nottingham County Council were undertaking a consultation process with current providers and will be going out to tender for a new County wide weight management service in Nottinghamshire from August 2014.
- Moving forward - weight management services include Exercise Referral, pulmonary rehab and the nutrition and dietetics teams.
- It was estimated that funding had to be secured at a minimum level of £36,600 to ensure continuation of the exercise referral scheme beyond Apr 2014.⁴⁶

⁴⁶ Bringing People Together Delivery Plan, Broxtowe Council, p22

- **The cardiac rehabilitation (Heartbeats) programme receives no external funding; the service is self-funded via the leisure centres with participants paying £4.40 per session (opposed to £2.35-£2.80 for exercise referral sessions)**

5.7 Staff – training and qualifications

- All staff are qualified to REPS Level 3 – Exercise Referral
- Heartbeats staff (n=3) in addition are BACPR level 4 qualified

5.8 Key Successes

- Established referral pathway and inclusion criteria
- Standardised exercise referral and cardiac rehabilitation forms
- Structured data reporting procedure between service provider and commissioner
- Wide variety of activities available to referred participants due to service sitting within local authority sports development department (e.g. walking football, walking netball, walk and talk)
- Clear exit strategy from Heartbeats programme into mainstream activity – selection of activities available post phase IV
- Continued subsidised access for exercise referral participants post 12 week programme
- Good links with referring clinical rehabilitation services

5.9 Key Challenges

- Short term service funding – re-commissioning of services
- Staff turnover due to uncertainty of programme sustainability
- Programme variance - alternative programmes (7) being offered in each neighbouring borough/council
- Short term pilot sessions for condition specific groups – e.g. strokeability sessions
- Time limited programme for both exercise referral and „Heartbeat“ participants
- Performance indicators not necessarily aligned with programme aims
- Stroke and respiratory patients referred into mainstream exercise referral service
- Programmes only offered in a leisure/sports facility

5.10 Participant Satisfaction / Evidence of Impact

- **Feedback from the Strokeability sessions**

“Really enjoyed the class and meeting new people”

“I really enjoyed the classes and it has helped with my condition”

“The class has given me the motivation to try things instead of just sitting at home”

- As noted previously, data collection methods/analysis appears to focus on programme attendance, weight loss and demographic subgroups. No direct indicators of impact on health (stroke, cardiac and respiratory specific).
- **Evaluation of the ‘Heart Fit’ phase IV programme in Newark, Nottinghamshire by University of Lincoln noted;**

Using a process of thematic analysis, participants revealed six main themes as being important factors during the 12-week programme. These included the instructor’s influence, the social nature of the group, the availability of clinical observation, psychological development and the perceived beneficial physical improvements made.

Future phase IV cardiac rehabilitation programmes need to gain a greater insight into the patient experience. This will enable health planners and policy makers to generate a sense of context on how these programmes operate at local levels and develop models of best-practice⁴⁷.

5.11 Future Service Development

- Limited due to the uncertainty of programme funding and sustainability (applicable to exercise referral arm only)
- Proposal to rerun „Strokeability” sessions in Broxtowe
- Closer working relationship with community nutrition and dietetics department to introduce „healthy eating” workshops.
- Possible service redesign to include exercise referral within a weight management context - possible implications of this could be;
 - Amended inclusion criteria – BMI focused
 - Performance indicators/outcomes less transferable to long term conditions
 - Reduction in variety of services suitable to stroke, cardiac and respiratory patients – especially with significantly reduced functional capacity

⁴⁷ An evaluation of the success of the „Heart-Fit” phase IV cardiac rehabilitation programme in Newark, Nottinghamshire: A mixed-method approach, Woolley, E.R., et al. Presented at the BASES conference 2013

5.12 Innovations (clinical delivery pilot)

Service Integration

Nottinghamshire CHD Heart Failure Network in partnership with Pulmonary Rehabilitation services created a modified pilot rehabilitation service suitable for heart failure patients (based on the foundation of the existing pulmonary rehabilitation protocol).

A cohort of 12 participants (NYHA II/III) were recruited and enrolled onto the pilot for a period of 6 weeks⁴⁸

Primary outcomes included

- 11 out of 12 (90%) patients showed a clinically significant improvement in dyspnoea.
- 10 out of 12 (81%) patients showed a clinically significant improvement in Fatigue.
- 9 out of 12 (72%) patients showed a clinically significant improvement in Emotion & Mastery (the patient's feeling of control over their disease).

"The programme provided excellent assessment, careful guidance, support and challenge. The generous and caring staff gave freely a huge amount of encouragement, which enabled me to build my confidence"

Participant feedback

Therefore the innovative approach in combining cardiac and Pulmonary Rehabilitation locally could be of great advantage to the local health economy, heart failure patients and their carers to deliver the principles of effective integrated patient centred care.⁴⁹

5.13 Third Sector Involvement

Heart Support Groups

- 21 British Heart Foundation affiliated heart support groups across the East Midlands
 - 4 situated across the Nottinghamshire region

Groups generally meet on a monthly basis providing peer support, education and advice in relation to continued rehabilitation.

Local Stroke Services

- A range of services are available across the Nottingham area including;
 - 3 Stroke Association affiliated clubs
 - 3 Voluntary groups
 - 2 Information, Advice and Support Services
 - 1 Return to work service
 - 1 Arts and Crafts Club

⁴⁸ Pilot service pathway – Appendices – Figure 3

⁴⁹ Combined Heart Failure & Pulmonary Rehabilitation Service Pilot, NHS Nottinghamshire CHD network, Vanessa Holmes, June 2013 p 20

Respiratory Support Groups

- 4 British Lung Foundation „Breathe Easy Groups“
 - 2 of which offer community based exercise sessions – Tai Chi and Respiratory exercise class.
 - Respiratory class is has been designed to offer three levels (of each exercise), ensuring the session is inclusive for all.

“Classes are brill in that there are different levels for different people for example you can have a seated or standing warm up. After the warm up there are different activities/workstations that you go round. It's a place where you can exercise in safe hands.”⁵⁰

⁵⁰ British Lung Foundation Website - <http://www.blf.org.uk/News/Detail/New-Respiratory-exercise-class>

6.1 Brighton Exercise Maintenance Services – (Zest & Fit Clinic)

Contextual Overview

There are a number of commissioned, voluntary and privately run projects and groups offered across Brighton and Hove. For the purpose of this report, detail has been provided on the „Zest“ Exercise Referral Scheme and Fit Clinic (Community based cardiac rehabilitation).

6.1.1 Programme Background

Zest Exercise Referral Scheme (part of Zest People)

- „Zest People“ was established in 2005 and offers a number of services including;
 - Exercise Referral Scheme
 - Falls Prevention Programme – feel good and balanced
 - Evaluation and consultancy support for other exercise referral schemes
 - Health development consultancy support and tendering
- Commissioned by Public Health, Brighton & Hove County Council to deliver – Exercise Referral Scheme.
- Programme aims include;
 - Initiate long-term lifestyle change with a programme of supported physical activity options for residents of Brighton and Hove.
 - To assist with the management of Chronic Disease and to encourage the continued benefits of rehabilitation following physiotherapy.

Fit Clinic (community cardiac rehabilitation)

- Cardiac rehabilitation classes established since 2004
- Small organisation (team of 3) offering across Brighton and the south-east;
 - Cardiac Rehabilitation phase IV classes
 - Tai Chi
 - Personal Training
 - Weight management and lifestyle advice
- Employed by a number of local support groups including „Brighton Take Heart Group.“
- Organisation aims;
 - Using evidence-based methods to help bring about sustainable improvements in physical health, physical fitness and wellbeing.

6.1.2 Inclusion Criteria

Zest Exercise Referral Programme

- **Activity and Behaviour Levels**

- Sedentary behaviour i.e. not moderately active for 3 or more times per week
- De-conditioned through age or inactivity
- Exhibits a desire to become more active in the next month

Medical Conditions (minimum two or more)

CHD Risk factors

- Controlled Hypertension (see exclusions)
- Weight management
- BMI greater than 29
- Controlled diabetes
- Impaired glucose tolerance
- Hyperlipidemia
- Referral from Cardiac Rehabilitation Schemes (from Phase IV only)

Mental Health

- Clinical depression
- Other stable conditions (details required)

Musculoskeletal

- Osteoporosis
- Arthritis (mild/moderate)
- Musculoskeletal (physiotherapy referrals only)

Respiratory/pulmonary

- Mild/well controlled Asthma, Bronchitis, Emphysema)

Stable Neurological Conditions

- Multiple sclerosis
- Parkinson's Disease
- Motor Neuron Disease

Other

- Stroke/TIA (> 3 months and stable)
- Chronic fatigue/ME
- HIV symptomatic
- Fibromyalgia

Exclusion Criteria

- Under the age of 16
- Re-referral within 12 months of COMPLETION of the scheme
- Unstable/newly diagnosed angina (within 6 months)
- Blood pressure 180/100 (in either) or above and/or uncontrolled or poorly controlled hypertension
- Unexplained dizzy spells
- Excessive or unexplained breathlessness on exertion
- Uncontrolled or poorly controlled diabetes
- Uncontrolled or poorly controlled epilepsy
- History of falls or dizzy spells in the last 12 months
- Uncontrolled or poorly controlled asthma (severe COPD)
- First 12 weeks of pregnancy
- Awaiting medical investigation
- Aneurysms
- Stroke/TIA (recent <3 months)

Exclusions (Established Coronary Heart Disease)

- Cardiomyopathy
- Uncontrolled tachycardia
- Cardiac arrhythmia
- Valvular heart disease
- Congenital heart disease
- Myocardial infarction (unless stable > 1 year)

Fit Clinic Inclusion / Exclusion Criteria

- As per BACPR guidelines – contraindications to exercise

6.2 Service Provision

Zest Exercise Referral Scheme

- Programme offered across 8 leisure centre and community venues
 - Within leisure centre setting delivered in partnership with Freedom Leisure provider
- 3 months subsidised access to a range of leisure activities
- 1-1 assessment and up to 4 follow up assessments in 3 month period – depending participant requirement and activity undertaken
- 1-1 exercise gym plan (if applicable)
- Follow up questionnaire at 3 and 6 months

Fit Clinic (Community Cardiac Rehabilitation)

- Classes offered across a range of venues including;
 - Leisure centres
 - Social clubs
 - Community hall
- 17 classes offered per week
- Initial assessment – unlimited access to exercise sessions
- Pay as you go or monthly membership rates
- Direct integration with phase III and community support groups
- Option for carers and relatives to join exercise session
- Variety of equipment used (depending on class location) –
 - spin bikes, concept rowing machines

6.3 Referral Processes

Zest Exercise Referral Scheme

- **1 standardised referral form for multiple services in Brighton – Zest Exercise Referral Scheme, Community Health Trainers & Healthy Weight Referral Scheme⁵¹**
- 76% of referrals to Zest are received on line via „Refer-All“ on line database system⁵²

	Primary Care	Secondary care	Social Services	Voluntary/ Third Sector	Health Education/ Programmes	Other
Sectors referring to Exercise Referral & Heartbeats	Yes	Yes	No	No	Yes	No

Fit Clinic

- Standard BACPR phase IV transition form

	Primary Care	Secondary care	Social Services	Voluntary/ Third Sector	Health Education/ Programmes	Other
Sectors referring to Exercise Referral & Heartbeats	Yes	Yes	No	No	No	No

⁵¹ Appendices – Figure 4 – generic referral template

⁵² Refer-All website link - <http://www.refer-all.net/>

6.4 Audit and Evaluation

Zest Exercise Referral Scheme

DATA	Not collected	Leisure services	CHP	Academic institution	NHS	Other
Referral source data		✓				
Condition breakdown of referrals		✓*				
Follow on data		✓				
Cost effectiveness	✓					
Drop outs positive or negative		✓				
Person centred data		✓				

*Data is split by 20 medical conditions including CHD, respiratory and stroke/TIA

- From Apr 2012 – Mar 2013 – 1289 referrals were received
 - Of which 637 (49.4%) have started or intend to start the programme
 - 60.7% of referrals received were from a physiotherapist
- In relation to medical conditions*;
 - 1% (14) had CHD
 - 8.4% (108) had a respiratory condition (including chronic asthma)
 - 0.85%(11) had a stroke/TIA

*participants were referred with multi-morbidities and were counted under all conditions noted
- Average activity sessions attended by participants was 12.1

Fit Clinic

As this service operates as a community based rehabilitation programme and is not time limited (some members attending for 10+ years) numbers are monitored in terms of attendance to ensure safe staff to participant ratios:

- E.g. the Hove class has over 100 registered members

6.5 Data Collection

Zest Exercise Referral Scheme

PARTICIPANT DATA COLLECTED	Data Collection - Stage			
	Referral	Baseline	3 Months*	6 Months*
Gender	✓			
Age	✓			
Demographics	✓			
Ethnicity	✓			
Socioeconomic data	✓			
Referral Source	✓			
Referrer Role	✓			
NHS Health Check	✓			
BMI	✓			
Blood pressure/RHR	✓			
Reason for Referral	✓	✓		
Past medical history		✓		
Goal Setting*		✓	✓	✓
Stage of Change		✓	✓	✓
Physical Activity (self-reported)			✓	✓

*Data collected at the 3 and 6 month stage is via phone or questionnaire.

6.6 Funding

Zest Exercise Referral

- Commissioned by Public Health, Brighton and Hove County Council on a 12 month basis
- Participant usage highly subsidised
 - E.g. participant would £20 per month for 3 months activity
 - Public Health would pay £49.95 to leisure facility per participant⁵³
- If attending on a pay as you go basis Public Health would pay service provider 50% of class costs (up to a maximum of 20 attendances)

Fit Clinic

- **Independent exercise provider (no external funding)**
- **Participant pays £5-6 per session (depending on location)**
 - **Option of unlimited monthly attendances for £50 per month**

6.7 Staff - Training / Qualifications

Zest Exercise Referral

- All fitness staff holds an Exercise Referral Qualification at REPS level 3.

Fit Clinic

- Delivery staff hold BACPR level 4 qualification
- Additional qualifications include
 - Level 4 Advanced Instructor
 - MSc in Exercise & Behavioural Medicine
 - Tai Chi for Cardiac Rehabilitation

6.8 Key Successes

Zest Exercise Referral

- Established Service (7+ years)
- Central co-ordinator – overseeing service delivery in 8 sites
- Robust paper referral and on line referral pathway
 - 76% of referrals on line
 - 75% of inappropriate referrals received on paper
- Extensive reporting mechanism available via on line database
- Good links with referrers (73 referring organisations)
- Integrated with community services – Healthy Living Referral Steering Groups
- Overarching company offers multiple services – more sustainable model
- Bi annual newsletter to all referring organisations (communication)

⁵³ Annual Report for ZEST ERS, 2012/2013 – p 29

Fit Clinic

- Established service (10+ years)
- Non-complicated referral pathway – standard BACPR template forms
- Strong links with primary and secondary care
 - Selected classes offered in same facility as phase III rehabilitation – seamless transition
- Embedded within community support groups – integrated service offering physical activity and/or social support
- Independent service therefore not relying on commissioning protocol/funding
- Participant engagement is non-time limited – some participants been attending 10+ years
- Participant cost consistency
- Evening classes offered for participants in employment/day time commitments
- Venue accessibility noted on the website
- Additional communication via newsletter and social media
- Drop in facility – no waiting list

6.9 Key Challenges

Zest Exercise Referral

- Limited referrals for Cardiac, Stroke and Respiratory participants
- Cardiac referrals accepted post **phase IV** only
- Limited activities for participants with more complex needs
- Staff turnover due to sessional delivering consultations
 - As a result leisure provider has employed WTE post
- Low referral uptake rate
- Follow up data/assessment collected via telephone/questionnaire
- Low response rate to questionnaire follow up (approx. 20-30%)
- Time limited participation (3 months)
- Yearly funding – relying on service being re-commissioned
- Relying on leisure provider collating and forwarding attendance data
- Increased level of competing services in the region

Fit Clinic

- Number of similar service providers operating in the region
- Keeping overheads low and participants' costs down
- Staff cover – holidays / sickness

6.10 Participant Satisfaction / Evidence of Impact

Zest Exercise Referral Scheme

“Pleased, practical, real results, swimming four times a week. Increased mobility, flexibility and strengthening for my back”

“I found the scheme tremendously helpful and motivating”

In 2011 Zest evaluated the average length of time a referral patient continued with their membership and reported that 65% continued with membership post intervention for an average period of 8 months.

63.7% achieving 3 days or more of 30 minutes physical activity post intervention compared to 31.8% at baseline.

Fit Clinic

“I am living proof that there is a great life after a heart problem and to be honest, I feel even better now than I did before.”

Participant feedback

Large percentage of participant base returning month on month, additional classes added due to demand.

6.11 Future Service Development

Zest Exercise Referral

- Include 12 month assessment questionnaire
- Opportunity to further develop „falls prevention“ reach
- Improve links with secondary care
- Plan to introduce a participant satisfaction tool as part of assessment

6.12 Third Sector Involvement

Fit Clinic

This service has strong links with a number of local cardiac support groups – exercise classes are offered the hour preceding the support group to allow participants to benefit from both the physical and social support aspects in one visit.

There are a number of local cardiac support groups; one example is Take Heart.

Brighton Take Heart Support Group

- Patient led cardiac support group – established 1993
- Exercise IV classes delivered by Fit Clinic
- Tai Chi and swimming also available
- Number of social and fundraising activities
- Grant funds received from Sussex Heart Charity
- Produce bi-annual members magazine
 - Activity timetable
 - Recipe ideas
 - Health advice / medication adherence

Stroke Association

- 2 affiliated clubs within the Brighton area

British Lung Foundation

- 1 Breathe Easy group – monthly meeting

7. Conclusion

The four programmes reviewed across England and Northern Ireland, although eliciting evidence of impact and participant satisfaction, did encounter a number of operational issues due to both the nature and duration of funding. As a result, the programmes often struggled to embed themselves as a „constant“ in the pathway of supported self-management for participants with a long term condition.

A number of common themes emerged from the scoping activity. These included:

- The level of variation in programme delivery and remit (both nationally and locally)
- Multiple pathways/referral routes incur a barrier for the referrer (and often confusion for the participant)
- Participant may receive a short term intervention – segmented pathway to supported self-management
- Variance across programme inclusion / exclusion criteria - programme may exclude participants with a long term condition
- Lack of equitable access to programmes for cardiac, stroke and respiratory patients
- Impact of time limited funding:
 - Staff retention issues due to short fixed term contracts
 - Programmes redesigned to secure funding not necessarily local need
 - Programmes in competition with private/third sector partners
 - Maintaining a knowledge of „current“ services difficult for the referrer and participant
- Data collected within the programme often not aligned to the overarching aims e.g. defining programme success by changes in BMI instead of wider health outcomes
- Partnerships vary locally – services/programmes may operate in „silo“
- Lack of consistency in instructor training/qualifications.

The catalyst for service redesign may be to secure additional funding rather than being driven by the need of the local community or in striving for equity of access. Variance in programme provision was expected nationally; however, this was also prevalent at a local authority level where multiple parallel services appeared to operate in silo, making the referral process arduous both for the referrer and participant. Lack of programme continuity and partnership involvement/support may be attributable to reduced levels of participant engagement, adherence and opportunity to long term supported self-management.

Appendices

Figure 1 – NICHHS – Stroke Service User Pathway

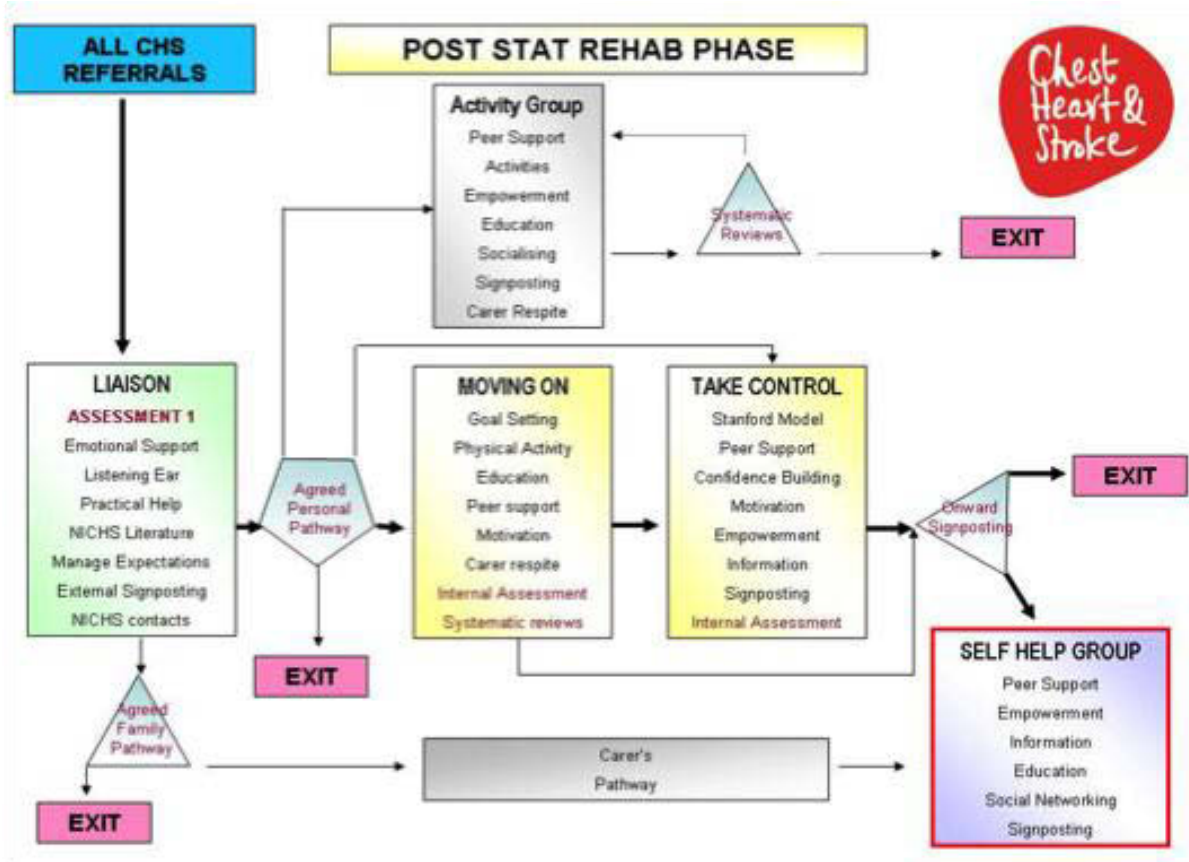


Figure 2 – Bassetlaw Council, patient-focused service integration model

Diagram 1:

Patient-Focused Model for Exercise On Referral

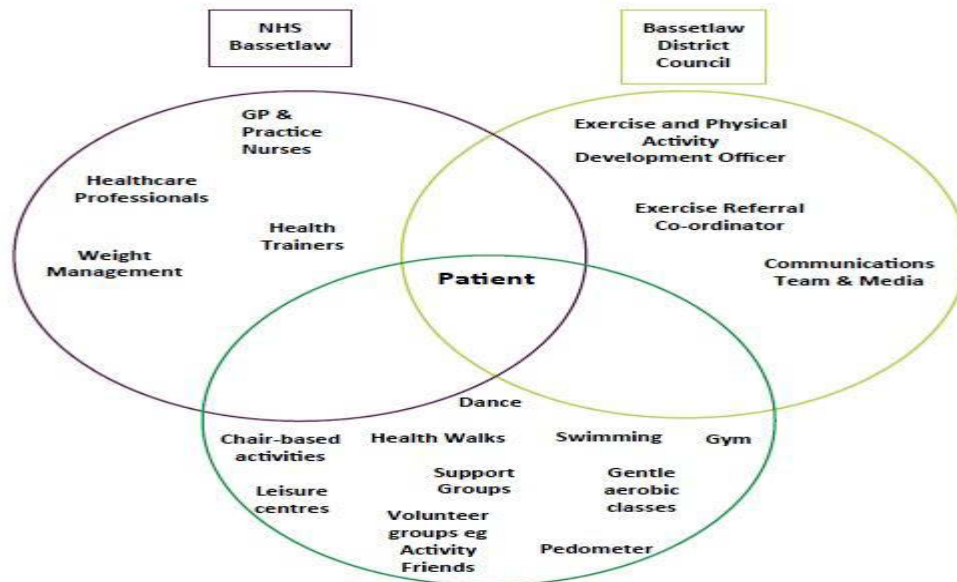
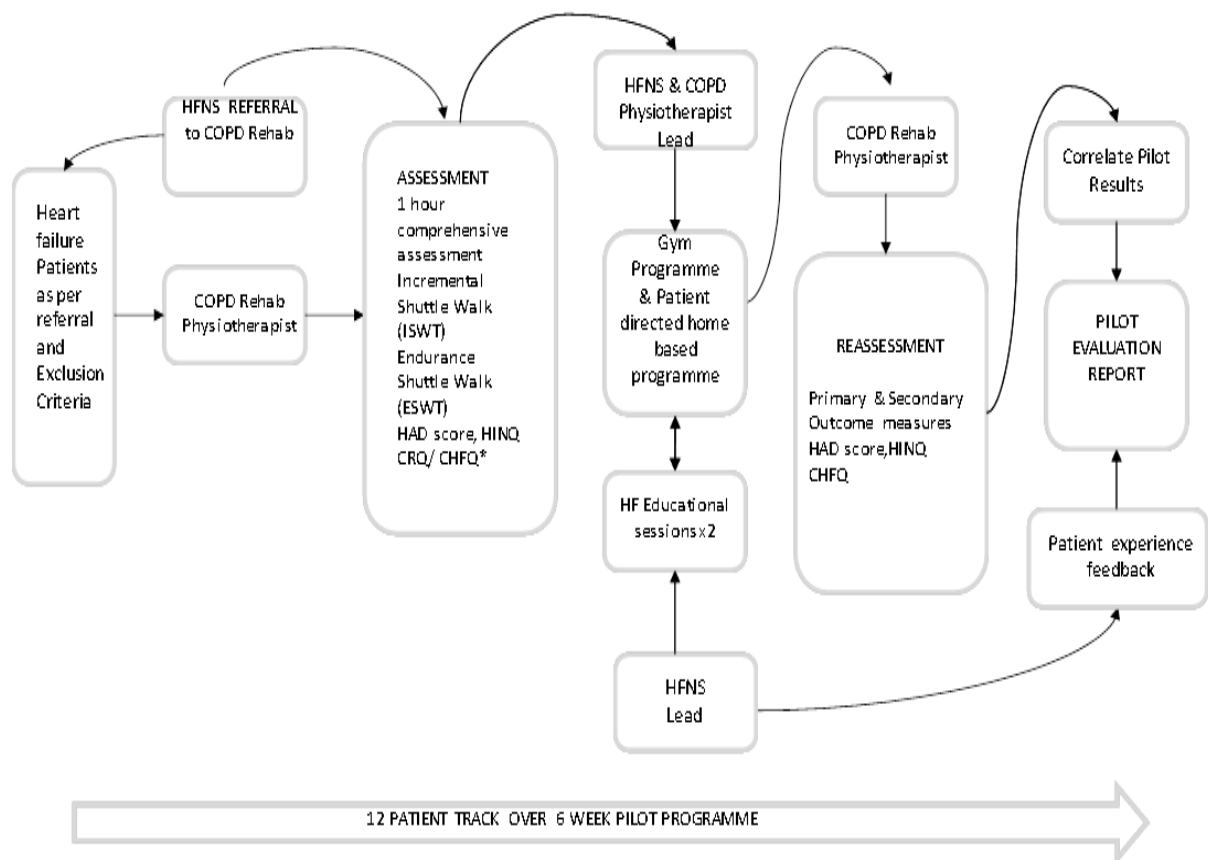


Figure 3

HEART FAILURE(HF) & PULMONARY(COPD) REHABILITATION PILOT PATHWAY MODEL




CRQ- Chronic Respiratory Questionnaire CHFQ- Chronic Heart Failure Questionnaire HINQ- Heart failure Information Questionnaire


Figure 4 – Brighton Generic Referral Form


BRIGHTON AND HOVE REFERRAL TO HEALTH


Please complete each section in turn




1. Referral to be sent to (please tick ☒)

☐ **Zest Exercise Referral Scheme**
TEL: 01903 660070
FAX: 01903 206685



☐ **East Brighton Healthy Living Centre**
TEL: 01273 294533
FAX: 01273 294542



☐ **Healthy Weight Referral Scheme**
TEL: 01273 431703
FAX: 01273 431719



☐ **Community Health Trainers**
TEL: 01273 296877
FAX: 01273 296873



Please refer to the guidance notes overleaf for each services inclusion/exclusion criteria


5. East Brighton HLC Referrals ONLY:
Please specify service required in order of priority (1 being most important, 5 being least)


☐ Mental Health: Advice and Support 

☐ Cookery: Advice and Support 

☐ Sexual Health: Advice and Support 

☐ Activity: Advice and Support 

☐ Substance Misuse: Advice and Support 

☐ Advice and Support for Carers 

6. Patient/Clinical Information

Date of Birth: _____ Age: _____ Sex: _____

Height: _____ Weight: _____

BMI (please state): _____

Medical History: (please tick current condition/s)

<input type="checkbox"/> Asthma (Exercise Induced)	<input type="checkbox"/> Asthma (Chronic)
<input type="checkbox"/> Arthritis	<input type="checkbox"/> Back Pain
<input type="checkbox"/> Bone Density	<input type="checkbox"/> Claudication
<input type="checkbox"/> COPD	<input type="checkbox"/> Diabetes (Type 1)
<input type="checkbox"/> Diabetes (Type 2)	<input type="checkbox"/> Diabetes (Type 2 Insulin treated)
<input type="checkbox"/> Depression/Family	<input type="checkbox"/> Fibromyalgia
<input type="checkbox"/> History CHD	<input type="checkbox"/> Hypertension
<input type="checkbox"/> Hyperlipidaemia	<input type="checkbox"/> IGT/IFG
<input type="checkbox"/> Joint replacement	<input type="checkbox"/> Neurological
<input type="checkbox"/> Obesity	<input type="checkbox"/> Osteoarthritis
<input type="checkbox"/> Osteoporosis	<input type="checkbox"/> Overweight
<input type="checkbox"/> Pregnancy	<input type="checkbox"/> Smoker
<input type="checkbox"/> Stress/Anxiety	<input type="checkbox"/> Stroke/TIA
<input type="checkbox"/> Surgery	<input type="checkbox"/> Other (Please state) _____

Most recent HbA1c _____

Date taken _____

7. Medication (please state or append most recent script)

2. Patient Details (if under 16 please include parent/guardian details)

Name _____

Address _____

Postcode _____

Telephone _____

Mobile _____

Email _____

3. Referrer Details (surgery stamp or insert)

Name _____

Address _____

Postcode _____

Telephone _____

Email _____

4. Reason for referral: (i.e. Weight loss, becoming more active etc)

Is there anything we need to know about this referral that could impact on the personal safety of this patient and our staff?

☐ Yes ☐ No (If Yes, please specify) _____

Patient's Signature





I have been fully informed about the service I am being referred to and I agree for my information to be passed to the relevant service provider who will contact me in due course.

Referrer's Signature

The information contained on this form is an accurate representation of this patient's health status. I agree to inform the relevant service provider if the health status changes.

Print Name _____	Role _____	Signature _____	Date _____
------------------	------------	-----------------	------------

The Brighton referral System is a partnership between Brighton & Hove Food Partnership, Community Health Trainers, East Brighton HLC, and Zest People Ltd, with funding from Brighton & Hove PCT. All information will be treated as confidential and will be handled in accordance with the data protection act 1998.

<p>Zest Exercise Referral Scheme</p> <ol style="list-style-type: none"> Please refer to ZestERS inclusion guidance when referring, taking into consideration any additional clinical information and referring to ZestERS inclusion and exclusion guidance, as provided. <ul style="list-style-type: none"> > Currently inactive (less than 3 x week for 30 mins) > Ready to change and adopt a more active lifestyle > Requires specialist help and support with regards to exercise > Patient is over the age of 16 Please complete all sections of the referral form (apart from section 5). This is necessary to ensure safe and effective exercise programming. <p>Once referred, we will:</p> <ul style="list-style-type: none"> > Contact your patient to discuss suitable activity options > Arrange the initial activity consultation on behalf of the patient > Support the patient throughout their referral Once complete please fax or post one copy of the completed referral to: <p>Thandi Rudin Zest Exercise Referral Scheme, Zest People 5 Field Row, Worthing, BN11 1TD Tel: 01903 660070 Fax: 01903 206685 thandi@zestpeople.co.uk www.zestpeople.co.uk</p> 	<p>East Brighton Healthy Living Centre</p> <p>The East Brighton Healthy Living Centre (HLC) uses a multiagency approach to provide support to patients within East Brighton who might benefit from taking positive steps to improve their health.</p> <p>How can you refer?</p> <ul style="list-style-type: none"> > Step 1 Identify additional support with the patient and complete referral form, including section 5. > Step 2 Ensure that the patient has provided their consent for being referred by signing the form. > Step 3 Hand the patient their copy of the form. > Step 4 Fax or post a copy of the referral form to East Brighton Healthy Living Centre (Fax number and address below). > Step 5 The relevant Health Worker will contact the patient. Please indicate priority of support needed if patient is addressing more than one health issue. <p>Healthy Living Prescription Referral Scheme The Healthy Living Centre Moulsecroomb Children's Centre, Hodshrove Lane, Brighton, BN2 4SE Tel: 01273 290223 Fax: 01273 294542 sarah.withers@brighton-hove.gov.uk www.healthylivingcentre.org.uk</p> 
<p>Healthy Weight Referral Scheme</p> <ol style="list-style-type: none"> The inclusion and exclusion criteria are based on BMI for adults and BMI for age assessment for children. Please refer to the HWRS inclusion guidance when referring. <p>Adults</p> <ul style="list-style-type: none"> > Ready to change and willing to access one of our services > BMI 26 – 40 (with no un-controlled co-morbidities and no insulin treated diabetes) > Refer to Healthy Weight Referral Scheme <p>Please note Adults with a BMI >28 with uncontrolled comorbidities including Insulin treated diabetes, HbA1c > 7.5% or BMI >40 should be referred to BSUH Nutrition and Dietetics Department.</p> <p>Children</p> <ul style="list-style-type: none"> > Ready to change and willing to access one of our services > BMI 91st Centile and above (with no co-morbidities) > Refer to healthy weight Referral Scheme <p>Please note children with a BMI above 99.6th centile should be referred to secondary care.</p> Once referred we will contact your patient to find a programme suitable for their needs Once completed please send one of the copies of the referral form to <p>Healthy Weight, Brighton & Hove Food Partnership, Emmaus Manor Offices, Drove Road, Brighton, BN41 2PA Tel: 01273 431703 Fax: 01273 431719 healthyweight@bhfood.org.uk www.bhfood.org.uk</p> 	<p>Health Trainers</p> <p>The Health Trainer service can take referrals from the following wards: Brunswick & Adelaide, Central Hove, East Brighton, Goldsmid, Moulsecroomb & Bevendean, Queens Park, St Peter's & North Laine, South Portslade.</p> <p>Health Trainers offer information, support and motivation to people wanting to achieve lifestyle changes in relation to: becoming more active, stopping smoking, reducing alcohol intake, healthy eating & improving general wellbeing. Health Trainers are not specialists in any particular area however they are trained in the use of behaviour change techniques and are knowledgeable about local services and activities.</p> <p>Consider referring to a Health Trainer if:</p> <ul style="list-style-type: none"> • Patient has expressed they are ready and willing to make a change in relation to their health and lifestyle • Patient would benefit from some general information, motivation or confidence building to help them achieve this change • The change can be achieved through realistic and manageable steps • Patient is aged 18+ and does not have an identified clinical problem that requires specialist support <p>Once completed please fax or post one copy of the form to us. We will then contact the patient directly.</p> <p>NB: In our experience self referrals tend to be more successful in achieving change; if appropriate please encourage your patient to self-refer by contacting us directly.</p> <p>Health Trainers Brighton & Hove City Council 3 Palace Place Brighton BN1 1EF Tel: 01273 296877 Fax: 01273 296873 Email: healthtrainers@brighton-hove.gov.uk</p> 

The PARCS Project

**Person-centred Activities for people with Respiratory, Cardiac and
Stroke conditions**

SECTION D

Review of comparable activity elsewhere in the UK

2. Wales

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Figure 2 – Cardiac Phase IV Referral Pathway

Figure 3 – Respiratory Referral Pathway

Figure 4 – Stroke Referral Pathway

Figure 5 – Generic Level 3 Pathway

1. Introduction

A scoping exercise and review of comparable activity across Wales was undertaken between March 2013 and February 2014. The aim was to support the development of the overarching PARCS project recommendations and proposed national framework.

The National Exercise Referral Scheme (NERS) for Wales was reviewed both as a national programme and regionally, with the four areas of focus selected as Cardiff, Carmarthenshire, Powys and Vale of Glamorgan. These areas were identified to compare and contrast service provision and programme delivery across urban, semi-rural and rural populations. This ranged from 98.3% urban in Cardiff to 13.5% in Powys, representative of similar demographic variance in Scotland.

Programme insight and evidence was collated both by desk review and direct programme engagement (both nationally and regionally). The review focuses and reports on the following key themes: service development and provision, referral processes, clinical services and partner engagement, audit and evaluation, instructor qualifications and evidence of impact. Additional detail is reported on local areas of innovation, key challenges and service uptake.

In the wider context, national health policies, frameworks and delivery plans have been cited to highlight the value, recognition and integration of NERS.

Wales / District Overview

2.1 NATIONAL / DISTRICT PROFILE⁵⁴

Area	Total Population	Urban	Rural
Wales	3,095,837	67.2%	32.8%
Powys	132,976	13.5%	86.5%
Cardiff	346,090	98.3%	1.7%
Carmarthenshire	183,777	48.5%	51.5%
Vale of Glamorgan	126,336	80.6%	19.4%

2.2 HEALTH INDICATORS⁵⁵

Area	% who currently smoke	% who have BMI > 30 (Obese)	% who have had a MI / angina	% who have had a stroke	% who have high blood pressure	% who have high cholesterol
UK	20.6	21.1	1.3	0.8	18.7	26.7
Wales	21.5	22.6	1.6	0.8	20.0	27.2
Powys	17.0	22.4	1.7	0.7	22.8	29.2
Cardiff	21.3	19.4	1.1	0.6	16.1	25.0
Carmarthenshire	19.4	22.8	1.7	0.8	21.6	28.3
Vale of Glamorgan	19.0	20.8	1.3	0.6	18.7	27.4

Figures from the 2011 Census reveal that five of the ten local authority areas in England and Wales with the worst health are in Wales⁵⁶

Around 1 in 6 adults (17%) reported that they had talked to a GP about their own health in the past two weeks⁵⁷

2.3 STRUCTURED CLINICAL REHABILITATION

2.3.1 CARDIAC⁵⁸

	Wales	North Wales	South Wales
Number of Cardiac Rehabilitation Programmes	24	5	19
Cardiac Rehabilitation Referral Population	7,373 (MI 4,763 / PCI 1,712 / CABG 898)	1,959 (MI 1,272 / PCI 472 / CABG 215)	5,414 (MI 3,491 / PCI 1,240 / CABG 683)
Patients Receiving Cardiac Rehabilitation	2,789 (MI 1,919 / PCI 257 / CABG 613)	556 (MI 421 / PCI 61 / CABG 74)	2,233 (MI 1,498 / PCI 196 / CABG 539)
% Uptake of Cardiac Rehabilitation	38% (MI 40% / PCI 15% / CABG 68%)	28% (MI 33% / PCI 13% / CABG 34%)	41% (MI 43% / PCI 16% / CABG 79%)

⁵⁴ Wales Census (2011) – Office for National Statistics; Key Statistics for Wales - <http://www.ons.gov.uk/ons/rel/census/2011-census/> (Table 1)

⁵⁵ Acorn (2013) - Wales: © CSSIW - Care and Social Services Inspectorate Wales 2012

⁵⁶ Transforming Health Improvement in Wales – Working together to build a healthier, happier future p 5

⁵⁷ Welsh Health Survey (2012) – p3 www.wales.gov.uk/statistics

⁵⁸ The National Audit of Cardiac Rehabilitation – Annual Statistical Report (2013) 2011-12 Data Set

2.3.2 STROKE

Estimated Strokes per annum in Wales ⁵⁹	11,000
Living with the effects of Stroke ⁶⁰	65,100
Stroke Mortality ⁶¹	2,796 (Male 1,085 Female 1,711)
Patients given a personalised rehabilitation Discharge plan ⁶²	93%
Stroke service has formal links with community user groups for stroke ⁶³	100%

“Since August 2013 every stroke survivor discharged home from hospital receives a follow up phone call within two weeks of going home to ensure that the appropriate support is available and to signpost stroke survivors to the most relevant services” ⁶⁴

2.3.3 PULMONARY

Emergency Admission Rates – Age Standardised per 100,000 Population 2011/12⁶⁵

All Respiratory Diseases				
Wales	Powys	Cardiff	Carmarthenshire	Vale of Glamorgan
1,294	924	1,184	1,118	1,278
COPD				
166	100	138	124	136

Around 1 in 7 adults (14%) reported currently being treated for a respiratory illness⁶⁶

Pulmonary rehabilitation audit - Mapping of pulmonary rehabilitation services in England and Wales is currently taking place (**October 2013 – March 2014**). This is being undertaken by the **British Thoracic Society**⁶⁷

From the 2008 Audit (UK perspective) - Only 49% of units fully met the standard of having annual audits of the service that includes patient numbers AND outcomes AND patient satisfaction.

Only 30% of units fully met the standard of having a continuation phase, run by people trained in pulmonary rehabilitation, in the community⁶⁸.

⁵⁹ Stroke Association Available at www.stroke.org.uk/news/stroke-facts-and-statistics-your-area

⁶⁰ Stroke Association Available at www.stroke.org.uk/news/stroke-facts-and-statistics-your-area

⁶¹ British Heart Foundation Coronary Heart Disease Statistics 2012, p 20

⁶² Sentinel Stroke National Audit Programme (SSNAP) Acute Organisational Audit 2012, p73

⁶³ Sentinel Stroke National Audit Programme (SSNAP) Acute Organisational Audit 2012, p73

⁶⁴ Powys Teaching Health Board Stroke Annual Report- April 2012 to August 2013

⁶⁵ <https://www.healthmapswales.wales.nhs.uk/IAS/dataviews/report>

⁶⁶ Welsh Health Survey (2012) – p23 www.wales.gov.uk/statistics

⁶⁷ National COPD Audit Programme Newsletter 2, December 2013

⁶⁸ Report of The National Chronic Obstructive Pulmonary Disease Audit 2008: Resources and Organisation of care in Acute NHS units across the UK Sept 2008

3. MAINTENANCE OF EXERCISE

3.1 NATIONAL EXERCISE REFERRAL SCHEME (NERS) – WALES

3.1.1 Scheme Background

- In development since 2007 – initial scheme aim was primary prevention, to support referred clients ‘at risk’ of developing a chronic condition.
- Scheme rolled out in 3 phases⁶⁹
 - **Phase 1 – July 2007** Bridgend, Blaenau Gwent, Cardiff, Conwy, Neath Port Talbot and Swansea
 - **Phase 2 – April 2008** - Flintshire, Denbighshire, Monmouthshire, Torfaen, Vale of Glamorgan, Pembrokeshire and Ceredigion
 - **Phase 3 – January 2009** - Carmarthen, Rhondda Cynon Taff, Merthyr, Caerphilly, Wrexham, Powys, Gwynedd, Anglesey and Newport.
 - **Post March 2009 operational in all 22 local authorities.**

In 2009 NERS developed into two distinct but inter-related components:

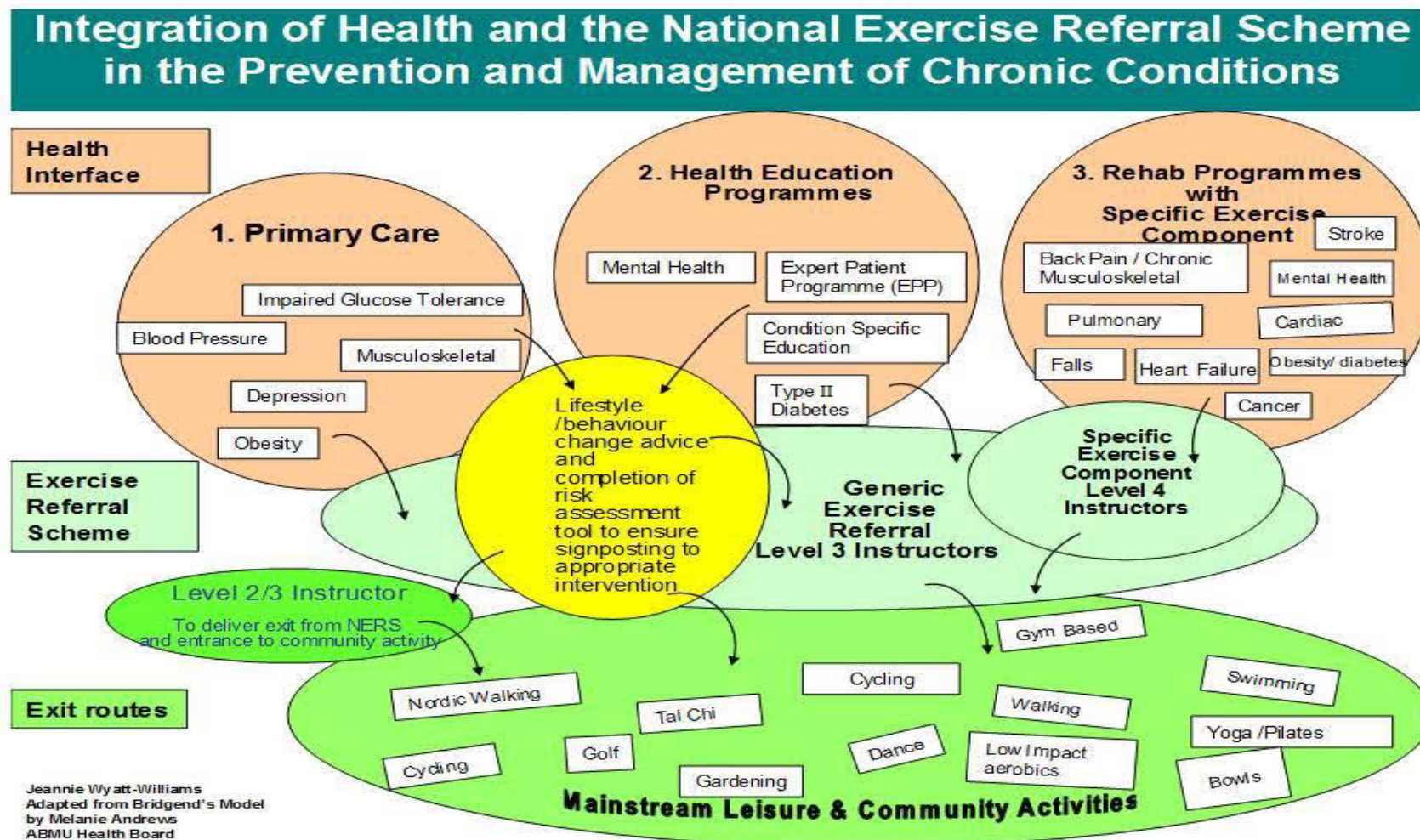
- Exercise Professionals that are registered at Level 3 of Register of Exercise Professionals (REPs) provide „generic“ NERS sessions for „low risk“ population groups that need some support to increase fitness and reduce general risks of developing chronic conditions – **primary prevention**. (16 week programme)
- Level 4 (REPs) Exercise Professionals provide more specialist NERS sessions for population groups deemed to be „higher risk“ and needing to undertake tailored exercise sessions as part of their rehabilitation following an intervention by the NHS or to manage a chronic condition and use exercise as a means of **secondary prevention**. (16-48 week programme) – *figure 1*

Specific Conditions/Sessions (include)

- Cardiac
 - Stroke
 - Respiratory
 - Cancer
 - Back Care
 - Mental Health
 - Weight Management
 - Falls Prevention
- 9 referral pathways exist for NERS –
 - 1 generic level REPS level 3
 - 8 specialist level REPS level 4

⁶⁹ National Exercise Referral Scheme, Wales 2010 p 5

3.1.2 Fig 1 – NERS Referral Flow Chart



3.1.3 Delivery

	Long term conditions	Cardiac	Respiratory	Stroke	Ex referral Generic	Ex referral Older adults	Other
Generic or condition specific	Yes*	Yes	Yes	Yes	Yes	No	Yes
Established Pathways to exercise maintenance	Yes*	Yes ⁷⁰	Yes ⁷¹	Yes ⁷²	Yes ⁷³	No	Yes
Availability across Wales	Yes*	Yes	Yes	Yes	Yes	No	Not all regions offer all 8 Level IV models
Self-referral	All participants must be referred via Primary or Secondary Care. Participant can initiate/request referral.						

***Regional Variance – due to low referral rates, regions may merge pathways (E.g. Stroke and Falls Prevention) to offer a sustainable class/service.**

3.1.4 Referral

- 9 nationally standardised referral forms and pathways
 - 1 „generic“ exercise referral pathway (Primary Prevention)
 - 8 „specialist“ condition specific services (Secondary Prevention) – all regions do not offer all 8 condition specialist services.

	Primary Care	Secondary care	Social Services	Voluntary/ Third Sector	Health Education/ Programmes	Other
Sectors referring to exercise maintenance	Yes	Yes	No	No	No	No

3.1.5 Audit/Evaluation

DATA	Not collected	Leisure services	CHP	Academic institution	NHS
Referral source data		✓			
Condition breakdown of referrals		✓			
Follow on data		✓			
Cost effectiveness – e.g. NHS service usage				✓	
Drop outs positive or negative		✓			
Person centred data		✓			

⁷⁰ Appendices – figure 2 Cardiac Rehabilitation phase IV NERS flow chart

⁷¹ Appendices – figure 3 Respiratory Rehabilitation NERS flow chart

⁷² Appendices – figure 4 Stroke Rehabilitation NERS flow chart

⁷³ Appendices - figure 5 – Generic Level 3 NERS flow chart

3.1.6 Funding

National Exercise Referral Scheme (NERS)

- **Welsh Assembly Government funded Scheme**
 - **The estimated total setup costs incurred by the Welsh Government were £365,875⁷⁴ (for the 6 pilot areas - Bridgend, Blaenau Gwent, Cardiff, Conwy, Neath Port Talbot and Swansea in 2007)**
 - **Annual operating costs for NERS in 2007/08 - £1.36 million⁷⁵.** Operating costs are inclusive of salaries for coordinators, exercise professionals, printing, administration, travel, staff management, additional training and room hire **(operating in 13 out of the 22 local authorities).**
- **NERS (along with 70% of the Public Health Initiatives) now managed by Public Health Wales – 2012 onwards**
- **Total cost of current initiatives - £17,573, 875**
 - **Nutrition based projects - £4,500,000**
 - **Physical Activity initiatives (including NERS) - £3,500,000**
- **NERS has secured funding until 31st March 2014⁷⁶**
- **NERS has been identified as a one of three key initiatives to be ‘maintained and improved’** - recognised their strengths and supports continued investment but also noted that larger-scale change and reach could be achieved from such programmes⁷⁷
- However it was also cited that from the Health Economics and Programme Budgeting and Marginal Analysis (PBMA) findings – the PBMA group voted to recommend the potential for partial disinvestment in NERS⁷⁸
- **Additional NERS sessions (if required) funded locally by leisure service providers**

⁷⁴ Cost-effectiveness of a national exercise referral programme for primary care patients in Wales: results of a randomised controlled trial - *BMC Public Health* 2013, **13**:1021 – table 1

⁷⁵ Cost-effectiveness of a national exercise referral programme for primary care patients in Wales: results of a randomised controlled trial - *BMC Public Health* 2013, **13**:1021 – table 1

⁷⁶ <http://www.wlga.gov.uk/ners>

⁷⁷ Transforming Health Improvement in Wales – Working together to build a healthier, happier future p 32

⁷⁸ Transforming Health Improvement in Wales – Working together to build a healthier, happier future p 20

3.1.7 SAFETY – (overseeing programme delivery)

Collaborative working group (s) for governance of exercise maintenance	None	Long term conditions	Cardiac	Respiratory	Stroke	Ex referral
		Yes	Yes	Yes	Yes	Yes

“All protocols went through ethical approval, and the British Medical Association in Wales was consulted as part of the development of the Scheme”⁷⁹

QUALITY STANDARDS

All staff delivering NERS are trained to a minimum of NVQ Level 3 - meeting occupational standard D449 working with referred patients.

3.1.8 Staffing – Training & Qualifications

- **1 National Co-ordinator**
- **22 Regional Co-ordinators**
- Total NERS staff – 150 (equating to 91 WTE)
 - Powys – 8, Cardiff 7.5, Carmarthenshire 5, Vale of Glamorgan 4.5
- **All staff (150) trained to a minimum of REPS level 3**
- **Additional Qualifications**

Qualification	Number of Staff
Phase IV Cardiac Rehabilitation Instructor	137
Level 4 Respiratory Disease Instructor	90
Level 4 Exercise after Stroke Instructor	40
Level 4 Postural Stability Instructor (Falls Prevention)	81
Level 4 Back Care Specialist Instructor	34
Level 4 Mental Health Instructor	28
Level 4 Cancer Rehabilitation	37
Level 4 Obesity and Diabetes Instructor	48

⁷⁹ NERS Quality Standards - <http://www.wlga.gov.uk/ners>

KEY CONTEXTUAL OVERVIEW

NERS is delivered in all 22 local authorities across Wales. Standardised referral forms and pathways have been implemented nationally, however not all local authorities offer all eight specialist level 4 services (Cardiac, Stroke, Respiratory, Cancer, Back Care, Mental Health, Weight Management and Falls Prevention). Specialist level 4 services have been implemented locally based on condition prevalence and local „health improvement“ priorities.

4. Clinical Rehabilitation

4.1 Cardiac rehabilitation (CR)

- **Delivered both within hospital and community settings**
- **Mean CR uptake 2011/12 was 38%⁸⁰ , however local health boards estimate uptake as high as 60-65%⁸¹**
- **Urban centres (such as Cardiff) operate as a tertiary centre – 1,700 referrals per annum – with 700 attending rehab within Cardiff and remaining 1,000 being referred back to local CR services**
- **Most areas offer a standard CR model of 6 weeks of 2 sessions per week incorporating physical activity and education sessions**
- **Heart manual usage is sporadic – reported limited success – some health boards no longer subscribe**

4.1.1 Cardiac exercise maintenance

- **Standardised referral pathway from clinical rehabilitation to exercise maintenance**
- **Standardised referral form from clinical rehabilitation to exercise maintenance**
- **BACPR exercise inclusion/exclusion upheld⁸²**
- **Specialist NERS level 4 exercise sessions**

4.2 Pulmonary Rehabilitation

- **Delivered to British Thoracic Society (BTS) Guidelines⁸³**
- **Delivered both within hospital and community settings**
- **Standard model of 7 weeks of 2 sessions per week – including pre and post rehabilitation assessment**
 - **Shuttle Test**
 - **Questionnaires include – St. Georges, HADS, CAT and Bristol Respiratory**
- **MDT approach - Educational sessions by dietician, pharmacist, occupational therapist and psychologist**

⁸⁰ The National Audit of Cardiac Rehabilitation – Annual Statistical Report (2013) 2011-12 Data Set

⁸¹ Telecom Interview – Rachel Owen Clinical Nurse Specialist, Cardiac Rehabilitation. Cardiff & Vale UHB Oct 2013

⁸² http://www.bacpr.com/resources/BACPR_Protocol.pdf

⁸³ BTS Guidelines on Pulmonary Rehabilitation – Thorax – September 2013, Volume 68 Supplement 2

4.2.1 Pulmonary Exercise Maintenance

- **Standardised referral pathway from clinical rehabilitation to exercise maintenance**
- **Standardised referral form from clinical rehabilitation to exercise maintenance**
- **Specialist NERS level 4 exercise sessions**

4.3 Stroke Rehabilitation

- **Delivered both within hospital and community settings**
- **All health boards piloting the 'Stroke Passport'⁸⁴**
- **1000 Lives + – Life After Stroke Learning Collaborative –launched Feb 2013**
 - **National improvement programme** supporting organisations and individuals, to deliver the highest quality and safest healthcare for the people of Wales

4.3.1 Stroke Exercise Maintenance

- **Standardised referral pathway from clinical rehabilitation to exercise maintenance**
- **Standardised referral form from clinical rehabilitation to exercise maintenance**
- **Specialist NERS level 4 exercise sessions**

4.4 Transition - Clinical Rehabilitation to Exercise Maintenance

4.4.1 KEY SUCCESSES (from a Clinical Rehab perspective):

- **Standardised single point of referral (NERS) post clinical rehabilitation**
- **Standardised 'patient pathway' post clinical rehabilitation**
- **Rehabilitation integration –**
 - **clinical rehabilitation may be offered in the same venue as exercise maintenance**
 - **exercise maintenance (NERS) instructor attending clinical rehabilitation sessions and promoting exit strategy/exercise maintenance**
 - **NERS session taking place one hour preceding /following clinical rehabilitation – increasing likelihood of attendance to exercise maintenance – seamless transition**
- **Communication between Clinical Rehabilitation and Exercise Maintenance**
- **Opportunity to 'fast track' standard PCI patients to NERS**

4.4.2 KEY CHALLENGES

- **Clinical rehabilitation teams (Cardiac, Stroke and Pulmonary) all reported low levels of staffing – illness and maternity leave have a major impact on service delivery**
- **Piloting new initiatives can be difficult as staff resources stretched delivering ‘core business’**
- **Stroke rehabilitation in a rural setting (Powys) – multiple acute providers therefore often difficult to track/follow up patients post discharge**
- **Multiple localities within health board incur difficulties to deliver a co-ordinated / standardised clinical rehab intervention (not applicable to NERS)**

4.4.3 INNOVATIONS

- Powys has piloted a „bridging“ stage (Stroke Group) between stroke rehabilitation and NERS in the Newton area – positive evaluation. Will consider roll out depending on resources
- North and South Powys have amended their goal planning meetings to ensure „stroke survivors“ are involved in the planning of their rehabilitation⁸⁵
- Nationwide Stroke prevention campaign delivered via 712 community pharmacies - lifestyle advice and medicine use review (MUR) consultations offered to patients on anti-hypertensive or oral anticoagulant medication to reduce their stroke risk. 10,059 MUR consultations were undertaken with people whose medication indicated they were at an increased risk of stroke⁸⁶.
- Swansea Pulmonary Rehabilitation Physiotherapists deliver pre-assessment clinics one month prior to enrolling patients onto clinical rehabilitation – additional screening has led to reduced attrition levels within clinical rehabilitation.
- Delivering cardiac rehabilitation phase III and phase IV simultaneously in rural communities - sustains core service, reduces operating costs, increases likelihood of continued attendance into exercise maintenance and incorporates peer mentoring model.

⁸⁵ Together for Health – Stroke Action Plan 2013 p 22

⁸⁶ Together for Health – Stroke Action Plan 2013 p 12

5. USAGE OF EXERCISE MAINTENANCE SERVICES

5.1 DATA COLLECTION - EXERCISE MAINTENANCE

(NERS) SERVICE DATA COLLECTED	Service Total	Condition Specific Total
Total number of referrals	✓	✓
Regional distribution	✓	✓
GP Practice/Referrer	✓	✓
Referral uptake	✓	✓
Adherence	✓	✓
Drop outs	✓	✓
Cost effectiveness – via external academic evaluation		

PARTICIPANT DATA COLLECTED	Data Collection - Stage			
	Referral	Baseline	16 Weeks	52 Weeks
Gender	✓			
Age	✓			
Demographics	✓			
Ethnicity	✓			
Socioeconomic data	✓			
BMI	✓	✓	✓	✓
Blood pressure/RHR	✓	✓	✓	✓
Reason for Referral	✓			
Past medical history	✓			
Goal Setting		✓	✓	✓
Physical Activity Levels/Status (SPAQ)		✓	✓	✓

5.2 **CONDITION SPECIFIC DATA** *(in addition to participant data)*

5.2.1 **CARDIAC**

DATA COLLECTED	Data Collection - Stage			
	Referral	Baseline	16 Weeks	52 Weeks
Cardiac history/status (inc. investigations)	✓			
Co-morbidities	✓			
Medication	✓			
Rehabilitation profile	✓			
Health questionnaire		✓	✓	✓
EQ-5D		✓	✓	✓
Timed Up and Go (TUAG) Test – 3m Or Chester Step Test Or 6 min walk test		✓	✓	✓

5.2.2 **STROKE**

DATA COLLECTED	Data Collection - Stage			
	Referral	Baseline	16 Weeks	52 Weeks
Stroke history/status (inc. investigations – Berg Balance or Tinetti Score)	✓			
Co-morbidities	✓			
Medication	✓			
Rehabilitation profile	✓			
Health questionnaire		✓	✓	✓
EQ-5D		✓	✓	✓
Timed Up and Go (TUAG) Test – 3m Or 6 min/10M walk test		✓	✓	✓
Stroke Impact Scale (no longer measured)				

5.2.3 PULMONARY

DATA COLLECTED	Data Collection - Stage			
	Referral	Baseline	16 Weeks	52 Weeks
Respiratory history/status (inc. – FEV1, FVC, O ₂ Sats)	✓			
Co-morbidities	✓			
Medication	✓			
Rehabilitation profile	✓			
Health questionnaire		✓	✓	✓
EQ-5D		✓	✓	✓
Timed Up and Go (TUAG) Test – 3m Or ISWT/6 min walk test		✓	✓	✓

5.3 KEY DATA CONTRIBUTING TO EVIDENCE BASE

REFERRALS	<ul style="list-style-type: none"> • National target - 20 referrals per month per WTE member of staff • Referrals per annum – nationally 25,000 <ul style="list-style-type: none"> ○ Cardiff – 2400-2600 ○ Powys - 850 ○ Vale of Glamorgan - 996 ○ Carmarthenshire - 1380
ATTENDANCE (Referral uptake)	<ul style="list-style-type: none"> • National target - 75% of total referrals attending a BL assessment <ul style="list-style-type: none"> ○ Vale of Glamorgan – 70% ○ Carmarthenshire 75-80% <p><i>*requested additional national/regional data</i></p>
ADHERENCE	<ul style="list-style-type: none"> • National target – 50% still engaged with service at week 16 <ul style="list-style-type: none"> ○ Currently achieving 62-63% ○ Carmarthenshire achieved 72% • National target – of those still engaged at week 16 – 50-70% still to be engaged/physically active at 12 months <p><i>*requested additional national/regional data</i></p>
BREAKDOWN OF REFERRALS	<ul style="list-style-type: none"> • Estimated nationally 10% of all referrals are specialist level 4 <ul style="list-style-type: none"> ○ Carmarthenshire – total referrals 1380 ○ Cardiac- 95(6.9%) Stroke- 33(2.4%) Pulmonary- 73(5.3%) ○ Vale of Glamorgan – total referrals 996 ○ Cardiac- 60(6.0%) Stroke- 25 (2.5%) ○ Powys – total referrals 850 ○ Cardiac- 71 (8.4%) • Significant regional variance – Powys 10-15% of total referrals are level 4, in Newton this increases to 40%

5.4 NERS Reach/Sessions Delivered

- Cardiff
 - 10 leisure facilities (6 pool based + 4 community based)
 - 50 NERS level 3 classes + 12 level 4 classes per week
- Carmarthenshire
 - 4 leisure facilities + 6 community venues
 - 80 NERS sessions per week (attendance >680)
- Vale of Glamorgan
 - 4 leisure facilities (2 rural venues)
 - 45 NERS sessions per week
- Powys
 - 7 leisure facilities
 - 22 NERS Cardiac sessions + 22 AAA sessions
 - Utilise the AAA (Get Active, Stay Active, Be Active) sessions for exercise maintenance – 50+ - includes social support aspect

5.5 KEY SUCCESSES – (from a NERS professional perspective)

- Standardised forms, pathways and inclusion / exclusion criteria
- Multifaceted model of delivery to include clearly defined exit strategies
- Specialised training (BACPR, Exercise after stroke, Respiratory disease) allows staff to support referred participants confidently
- Clinical rehabilitation and NERS sessions delivered in same venue
- Simultaneous delivery of Cardiac Rehabilitation phase III and IV
- Venues include urban, rural and community centres (increases reach)
- All referrals received and screened by a designated regional co-ordinator
- Most areas have close links with clinical rehabilitation teams – service integration
- NERS is recognised and detailed in Government Health Strategies (Scheme profile/future funding)
- Peer support from regional/national co-ordinator(s)
- Fostering social support networks -key mechanism for reducing programme dependence.

5.6 KEY CHALLENGES

- National performance indicators – identical for rural/urban centres
- Limited staff resources – reduce opportunities to develop scheme
- Yearly funding – job security / scope to develop service
- Hall availability within main leisure centres (mostly off peak)
- Promotional opportunities within leisure centres
- Session fragility if numbers are low
- Respect from HCPs (importance of job title)
- Not all level 4 pathways are delivered in all regions
- Partners deal in various currencies (income generation, throughput, health improvements...)
- Local authorities/health boards – differing health priorities

- Inappropriate referrals (participants not requiring specialist support)
- Time – to fully support participants with increased needs
- Replicating NERS sessions in rural locations – balancing variety and accessibility

5.7 FUTURE SERVICE DEVELOPMENT

- Develop referral pathway for neurological conditions
- Transition from a „general“ exercise model of delivery to become more health focused
- Incorporate the PARQ+⁸⁷ as additional screening tool
 - Result in reduced generic level 3 referrals (who can access mainstream activities independently)
 - Increase capacity for specialist level 4 referrals
 - Deliver additional NERS level 4 sessions
- Database integration – aligning NERS database and NHS database
 - Via Secure Anonymised Information Linkage Databank (SAIL)
 - Improve ability to track patients throughout the „patient journey“

5.8 PARTICIPANT SATISFACTION / EVIDENCE OF IMPACT

Cardiac Rehabilitation Referral

“Following a Heart Attack in April 2010 as part of the rehabilitation I attended the referral scheme at Carmarthen Leisure Centre.

“It has changed my life completely. My health is better now than it was prior to my heart attack. I am no longer on beta blockers, I feel fitter and stronger. I would encourage anybody to attend the referral scheme – it has improved my life 100%.”

Weight Management Referral

Patient referred with diabetes, renal problems, and back pain.

1st week assessment

Weight: 121kg

Waist circumference: 134cm

6MWT: Not well enough to walk

16th week assessment

Weight: 112kg

Waist circumference: 121cm

6MWT: 400 meters

NERS received a letter from patient’s renal physician consultant 6 months after completing scheme stating that they had lost another 9 kg and that they had seen beneficial effects on patient’s diabetes, high BP and kidney problems, resulting in reductions in their medication.

⁸⁷ <http://www.csep.ca/english/view.asp?x=698>

5.9 Evaluation of NERS (2007-2008)* – Randomised Control Trial (RCT)⁸⁸

**prior to implementation NERS specialist level 4 chronic condition pathways*

5.9.1 Key Data

- 1080 participants assigned to NERS intervention –
 - 913 (84.5%) attended BL consultation
 - 621 (57.5%) adhered for 4 weeks
 - 473 (43.8%) adhered for 16 weeks – favourable result compared to alternative exercise referral schemes (25-26%)⁸⁹⁹⁰
- Participant profile (referral stage)
 - Age >40 (67.7%)
 - Female (65.6%)
 - Inactive (57.7%)
 - Car owner (71.5%)
- Completer profile (16 weeks)
 - Age >40 (76.1%)
 - Female (64.5%)
 - Inactive (53.3%)
 - Car owner (74.2%)
- At 12 months those in the intervention group (NERS) had higher levels of physical activity, lower levels of anxiety and depression than those in the control group.
- Cost Effectiveness – **QALY of £12,111** (within NICE threshold of £20,000-30,000) as participants indicated a willingness to £2 per exercise session this would reduce QALY to <£10,000.
- Mean cost per participant - **£385**

5.9.2 Key Messages / Recommendations

- Importance of designated national/regional co-ordinators
- Standardised method of data collection/monitoring
- Importance of on-going motivational interviewing training/reflection
- Positive impact of peer support and mentoring
- Impact on service of „referral seekers” – NERS utilised to overcome standard gym PARQ (inappropriate referrals?)
- Increased variety of sessions/times
- Clear exit strategies – improved transition from ERS to mainstream exercise

⁸⁸ A pragmatic randomised controlled trial of the Welsh National Exercise Referral Scheme: protocol for trial and integrated economic and process evaluation *BMC Public Health* 2010, **10**:352

⁸⁹ Stevens et al, Cost-effectiveness of a primary care based physical activity intervention in 45-74 year old men and women: A randomised controlled trial. *British Journal of Sports Medicine* 1998, **32(3)**:236-241.

⁹⁰ Munro et al: Cost effectiveness of a community based exercise programme in over 65 year olds: Cluster randomised trial. *Journal of Epidemiology & Community Health* 2004, **58(12)**:1004-1010

6. THIRD SECTOR INVOLVEMENT

- **31 BHF Heart Support Groups throughout Wales**
 - **Cardiff (1) Powys (1) Vale of Glamorgan (1) Carmarthenshire (4)**
- **330 Stroke volunteers and 30 locally based stroke co-ordinators in Wales**
- **17 Breathe Easy Groups (British Lung Foundation) in Wales**
 - Pilot project in Llandudno and Blaenau Gwent designed to increase uptake of exercise and education amongst people with lung problems. Focused on co-production, whereby service users and providers develop their services together to improve the link to exercise.
 - Groups meet regularly with members of the pulmonary rehabilitation team and exercise instructors, before the NERS session takes place.
 - BLF are currently assessing the impact these groups have on the uptake of exercise and those accessing Breathe Easy.
 - BLF believe this joined-up approach will deliver better outcomes for people with lung disease, and will deliver a model service for which the NHS could roll out across Wales

7. CONCLUSION

Although initially created as a national model of standardised primary prevention (via exercise referral), NERS has now evolved to focus on offering tiered support to participants with a long term condition, establishing clear and recognised referral pathways and processes on a national plane, while remaining engaged with the community on a local level. The programme is sensitive to local need, condition prevalence, budget, demographics and appears to adapt accordingly.

From the review, both nationally and regionally a number of key findings were identified as critical to overarching success to the programme:

- Programme management – national co-ordinator and 22 regional co-ordinators – recognised central point of contact/referral
- Nine standardised national referral pathways (one primary prevention and eight LTC including cardiac, stroke and respiratory)
- Standardised data collection tools and methods nationwide
- Instructors qualified and trained to REPS level 4 – national framework for instructor training
- Established partnerships with primary care, secondary care and third sector
- Partnership funding – long term vision, which allows the service to be viewed as a „constant“ in the overall service pathway
- Participant perceived seamless transition from clinical care to community provision
- National programme delivery appears flexible to local demographics

However it should be noted that the service does face similar challenges to those delivered across the UK. These include:

- Performance indicators set at a national level – difficult to achieve similar outputs in an urban and rural setting
- Staff retention – although funding is agreed longer term, employees have a fixed term contract
- Fragility of sessions if numbers are low/drop
- Partners viewing success differently (health improvements v numbers attending)
- Availability and accessibility of sessions – times sometimes dictated by the facility rather than participant need.

Moving forward, NERS aims to predominantly focus on referrals for participants with a long term condition and requiring additional and guidance. By incorporating the PARQ+ it is believed the number of generic level 3 referrals will drop as they will be able to access mainstream activities independently.

Appendices

Table 1

KS101EW - Usual resident population

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Rural Urban	Cardiff	Carmarthenshire	Powys	The Vale of Glamorgan
Total	346,090	183,777	132,976	126,336
Urban (total)	340,177	89,154	17,911	101,808
Urban major conurbation	0	0	0	0
Urban minor conurbation	0	0	0	0
Urban city and town	340,177	73,300	6,554	101,808
Urban city and town in a sparse setting	0	15,854	11,357	0
Rural (total)	5,913	94,623	115,065	24,528
Rural town and fringe	4,667	24,932	2,981	8,956
Rural town and fringe in a sparse setting	0	4,127	34,025	0
Rural village	1,246	15,378	9,821	13,682
Rural village in a sparse setting	0	16,545	30,862	0
Rural hamlet and isolated dwellings	0	14,502	3,781	1,890
Rural hamlet and isolated dwellings in a sparse setting	0	19,139	33,595	0

Figure 2 – Cardiac Phase IV Referral Pathway

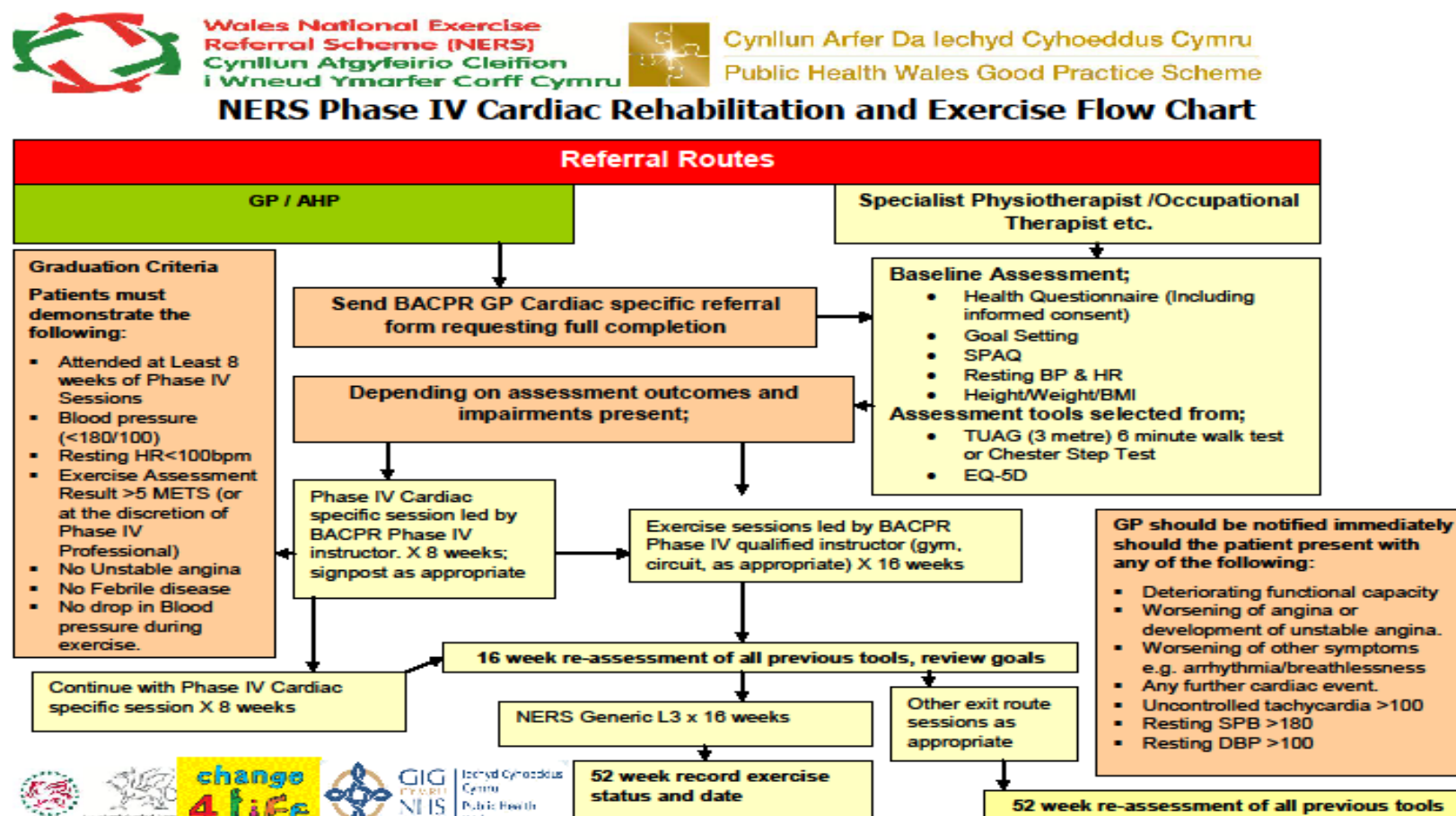


Figure 3 – Respiratory Referral Pathway

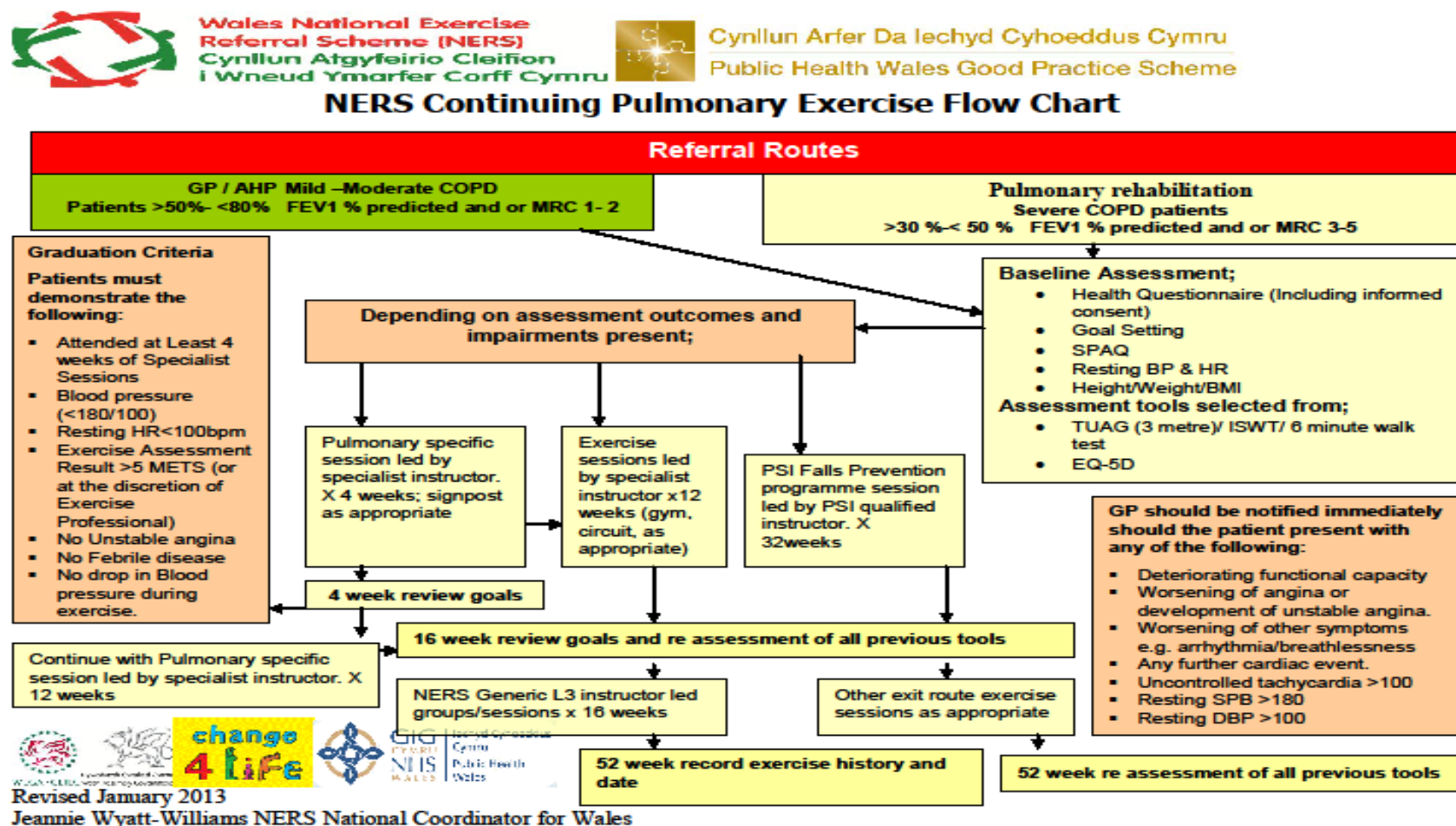


Figure 4 – Stroke Referral Pathway

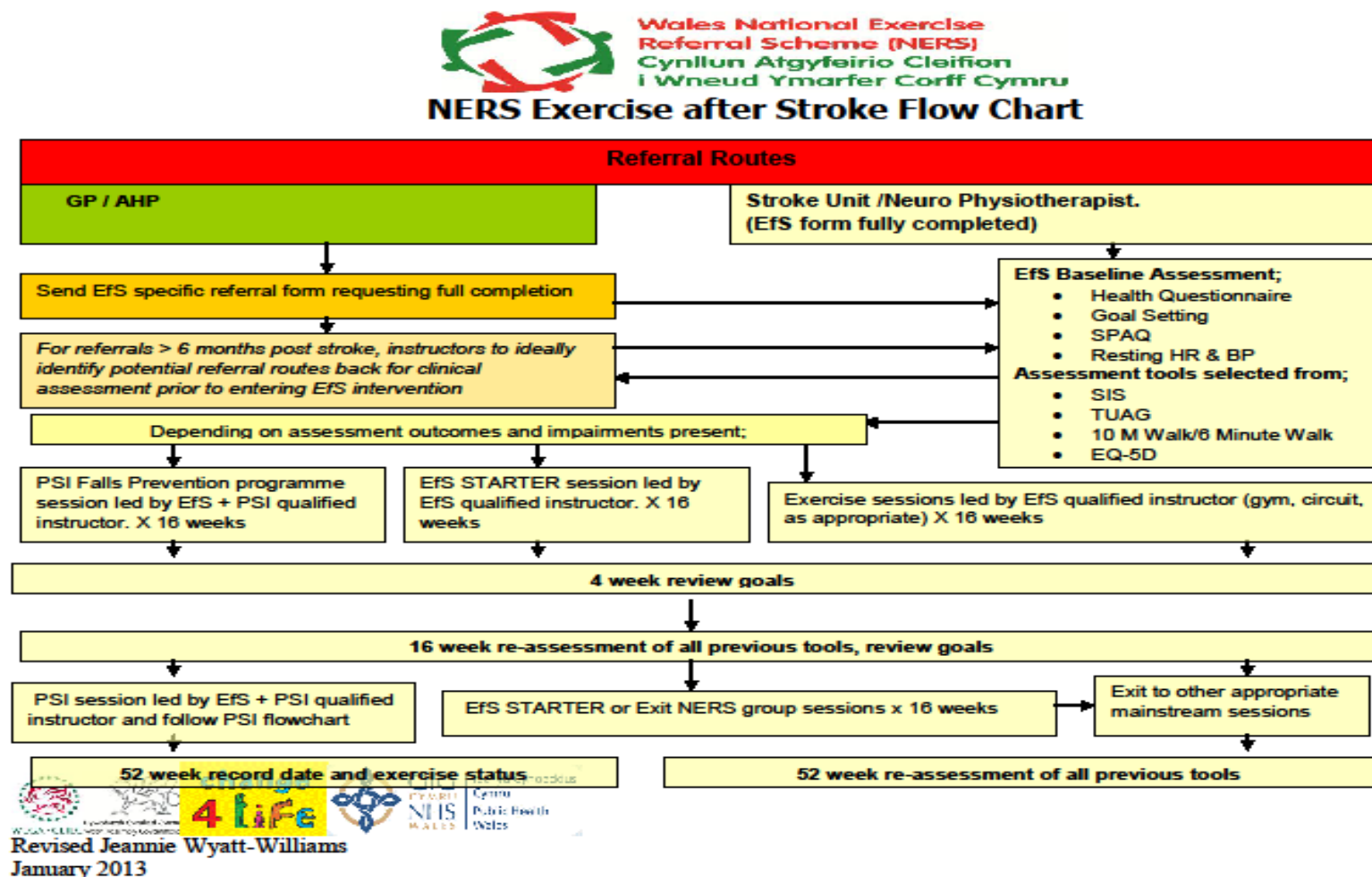
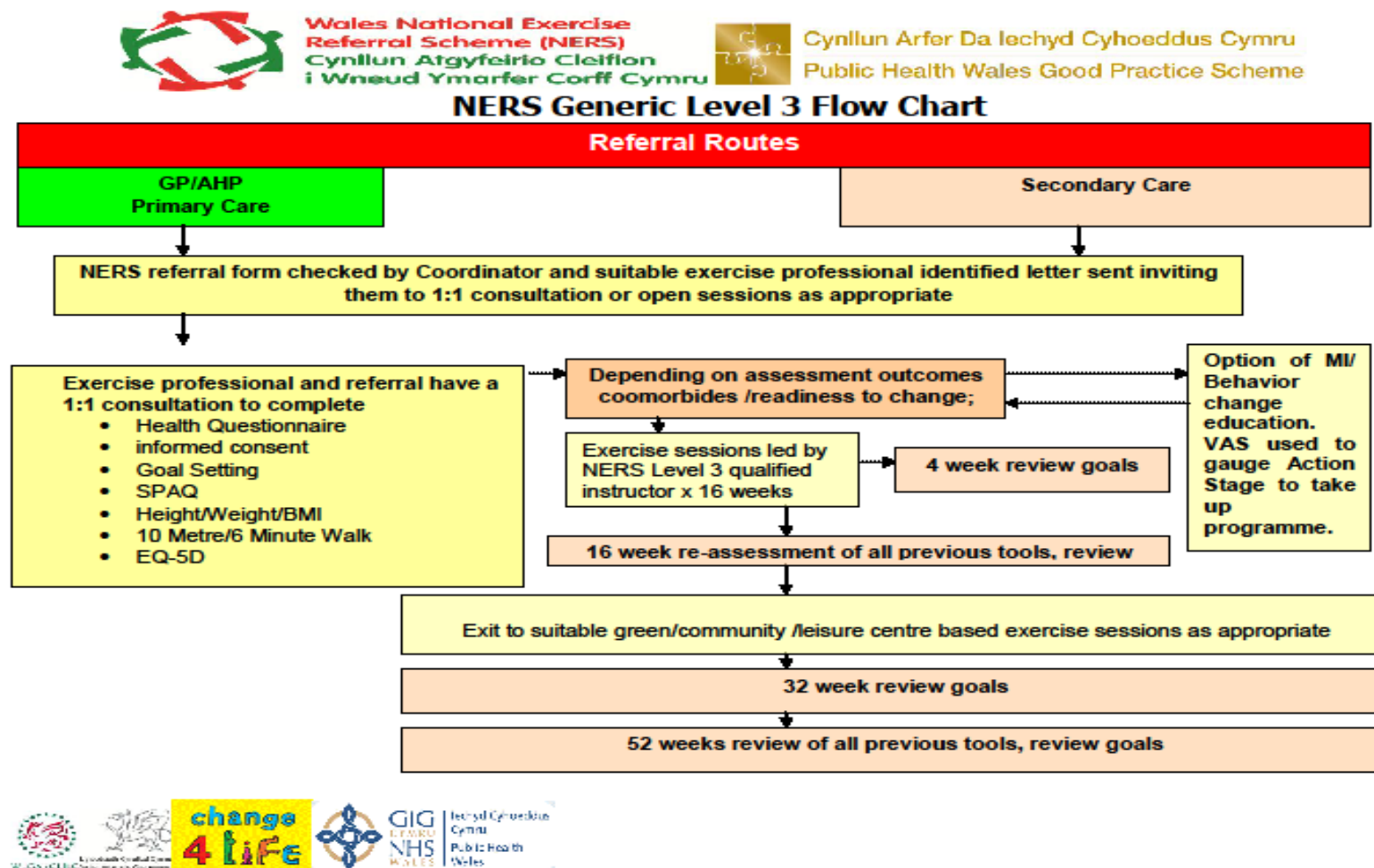


Figure 5 – Generic Level 3 Exercise Referral Pathway





The PARCS project

Person-centred Activities for people with Respiratory, Cardiac and Stroke conditions

SECTION C

Scoping exercise of current activity in Scotland

- 1. Overall summary of scoping exercise**
- 2. Health Board area profiles (Appendix 7 pp198-280)**

The PARCS project

Person-centred Activities for people with Respiratory, Cardiac and Stroke conditions

SECTION C

The overarching objective of the PARCS CHSS project was to scope current delivery of physical activity/exercise maintenance in the community for long term conditions, focusing on cardiac, respiratory and stroke conditions.

“I believe the result of exercise has been of great benefit to my wellbeing.

In fact without [the exercises], I may not be alive today.”

Service user

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1: Scoping exercise of current activity in Scotland

EXECUTIVE SUMMARY

Background

There is strong evidence of the benefits of physical activity (PA) for those with long term conditions (LTC), including cardiac, respiratory and stroke conditions and the effectiveness of rehabilitation. There is evidence from systematic reviews that exercise after stroke improves function; supervised PA/exercise maintenance (EM) after rehabilitation, for chronic obstructive pulmonary disease (COPD), is effective at increasing PA and in the short and medium term improving exercise capacity, and evidence that maintaining PA is beneficial for those with cardiac conditions. However, individuals with these conditions do not achieve PA targets and evidence suggests that after rehabilitation, PA/exercise is not maintained. Qualitative research evidences multiple benefits, barriers and enablers. Optimal PA/EM interventions are likely to include PA/exercise, with self-management and behaviour change supported by professionals and peers.

PARCS Advisory Groups

- 1) PARCS Advisory Group consisted of representation from: Managed Clinical Networks" (MCN) managers, clinical leads: healthcare professionals (HCPs) and MCN Lead Clinician, Leisure Services, NHS Health Scotland, the three charities: Chest Heart & Stroke Scotland (CHSS), British Heart Foundation (BHF) Scotland and British Lung Foundation (BLF) Scotland, and an academic institution (professorial lead). This group advised throughout the lifespan of the project.
- 2) PARCS Advisory Sub Group – this consisted of similar representation with another key academic related to the national body in relation to instructor qualifications and training. This group reached consensus on the recommendations for a framework for delivery and instructor training which was endorsed by the wider PARCS Group.
- 3) Service User Advisory Group, representing all three conditions, cardiac, respiratory and stroke, and differing geographical regions. This group was consulted on issues from a service user perspective.

Scoping

The PARCS scoping evaluated the current service delivery of PA/EM in Scotland, in the community for LTC, focusing on cardiac, respiratory and stroke conditions. The full list of objectives, methods and outcomes/results can be found in Appendix 1 of section C. One key output was the production of overview profiles of current service delivery for the 14 Health Board regions of Scotland.

Methods

The production of the 14 overview profiles involved engaging with multiple stakeholders via surveys to MCNs (n=14), HCPs (n= 274), GPs (n=146), service users (n=221), service providers (mainly leisure) (n= 40), and meetings with a cross section of stakeholders (n=63).

Results

Service delivery, pathways, funding approaches and data collection varied across and often within the 14 Health Board regions. Key issues were:

- service delivery: approaches and systems of delivery and specialist instructor training
- pathways: effective referral and a single point of referral
- economics/impact: including lack of or inconsistent data collection, collation and service/role collating this, and varied approaches to funding. Impact from a service user perspective of attending exercise groups, included achieving physical activity targets, improvement in their condition(s), and benefits of social support/interaction, motivation to exercise, remaining more active and 74% (n=165) reported no admissions to hospitals in the last year. Partnership and collaborative working (incorporating professional and peer support) were evidenced as most effective for service delivery.

Conclusion

Recommendations were made after wider consultation with the PARCS Advisory Groups and Sub Groups and management groups that were based on the findings of all strands of the CHSS, BHF and BLF PARCS partnership project (See Appendix 9). These relate to key issues and include:

- 1) a framework for service delivery
- 2) local service delivery (incorporating key elements: a person centred, multimorbidity/LTC and partnership approach, single point of referral, peer and professional support, innovations and telehealth
- 3) resources to facilitate implementation
- 4) tackling inequalities
- 5) a standardised approach to specialist instructor training
- 6) a standardised approach to audit, evaluation/data collection, to maximise impact and resources

OVERALL SUMMARY OF SCOPING

KEY ISSUES AND MESSAGES

OBJECTIVE 1 – EVIDENCE SUMMARY

Review the evidence in relation to the project – strategic drivers and evidence base

Key Strategic Drivers

NHS Quality Strategy

- person-centred, safe, effective, efficient, equitable and timely
- collaborative working with mutually beneficial partnership between patients, families, carers, service providers and third party sectors.

2020 Vision Route Map

- integrated health and social care, a focus on prevention, anticipation and supported self-management.

Key related priority areas

- *Quality of care – 1) integrated care* – work with NHS, (Local Authority) LA and third sector for health and social care partnerships 2) *Care for multiple & chronic illness, health inequalities*
- *Health of the population, Health inequalities* focus on deprived areas
- *Value and sustainability, workforce* empowerment
- *Innovation, efficiency and productivity* recommendation to increase shared services.

Heart Disease Improvement Plan

- *Management and Rehabilitation* – priority to support patients to live longer, healthier and independent lives, and contribute to other priorities, including prevention of coronary heart disease (CHD), enhancing mental health, support for people with heart failure and patient engagement.

Stroke Improvement Plan

Priority areas are to improve wellbeing and quality of life for people affected by stroke, and support self-management.

- *Living with Stroke*; exercise and self-management; other priorities including secondary prevention
- *Transition to the community*; community rehabilitation and post-discharge support

Let's make Scotland more active: A strategy for physical health (2003)

- 'Equal opportunities and access, regardless of age, sex, race, religion, social class, ability, disability, health status or geographic location'
- 'Gives equal value to social and emotional outcomes as well as the physical health benefits'
- 'To increase and maintain the proportion of physically active people in Scotland.' Targets: to achieve 50% of all adults aged over 16 meeting the minimum recommended levels of physical activity¹ by 2022. Increase activity levels across the entire population.
- „Adults later in life should have the opportunities and should be supported and encouraged to remain active in the community for as long as they choose“
- „Local community planning partnerships are given political support and enough resources to help them co-ordinate and put into practice actions to support the development of physical activity“.

A more active Scotland: building a legacy from the Commonwealth Games – Ten-year physical activity implementation plan (2014)

- *Delivery theme 3 - health and social care* within ten years of the 2014 Commonwealth Games, „More people will be physically active as a result of interventions by health and care services, resulting in fewer people requiring treatment“
- Increasing patient physical activity for the prevention and treatment of disease will be a routine part of primary care
- New links will be forged between the health system and the community, enabling signposting to local opportunities.

See Appendix 1 for a list of all identified strategies, guidelines and standards identified that align with PARCS project.

Evidence base

For definition of terms see page 12.

Long term conditions (LTC) have a high prevalence, with almost half the Scottish population affected. Cardiovascular and respiratory diseases are amongst the most prominent. There is strong evidence that physical activity (PA) is of benefit to individuals with LTC, including cardiac, stroke and respiratory conditions (COPD). Global and national strategies and clinical guidelines recommend on-going, long term PA/exercise for individuals with these conditions. However individuals with cardiac and respiratory (COPD) conditions and stroke in Scotland do not meet

¹ 'Adults should accumulate (build up) at least 30 minutes of moderate activity on most days' (Let's make Scotland more active: a Strategy for Physical Activity, physical activity task force (2003) <http://www.scotland.gov.uk/Resource/Doc/47032/0017726.pdf>). „Adults aged 18–64 should do at least 150 minutes of moderate-intensity aerobic physical activity throughout the week or do at least 75 minutes of vigorous-intensity aerobic physical activity throughout the week or an equivalent combination of moderate- and vigorous-intensity activity. The recommendations listed above are applicable to the following health conditions: cardiorespiratory health (coronary heart disease, cardiovascular disease, stroke and hypertension); metabolic health (diabetes and obesity); bone health and osteoporosis; breast and colon cancer and depression“. „The evidence is currently insufficiently precise to warrant separate guidelines for each specific disease“. „Adults aged 65 years and above should do at least 150 minutes of moderate-intensity aerobic physical activity throughout the week or do at least 75 minutes of vigorous-intensity aerobic physical activity throughout the week or an equivalent combination of moderate- and vigorous intensity activity“. „The recommendations listed above are applicable to the following health conditions: cardio-respiratory health (coronary heart disease, cardiovascular disease, stroke and hypertension); metabolic health (diabetes and obesity); bone health and osteoporosis; breast and colon cancer and prevention of falls, depression and cognitive decline'. (World Health Organisation Global Recommendations on Physical Activity for Health (2010), http://whqlibdoc.who.int/publications/2010/9789241599979_eng.pdf?ua=1)

PA targets. Rehabilitation is considered a gold standard intervention for cardiac, pulmonary and stroke conditions. Cardiac rehabilitation (CR) and pulmonary rehabilitation (PR) are clinically effective and cost effective interventions. After CR, PR and stroke rehabilitation and generally, individuals with these conditions largely do not maintain, or engage minimally in, physical activity. Therefore the benefits of these interventions are unlikely to be maintained.

Systematic reviews show:

- exercise after stroke is beneficial at improving function
- supervised PA/EM for a primary respiratory condition (COPD), is effective at increasing PA and in the short and medium term improving exercise capacity (lack of evidence for the long term)
- follow up interventions may be effective in maintaining PA/exercise in those with cardiac conditions.

Qualitative research shows:

- benefits of EM from a service user's perspective, and social support appears to influence PA and motivation to exercise
- barriers to EM include access, availability of groups and transport, and motivation
- enablers of EM are professional support, social interaction and peer support, and follow up/ongoing communication between service users and professionals. The evidence suggests that optimal PA/EM interventions are likely to include exercise training, with self-management and behaviour change supported by professionals and peers, although further research is needed. See Appendix 2 for the full review of the evidence that underpins this project and Appendix 3 for all the identified strategies, policies and guidelines that relate to this project.

Key messages

Key strategic drivers:

NHS Quality Strategy, 2020 Vision Route Map, Heart Disease and Stroke Disease Improvement Plans, Let's make Scotland more active: A strategy for physical health (2003), a more active Scotland, building a legacy from the Commonwealth Games - Ten Year Physical Activity Implementation Plan (2014)

Key evidence:

- Long term PA is beneficial and recommended for those with LTC, including cardiac, respiratory and stroke
- Individuals with cardiac, respiratory and stroke conditions do not meet PA targets
- Cardiac, pulmonary and stroke rehabilitation are „gold standard“ interventions
- The benefits of rehabilitation in terms of PA/exercise appear not to be maintained
- For individuals with cardiac, respiratory and stroke conditions, there are multiple benefits, barriers and enablers around PA/EM
- Multi intervention approaches which include exercise and peer and professional support may be most effective

OBJECTIVE 2 - SCOPING SUMMARY

Scope current delivery of physical activity/exercise maintenance in Scotland, in the community for long term conditions (LTC), focusing on cardiac, respiratory and stroke conditions

The key findings of the scoping are in relation to service delivery, pathway and economics/impact. The scoping involved engagement of multiple stakeholders, including surveys of MCNs, HCPs, GPs, service users and leisure services.

SERVICE DELIVERY

Service delivery is varied in terms of

- i) service availability
- ii) approaches and systems of service delivery
- iii) type of service delivery (i.e. generic LTC or condition)
- iv) specialist instructor training, with a wide variation in numbers of specialist instructors with the specialist skill set needed to deliver PA/exercise interventions for individuals with LTC.

Key messages for service delivery

- a structured approach to service delivery would appear to be of value, with menu-based options
- partnership and collaborative working appear most effective in relation to service delivery and governance, incorporating professional and peer support
- addressing the issue of instructor training is key to service quality, availability and delivery
- LTC models have evolved in well-established delivery models (urban, semi-rural and rural) from condition-specific delivery LTC models which appear to best maximise impact and resources.

PATHWAYS

Pathways are varied with a large variation in referral processes and signposting; inconsistencies are often within as well as between Health Board regions. Barriers to effective referral and signposting are lack of knowledge and availability of services, from both a referrer and service user perspective (prevalent in areas of rurality). Having a single point of referral/service co-ordinator appears to address this issue – the majority of Health Boards do not have this. Clinical rehabilitation (stroke rehabilitation, PR, CR) is a key intervention and linking this to maintenance is important in terms of local access and professional and peer/social support.

Key messages for an effective pathway

- Structuring services to incorporate a single point of referral/service co-ordinator is key
- Service availability is varied with a shortage of services in some regions and often a lack of knowledge and signposting/referral to services that are available
- Delivering rehabilitation in the community and linking this to exercise maintenance in terms of local access and professional and peer/social

ECONOMICS/IMPACT DEMONSTRATION

Data collection is often lacking and largely inconsistent in terms of data collection, collation and the role or service undertaking this. There are often inconsistencies within as well as between Health Board regions. This makes measuring and demonstrating impact challenging. Barriers are often around information sharing between agencies (e.g. NHS and Leisure) and the different needs of the agencies in terms of data collected.

Funding for instructor training shows variation and inconsistencies of approaches to funding and funding streams. Often short term funding only is needed to meet training costs. Approaches to training are often fragmented, i.e. individual providers training instructors. Health Board or CHP-wide approaches via collaborative working groups appear to maximise resources.

Funding streams for service delivery show a large variation, often with variations/inconsistencies of funding approaches and streams from statutory bodies for service provision. Integrated partnership funding is seen in well-established schemes with a large reach. Some services are self-sustaining once well established.

Key messages around economics and demonstrating impact and cost effectiveness

- Consistency in data collection is needed to demonstrate impact on both clinical effectiveness and cost effectiveness
- Regional approaches to funding instructor training appear to maximise resources and impact
- Integrated partnership funding is seen in well-established schemes with a large reach.

Person-centred service user impact

Achievement of physical activity targets of service users attending an exercise maintenance group: 76% (n=165) meet physical activity targets compared to national averages of 15% for chest, heart and stroke conditions. Attending an exercise group is linked to improvement in condition, with 76% (n=165) reporting feeling their condition has improved since joining the exercise group. Key benefits of the exercise class were motivation to exercise (n=130/222), remaining more active (n=130/222) and social support (n=130/222). Potential link to reduced hospital admissions, with 74% (n=165) of service users reporting having no hospital admissions in the last year.

Key messages on impact for service users

Service users (with cardiac, respiratory and stroke conditions) of exercise classes report:

- 76% (n=165) achieving physical activity targets
- 76% (n=165) reporting improvement in their condition(s)
- benefits of social support/interaction, including motivation to exercise and remaining more active (n=130)
- 74% (n=165) reporting no admissions to hospitals in the last year.

OBJECTIVE 3 – EXPLORATION OF INNOVATIONS AND TECHNOLOGY SUMMARY

Scope innovations and technologies available/emerging

Innovations and technology can address some of the barriers the project identified, in particular access issues and knowledge of services. Resources were also identified that offer PA/exercise education as part of a wider self-management and multi-intervention approach. Online training resources to support education and training in relation to self-management and heart disease as part of this wider agenda were also identified.

Key messages from innovations and technology

- take the service to the service user
- innovations and technology can address barriers, in particular access and knowledge of services
- there is a need to develop telehealth/care applications to promote PA in individuals with cardiac, stroke and/or respiratory conditions.

OBJECTIVE 4 – IDENTIFICATION OF RESOURCE NEED, SERVICE USER AND/OR SERVICE PROVIDER SUMMARY

Identification of primary resource need based on the all three strands of the project: PARCS CHSS, BHF and BLF.

Results: The PARCS Advisory Group considered that the primary need was a service provider resource

1) Resource need from service user perspective

- **A web-based resource, with sustained funding**, which acts as a repository of information with a person to facilitate and maintain/update this (although this may not be suitable for all).
- **Tailored professional local support** for people with complex needs, e.g. stroke, ideally one-to-one support so that individual conversations can happen, either with a person who is the single point of referral/service co-ordinator or with another person with appropriate knowledge to signpost/access relevant services.

2) Resource need from a service provider perspective

- **Production of service provider resource** to support service delivery for LTC PA/EM in the community

OBJECTIVE 5 – SUMMARY OF IDENTIFICATIONS OF GOOD PRACTICE MODELS, CRITICAL SUCCESS FACTORS AND PERSON CENTRED PATHWAY

- a) Identify good models of practice in differing geographical areas of Scotland – urban, semi-rural, rural
- b) Identify critical success factors in relation to NHS quality strategy for service delivery of EM
- c) Person centred pathway to maintenance in the community for LTC, based on user need.

Results/Outcomes: Good models of practice, critical success factors (in line with the NHS quality strategy) and a person-centred pathway were produced based on the findings from the scoping

OVERVIEW OF ADDITIONAL OBJECTIVES ACHIEVED

Objective 6: Produce a proposed national framework for transition from health to community based activity in the prevention and management of chronic conditions that can be recommended to SGHD.

Objective 7: Address issue of instructor training and reach conclusions and recommendations for SGHD.

ADDITIONAL UNFORESEEN BENEFITS OF PARCS PROJECT

- **Improved knowledge** in relation to physical activity and exercise opportunities available in Scotland, amongst various stakeholders
- **Influencing local policy and service delivery**
- **Sharing/spread of good practice** by PARCS project manager which included facilitating networking

PARCS CHSS Full Report

OBJECTIVE 1 – EVIDENCE SUMMARY

Review the evidence in relation to the project – strategic drivers and evidence base

Methods: Review of key evidence base including research (both quantitative and qualitative) and key strategies and guidelines to inform the project.

Definition of key terms

Cardiac Rehabilitation (CR): 'the sum of activities required to influence favourably the underlying cause of the disease, as well as the best possible, physical, mental and social conditions, so that [people] may, by their own efforts, preserve or resume when lost as normal a place as possible in the community" (4).

Community Health Index (CHI) number is the national unique number for any health communication related to a given patient. *Everyone in Scotland who is registered with a GP practice has their own unique CHI number.*

Chronic Obstructive Pulmonary Disease (COPD): chronic lung condition which is characterised by restricted airways leading to breathing difficulties, persistent coughing and abnormal sputum production (4).

Exercise or exercise training is defined as a subset of physical activity that is planned, structured, repetitive and performed with the intention of improving or maintaining one or more components of physical fitness. Physical fitness is defined as a set of physiological qualities that link to the ability to perform and tolerate certain physical activities (2).

Exercise maintenance (EM): for this project, refers to follow on exercise or physical activity opportunities delivered in the community after formal clinical/NHS rehabilitation is complete. (It is acknowledged that not everyone may have entered or completed rehabilitation).

Exercise referral schemes (ERS) aim to identify inactive adults in the primary care setting. The GP or healthcare professional refers the patient to a third-party service, with this service taking responsibility for prescribing and monitoring an exercise programme that is tailored to the individual needs of the patient.

Forced expiratory volume (FEV): the volume of gas exhaled in one second by a forced expiration from total lung capacity.

Health Care Professionals (HCP) Any clinical professionals involved in a patient's diagnosis, treatment and care, including doctors in hospital and community settings (e.g. consultants and general practitioners), nurses in hospital and community settings (including specialist nurses), allied health professionals (AHPs) in hospital and the community.

Journey: the stages a patient proceeds through and their experiences from symptoms/diagnosis to exercise maintenance; the healthcare professionals they encounter at each stage; the care and treatment they receive; the information they are provided with, and the decisions they make about their next steps.

Long term conditions (LTC): 'health conditions that last a year or longer, impact on a person's life, and may require ongoing care and support' (3).

Managed clinical networks (MCN): linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and Health Board boundaries, to ensure equitable provision of high quality, clinically effective services throughout Scotland

National Occupational Standards (NOS) are statements of the standards of performance individuals must achieve when carrying out functions in the workplace, together with specifications of the underpinning knowledge and understanding.

Pathway: the (locally or nationally) agreed stages to be followed in the care and treatment of patients who have a LTC or cardiac, respiratory or stroke condition.

Person-centred Activities for Respiratory, Cardiac and Stroke conditions (PARCS) project

Physical activity (PA) is defined as „any bodily movement produced by skeletal muscles that require energy expenditure" (1). There are many types of physical activity, including leisure, sport and occupational activities, and also active living such as walking, housework and gardening.

Pulmonary Rehabilitation (PR) can be defined as „an interdisciplinary programme of care for patients with chronic respiratory impairment that is individually tailored and designed to optimise each patient's physical and social performance and autonomy. Programmes comprise individualised exercise programmes and education" (6)

Register of Exercise Professionals (REPs) is an independent public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REPs provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards.

REPS level 3: The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions, including respiratory conditions such as asthma and chronic obstructive pulmonary disease (COPD); musculoskeletal conditions, cardiovascular conditions, hypertension, hypercholesterolaemia, psychological/mental health conditions, metabolic/immunological conditions e.g. diabetes type 1 and type 2, and obesity.

REPS level 4: The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology-specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising

in the medical setting) of an event when partaking in physical activity, e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the effects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease.

<http://www.exerciseregister.org/resources/exercise-referral>

Service user: anyone who is a patient or other user of health and/or social services

Stroke: „strokes are usually acute events and are mainly caused by a blockage that prevents blood from flowing to the heart or brain. The most common reason is a build-up of fatty deposits on the inner walls of the blood vessels. Strokes can be caused by bleeding from a blood vessel in the brain or by blood clots” (6).

Stroke rehabilitation (SR): „restoration of function after stroke and minimisation of long term disability after stroke” (5).

Support Group: a third/voluntary sector group created to support people with a specific condition; these groups may be affiliated to one of the charities involved in PARCS or not, and generally offer a range of services and support to members which may or may not include PA/exercise.

Third sector: collective term for community groups, voluntary organisations, charities, social enterprises, co-operatives and individual volunteers.

See Appendix 2 for the review of evidence for physical activity/ exercise and exercise maintenance and Appendix 3 for tables of strategies and guidelines that PARCS aligns to.

OBJECTIVE 2 – SCOPING SCOTLAND

- Scope current delivery of physical activity/exercise maintenance in Scotland, in the community for long term conditions (LTC), focusing on cardiac, respiratory and stroke conditions
- Produce overview profiles for 14 Health Board regions across Scotland in relation to exercise maintenance

The data produced in the overview profiles may not be representative of the full spectrum of available PA/EM opportunities available in any of the Health Board regions presented, and relies on the data provided to the project which presents potential for inaccuracies. The data presented in the overview profiles is a summary of the wider scoping that occurred with some further details presented in the sections to follow.

Methods:

Surveys: MCNs, n=11/14, HCPs n= 274 „hits“, GPs n= 146 „hits“, service providers (primarily leisure) n= 40, service users, n=221 (see Appendix 4 and 5).

Meetings: with service providers/stakeholders in service provision n= 63, HCPS n= 42 (35 face to face, 7 telecoms), Leisure services n= 20 (face to face, 7 telecoms), Local Authority n= 1

Meetings with service users/potential service users total with LTC n= 33 (included areas of social deprivation and ethnic minority group) and project manager attendance at various regional collaborative working groups in relation to delivery of exercise maintenance for LTC. Focus group findings from service users/potential service users (see Appendix 6). Meetings were largely opportunistic to align with existing work.

Identification and extrapolation of existing data: post pulmonary rehabilitation data x 4 regions, pilots of community exercise for stroke programmes x 2 regions, academic research funded by CHSS into optimising engagement into physical activity after stroke x 1 region, leisure services evaluations x 4 regions, person-centred groups evaluations in conjunction with HCP or academic institutions x 2 regions. This was identified through internet searches and through meetings with key leads. This data was reviewed by the project manager and relevant data was used for the profiles overview sections, key contextual overview sections as relevant and to inform the project.

All data incorporated within the PARCS scoping was collected in the period November 2012-January 2014. The PARCS surveys were completed between August 2013 and January 2014.

Survey and Data Synthesis Methods

For MCNs, the survey was in electronic format and sent via MCN managers to the respective regional MCN managers for dissemination. The HCPs, service providers/leisure services and GP survey was online on „Survey Monkey“. For HCPs, the dissemination process for completion was via professional networks: the Scottish Stroke Allied Health Professional (SSAHP) forum, Scottish Respiratory Action Group (SPRAG), Scottish Respiratory Nurse Forum (SRNF), Cardiac Rehabilitation Interest Group Scotland (CRIGS), Chartered Society of Physiotherapy (CSP) Scotland website/online forum, MCN Managers, Health Improvement (HI), Community Health Partnership (CHP), Nursing Midwifery and Allied Health Professional (NMAHP) leads for cascading and internally for stroke nurses in CHSS. Leisure services/service providers, via Physical Activity Health Alliance (PAHA), HI, Physical Activity leads and via identification of leisure services providers from online searches along with cross checking with a previous stroke audit and gained knowledge from the PARCS scoping to that point. The GP survey was via a CHSS list of GPs who had previous contact with CHSS and then targeted identification of practices/practice managers in regions with a no/low responses rate, by sending the link to the survey via post or email. Some questionnaires were completed in paper format during face-to-face meetings as part of the PARCS project and then manually input into the Survey Monkey

format (with permission). For service users, the surveys were posted out to all CHSS group leads to circulate via their respective groups. All data was protected in line with CHSS data protection and confidentiality policies and followed the ethical standards of the charity in line with charity business/service evaluation and development. This ethical approach was considered and agreed by CHSS line management.

The data represented in the overview profiles is compiled from a synthesis of data from PARC Surveys - MCNs, Health Care Professionals, and service providers (leisure services, third sector and private provider) responses. The data synthesis process that was used for each question/table response was in relation to the number of definitive responses to that question (i.e. yes and no answers only, unsure responses were not included in the tally). For Yes or No responses, if all stakeholders reported Yes, the table was populated with a Yes and the same process was used for No. If there was a mixed response from the different stakeholders, if the total responses for that question were high (>20), the majority response was used. If the total responses were low (below 20) if 2 or more stakeholders responded negatively (No) or positively (Yes), the answer was populated as „*some regions*. If the responses for that question were high (>20) and the results were mixed (i.e. a high number of yes and a high number of no), the answer was populated as *some regions*. If there was only a single response, either Yes or No, the respective response was used and populated, or populated as '*one region*' (as appropriate). If no responses, the section was left blank.

The data represented in key contextual overview and quotes sections (above the tables) is a data synthesis from the PARCS surveys (as detailed above and including service users), meetings detailed below and other data sources, e.g. reports, audits/evaluations, online resources (e.g. websites), identified as part of the PARCS scoping. Where information was missing, e.g. nil responses, the information was based on information available from other (e.g. online) resources. The accuracy of such information may not always be correct; the sense check detailed below was to enable a mechanism whereby any errors to be identified and corrected.

The overview profile shown above (tables and key contextual data) was circulated prior to final production to the respective Health Board MCN Managers for sense checking (checking that the information had no obvious errors). A two-week deadline was given (due to the time limited nature of the project). A nil response within a two-week period would lead to the assumption that the data was acceptable and required no corrections.

Thematic analysis for free text comments in all surveys was undertaken by the project manager with one other health care professional. Initially the comments were looked at independently and then general themes were identified and agreement reached on the emerging themes as they occurred in each respective survey. Each comment could have multiple themes. Random samples of responses were evaluated independently and cross checked for consistency to ensure a matched approach to the analysis. If a theme or themes for a comment were unclear, this was identified and discussed and consensus reached.

Results:

For the **overview profiles for the 14 Health Board regions** in relation to physical activity/exercise maintenance in Scotland, in the community for long term conditions (LTC), focusing on cardiac, respiratory and stroke conditions, see Appendix 6. An overview of the methods and key findings from all the surveys can be found in Appendix 4. Graphics of responses that summarise responses to questions from the HCP surveys, GP surveys, service user surveys and service providers (primarily leisure) can be found in Appendix 5. MCN responses are available on request from CHSS.

Key Outcomes/Results from the overview profiles and scoping detailed above

1) SERVICE DELIVERY OF EM – NHS Quality Strategy effectiveness

Availability of EM services

Availability EM services is varied throughout Scotland. This ranged from nil, minimal service or an establishing service in six Health Board regions (all rural/semi-rural), to established, in some to all CHP regions, in eight Health Boards. The majority of Health Boards had some aspects of a service, but not a fully menu based approach, and often not in all regions. In areas of rurality, if a service was delivered, it was often inconsistent, with large population regions generally better serviced, with more rural areas having poorer provision.

“Embedded ...programme that supports individuals to uptake /adhere to exercise following rehab ...which delivers standardised classes across the health board for long term conditions”

HCP, urban region

“Good service provided, patients have choice of onward referral, menu-based approach, walking groups, swimming and self-management group”

HCP, urban region

“My patients have no access to such services, therefore do not get benefits of exercise programmes”

GP, rural region

Leisure, rural region: “There is no exercise maintenance that follows from the clinical rehab that I know of”

Leisure, rural region

Positive Health Impact of service delivery where available

“The significance of having and promoting exercise maintenance opportunities has a massively positive impact on patient care, service provision and delivery methods. Without utilising the exercise maintenance opportunities which exist ...little opportunity or support to engage in longer term behavioural change ...having negative consequences both physically and emotionally. I cannot imagine being able to deliver the service we do without the option of onward referral for exercise maintenance”

GP

The positive impact of having a service was evidenced in the HCP and GP survey responses and from extrapolation of existing data. Positive impact was reported in terms of health and wellbeing, including improved physical and psychological health, social interaction with positive societal benefits. The impact of having an EM service for patients as reported from GPs' surveys included, in order prevalence:

- improved health and wellbeing,
- important for the delivery of health promotion and physical activity measure
- improved activity and function
- promotes self-management
- increases confidence
- social interaction and support
- improves psychological health
- promotes independent
- encourages physical activity and exercise.

In terms of HCP responses, the most prevalent reported success was delivering/having an EM service, followed by the positive impact of this service. The positive impact from a service user perspective is reported in detail in the person-centred evidence (see page 36).

Existing data identified as part of scoping were four leisure providers' large scale evaluations, and all showed positive outcomes. These included social return on investment evaluations, post-pulmonary rehabilitation data/EM data in four regions, pilots of community exercise after stroke in two regions and third sector/third sector in partnership evaluations of service delivery conducted by academic institutions in two regions. The majority of regions with an established service provision had also piloted and evaluated a service prior to larger scale role out. All reported overall positive impact of service delivery, which again included positive effects on physical health, e.g. improved function, improved psychological health, such as increased confidence, reduced depression, increased social interaction and support, and better self-management (see Appendix 11).

Reach of service

The reach of a service was greater in established services with a better developed structure for service delivery, including effective pathways. This was most widely achieved by a partnership approach. In areas with no, or minimal, service provision, reach was poor. In predominantly rural regions with large geographic coverage, the service delivery was less well established and therefore the reach was poorer. In other areas with a fragmented approach to service provision, the reach was also reduced.

Service structure and delivery

How the service is structured also varied. This can include offering EM as part of an exercise referral scheme (ERS), either a wide-ranging exercise referral scheme addressing primary prevention as well as secondary prevention, or as part of a long term conditions specific (ERS) or a condition specific approach. Some Health Board regions offer a combination of these delivery approaches, which can be dependent on providers and critical mass.

Generic models of delivery for LTC

These generic models of delivery have often evolved in well-established delivery models (urban, semi-rural and rural) from condition specific delivery. This generic LTC model encompasses cardiac, stroke and respiratory and other conditions, based on functional ability rather than the condition. These levels can range from seated or low level classes to circuit based classes with differing levels of intensity. These often also offer menu-based options for PA/exercise (see section below, page 23). This evolution to a LTC model has occurred in different geographical regions for a number of reasons:

- to meet service user need
- to address waiting lists situations for a condition specific classes
- to increase reach
- to address increasing demand
- to maximise resources
- to have the critical mass needed to make it feasible to deliver a class.

In rural areas in particular, the LTC delivery model has the potential to address the issues of critical mass needed to make a service viable. In urban areas, this was often a strategy to meet increasing demand for services and to not have a waiting list for services.

“We were finding it more and more challenging to provide disease specific classes so we consulted with a range of physiotherapists and implemented a circuit-based class which would be suitable for a whole range of participants – cardiac rehab, MS, COPD, etc.”

Service provider

Service providers

Service providers vary between regions, often with differing lead providers including Leisure Services, Local Authority and third sector providers. A combination of providers is often seen within a Health Board region, and these providers can be working in partnership or in silo. Working in silo does not appear to maximise impact for service users. This approach is often taken through lack of knowledge of services, service providers and other key stakeholders in the regions. Issues of sustainability are seen in terms of referral into groups/classes, and resources and may allow only provision in a single isolated geographical areas within a region. Providing a cohesive approach from all stakeholders can be challenging when services are already established, in order to meet different stakeholders' needs. Collaborative working groups and partnership working are central to overcoming these challenges.

Barriers to service delivery/development

A major barrier seen in areas attempting to establish or develop a service is the lack of an ideal framework and guidance around best practice for key implementation issues, such as instructor training. There are National Occupational Standards for exercise referral (7), other registration body guidelines (8, see also appendices 8 and 9) and best practice guidelines for the development of an exercise after stroke service in the community (9), which are useful. However, as a LTC approach to delivery has evolved, key questions remain, such as what condition areas (e.g. cardiac, stroke) instructors should be trained in across a spectrum of LTC, as with finite resources, training in all conditions is not always feasible. Safety and governance standardisation is another key issue across differing providers, e.g. leisure and third sector. At present, establishing regions are benchmarking against other, more established regions as national guidance is lacking and leads to inconsistency in service delivery. This also leads to resources not being used effectively, as collaborative groups in many different regions are investing time in investigating the rationale and guidance behind key issues and debating how best to address these. Additionally, developing and even established services are keen to identify or find solutions to „gaps“ in their service delivery which other regions may have already addressed.

Addressing service delivery barriers

Resources would be more effectively invested if there was a nationally accepted framework for delivery, guidance on key implementation issues and support for this. This could include a short term post to share and facilitate good practice around key issues and link regions in a „buddying“ type approach to share good practice. CHSS PARCS has already started work towards this in one region. This post could also support regions that have identified need and willingness to develop services but need local resource support around this.

Collaborative/partnership approach to governance and delivery

Collaborative/partnership approaches and working groups involving all stakeholders for service delivery and governance were both important and effective in maximising resources and impact. This is demonstrated in Health Board and CHP regions with good practice models. Benefits of this approach are offering different aspects of a service to provide a more holistic model with menu-based options. Partnership working is key to maximising resources, including increasing capacity to deliver in many geographical locations and thus increasing impact for the service user.

Good practice example

Partnership Working in Angus, Tayside

Be Active... Live Well offers a programme of activities for people with a LTC. It is a partnership organisation between Angus Cardiac Group (CHSS affiliated), Angus Council's Leisure Services, Angus Community Health Partnership, Angus Chronic Obstructive Pulmonary Disease (COPD) Groups, Volunteer Gold and the Angus Carers' Centre in collaboration with Angus Care and Repair. The programme has wide coverage throughout the region in leisure and community venues. There is also delivery in care homes by trained care home staff for seated exercise.

Recommendations in relation to a service delivery

Consensus was reached on an ideal framework for transition from health to community based activity in the prevention and management of chronic conditions for Scotland (see Appendix 9). This framework was agreed by the sub group and was subsequently endorsed by the wider PARCS Advisory Group. This ideal framework was based on:

- the framework for exercise referral currently in delivery in Wales identified by BHF PARCS scoping and as part of the wider exercise referral work
- CHSS scoping of service in Scotland
- key strategic drivers, including the shift of care to the community and the integration of health and social care
- expert opinion (from the Advisory Sub Group membership)
- the needs of all partners (represented on the Sub and wider Advisory Group).

For full details, see Appendices 8 and 9.

Specialist instructor training

See Appendices 8 and 9 and references 7, 8, 9 for details of specialist instructor training levels/requirements. There is a large variation in skill set in terms of numbers, and levels of expertise of specialist trained instructors for LTC. This ranged from:

- Health Boards regions that had no instructors trained at a level able to deliver classes for LTC (n=2) (e.g. training in seated exercise or respiratory only)
- Health Board regions that had some instructors trained in relation to specific condition delivery (e.g. cardiac) but not across all conditions (n= 8, the majority of Health Boards)
- Health Boards that had a cross section of training across the spectrum of LTC (n=4). These Health Boards had achieved this by NHS „in house training“ within their respective regions. Health Board or CHP wide approaches via collaborative working groups to achieve specialist instructor training appear most effective.

Barriers to specialist instructor training included:

- Funding instructor training across all or a wide spectrum of condition areas (e.g. cardiac, stroke, etc.)
- What condition areas (i.e. cardiac, stroke, etc.) to train instructors in with only finite resources
- Training instructors across different providers (e.g. differing leisure services providers and third sector providers)
- Different training providers with different standards, e.g. academic intuitions and professional groups
- Location of training (often outwith Scotland, incurring costs for travel and loss to service or gaps in service provision whilst the instructor was receiving training)
- Critical mass for training to be delivered (often providers would only deliver if 15 or more attendees were available; this required a role or group to organise this)
- Length of time to complete training, get certification and deliver classes
- Standardisation of pay bandings for instructors with additional training and career development (often these instructors remained on the same pay banding with no prospects for career development)
- Retaining specialist instructors in the region or service once training occurred (once trained, instructors would often move to a different region or service, or set up as private provider).

Clearly the ideal would be for instructors to be trained across all conditions. Some Health Board regions had addressed this by offering training „in house“ training via NHS staff and support for continuing professional development in LTC. This supplemented externally provided courses in conditions specific areas, e.g. cardiac provided by the British Association for Cardiovascular Prevention and Rehabilitation (BACPR). However, this means there is no standardisation between boards. Other Health Board regions have taken the approach of identifying what they considered to be key risk areas, e.g. cardiac and falls, and sending instructors on these initially until further funding/support became available. A condition specific delivery model which many schemes had started allowed easier implementation in relation to instructor training, as for example in cardiac, where only one course was needed and the instructor then had the appropriate skills to deliver classes.

Recommendations in relation to instructor training

Consensus was reached to **recommend to SGHD a standardised national approach to specialist instructor training**. It is recommended that a **generic LTC course** should be available and delivered within Scotland, covering all core principles, incorporating established best practice, Level 4² instructor qualifications pathways and evidence based exercise

² **Register of Exercise Professionals (REPs)** is an independent, public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REPs provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards. **DEFINITION OF REPS LEVEL 3:** The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions. This includes respiratory conditions such as asthma and chronic obstructive pulmonary disease (COPD), musculoskeletal conditions, cardiovascular conditions, hypertension, hypercholesterolaemia, psychological/mental health conditions, metabolic/immunological conditions, e.g. diabetes type 1 and type 2, and obesity. **DEFINITION OF REPS LEVEL 4:** The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver

interventions for clinical conditions at Level 4. Future work to take this forward would involve Scottish academic institutions developing and delivering this generic training for specialist instructors.

This recommendation was agreed by the Sub Group and was subsequently endorsed by the wider PARCS Advisory Group. This was based on evidence from PARCS:

- the framework for exercise referral currently in delivery in Wales identified by BHF PARCS scoping and a national approach to training as part of the wider exercise referral work
- CHSS scoping of service in Scotland
- key strategic drivers including the shift of care to the community and the integration of health and social care
- expert opinion (from the Advisory Sub Group membership)
- the needs of all partners (represented on the Sub and Wider Advisory Group).

For full details, see Appendix 8.

Good practice example

Collaborative approach to instructor training for stroke, Lothian

There is a multi-agency steering group, a partnership between NHS, all regional leisure service providers, and the third sector, including the Thistle Foundation and CHSS, sitting under the umbrella of the Stroke Managed Clinical Network (MCN). A small one-off grant from charitable funding was secured for training. This group, chaired by the AHP consultant lead, has overseen provision of training for fourteen exercise after stroke instructors. Service provision is intended across Lothian within four differing leisure providers and a third sector provider, within condition specific and generic LTC delivery models. CHSS also supported training instructors and non-clinical staff (e.g. reception staff) within leisure services in understanding and supporting stroke service users' needs (e.g. visual, cognitive speech). This ensures potential barriers are addressed.

Tailored exercise – menu-based approaches and exercise options

“Give patients access to evidence based, disease specific advice from appropriately trained professionals, physios and exercise staff”

HCP

exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity, e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the effects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease. <http://www.exerciseregister.org/resources/exercise-referral>

Exercise should be specifically adapted to meet the needs of service users with LTC and tailored to suit need and reduce risks. Menu-based approaches allow tailoring and can, as appropriate, meet service user preference, which may encourage engagement and adherence. Examples of menu-based options include different functional level of classes (to allow progression and regression, as exacerbations or changes in the condition dictates), and other physical activity options, e.g. walking groups. Other options include self-management, social and peer support groups and cultural activities, e.g. arts. The ability to offer these services relates largely to partnership working to offer different aspects of the service. See Appendices 8 and 9 for PARCS Advisory Group recommendations around the framework and instructor training that relate to this.

Good practice example

Menu-based options, Tayside

In addition to a variety of exercise referral programmes for long term conditions, with a range of function-based options ranging from seated exercise to circuit type gym class classes, other menu-based options are also offered. These include walking groups, support groups such as British Lung Foundation „Breathe Easy“, and various arts/cultural activities for LTC, e.g. singing for COPD and various arts activities for stroke. This is provided by Tayside Healthcare Arts Trust, a partnership, including NHS and Third sector pan Tayside.

HCP involvement in service design and delivery

HCP clinical leads are mainly physiotherapists and nurses but other HCP, e.g. occupational therapists and GPs, are leaders and key partners in developing and delivering services. These clinical leads often drive, lead or facilitate service design, implementation and delivery. In good practice models, clinical leads have been involved in developing the structure and content of exercise classes and supporting services providers (mainly leisure) with initial instructor training and ongoing continuous professional development. This also leads to effective referral as HCPs are assured that appropriate quality and safety standards are in place and are therefore confident to refer and signpost into a service. Strategies identified as part of this scoping that have enabled this include short term funding to „buy out“ a HCP's time by backfilling the post, enabling the HCP to scope services in the region, develop relationships with providers and potential providers, and support training of instructors/volunteers; also by building time into work plans for HCP clinical leads to ensure protected time to enable this. Once services are established and relationships developed, ongoing support is often seen to ensure quality and safety standards are maintained valued by specialist instructors and volunteers.

Professional support

Being able to tailor exercise and offer support is often incorporated as a multi-intervention approach to support behavioural change. Four Health Board regions offer one-to-one support in some or all CHP regions, with lifestyle advisors or specialist instructors.

Good practice example

Professional support, exercise and behavioural change, Greater Glasgow and Clyde (GGC)

LTC exercise maintenance is delivered pan GGC within the Exercise Referral Scheme (ERS), Live Active. There is a specialist component, Vitality, for LTC. It is delivered by leisure services, with support from NHS. Live Active offers 12 months" one-to-one behavioural change support via face to face and telephone consultations and individually tailored activity goals and support. The Local Authority also provides supervised exercise sessions, gym sessions and health led walks.

Peer support

"Peer support [is] important. Going with others for support and encouragement helps all. Otherwise regular support from key person, e.g. volunteer, to encourage participation helps"

HCP

"Knowing that you are not alone is a great support. We all support one another"

Service user

Peer support in particular, as well as social support and interaction was one of the three main benefits reported by service users (see Appendices 4, 5, 6) and, from the meetings with service users, was of primary importance and integral to the other two most commonly reported benefits, remaining more active and motivation to exercise. Peer support also helped to overcome barriers such as support to access services, e.g. transport, and support in taking steps towards behavioural change, e.g. „buddying" when going to a new class. Examples of effective peer support include peer visits to rehabilitation (CR and PR) to promote EM classes and support groups.

Good practice example

Peer support, Lanarkshire

A third sector CHSS affiliated support group, provided with training from CHSS, visits individuals on the cardiac wards (supported by NHS) to offer peer support. This support continues throughout in-patient treatment and rehabilitation, and into long term maintenance/self-management. Additional benefits are that „peers" provide individuals with knowledge of services that may be beneficial. This is in addition to offering social support and interaction, and often helping with transport to and from venues.

Access issues - Inclusive and local access

“We work in a deprived area. A lot of people do not have access to gyms etc. A lot of our patients with chronic health conditions would benefit from exercise. .. We sometimes hear of short term funded projects which we refer to then disappear when funding stops”

“Many of my patients live in remote areas and are often housebound. In order for any provision of exercise maintenance to be effective it would require trained individuals to deliver it in the patient’s home environment”

“Our elderly population can’t travel easily and need local classes. Please can we ensure equality of access for elderly as well as the poor”

“GPs have no access to referral for exercise that I am aware of in our locality. I am aware of some patients attending classes after referral by secondary care but they are rarely within our practice boundary”

GPs

Access overall was a key issue from a referrer perspective (see HCP and GP surveys, Appendices 4 and 5) and service user perspective (Appendices 4 and 5 and p. 36).

Issues with access included:

- availability within and across health board regions
- availability across all conditions, i.e. for all and not just specific conditions
- availability for all the population, e.g. housebound, deprived, elderly
- ability to refer into services e.g. not all GPs able to refer and sustaining services
- accessibility of services e.g. local services needed and the ability to get transport to venues
- Time-limited nature of some services.

The ability to access services locally was also important from a HCP, GP and service users’ perspective. This is examined in more detail in Section E. Good practice examples of addressing access issues include training volunteers, carers and social care staff to deliver exercise; specialist instructors travelling to community venues to deliver classes as opposed to the service user travelling to a venue, and delivering services across a Health Board region, as noted in the key successes, from the overview profiles.

Good practice examples

Addressing access issues, GGC and Lothian

GGC: Silver Deal is a partnership between Glasgow Housing Association (GHA) and Glasgow Life that provides free, regular, coach-led physical activity and arts sessions in GHA Sheltered Housing Complexes.

West Lothian: Xcite (Leisure) instructor delivering classes in community venues, e.g. working men’s clubs in ex- mining communities.

Value of Third Sector

“Largely with the support of CHSS, progress has been made in providing exercise maintenance”

HCP

The third sector's ability to be flexible is evidenced in this scoping. It can be seen from the scoping the role of the third sector is varied and includes:

- being the primary provider of services
- working in partnership with HCPs and other stakeholders to developing services, provide training and address the needs of services users
- networking between Health Board regions
- providing peer and social support networks
- addressing access issues, e.g. via social support and providing transport.

The third sector is often seen identifying and addressing the gaps in service delivery based on regional and service user need, and as having the ability to offer a more holistic approach, e.g. peer and social support, to provide the menu-based options that other partners are not able to offer.

2) PATHWAY JOURNEY

Effective referral

Effective referral is key to uptake and engagement with ongoing community EM and other services.

Referral into EM services was generally good to leisure services by HCP but poorer into community services and poor by GPs.

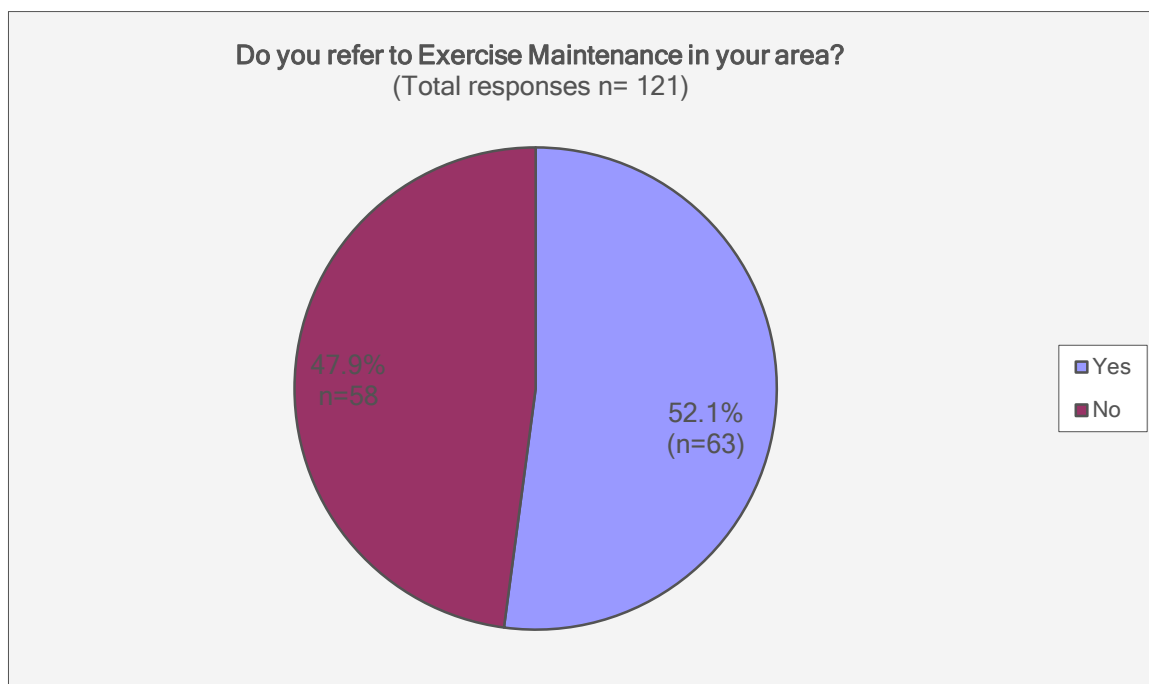
Referral to EM

By HCP (See Appendices 4 and 5)

- **Majority of HCP DO refer to leisure services 75.6% (n=161)**
- **Majority of HCP DO NOT refer to community services 54.5% (n= 111)**

By GPs (See Appendices 4 and 5)

Pie chart to show referral to exercise maintenance by GPs across Scotland (n= 121)



- DO refer to exercise maintenance - 52% (n=63)
- DO NOT refer to exercise maintenance - 48 % (n= 58)
- Not able to refer - 56.91% (n=70)
- In regions with lack of or poor service provision, largely rural, this increased and ranges from 80% -100% DO NOT refer.

Lack of knowledge of services/lack of services

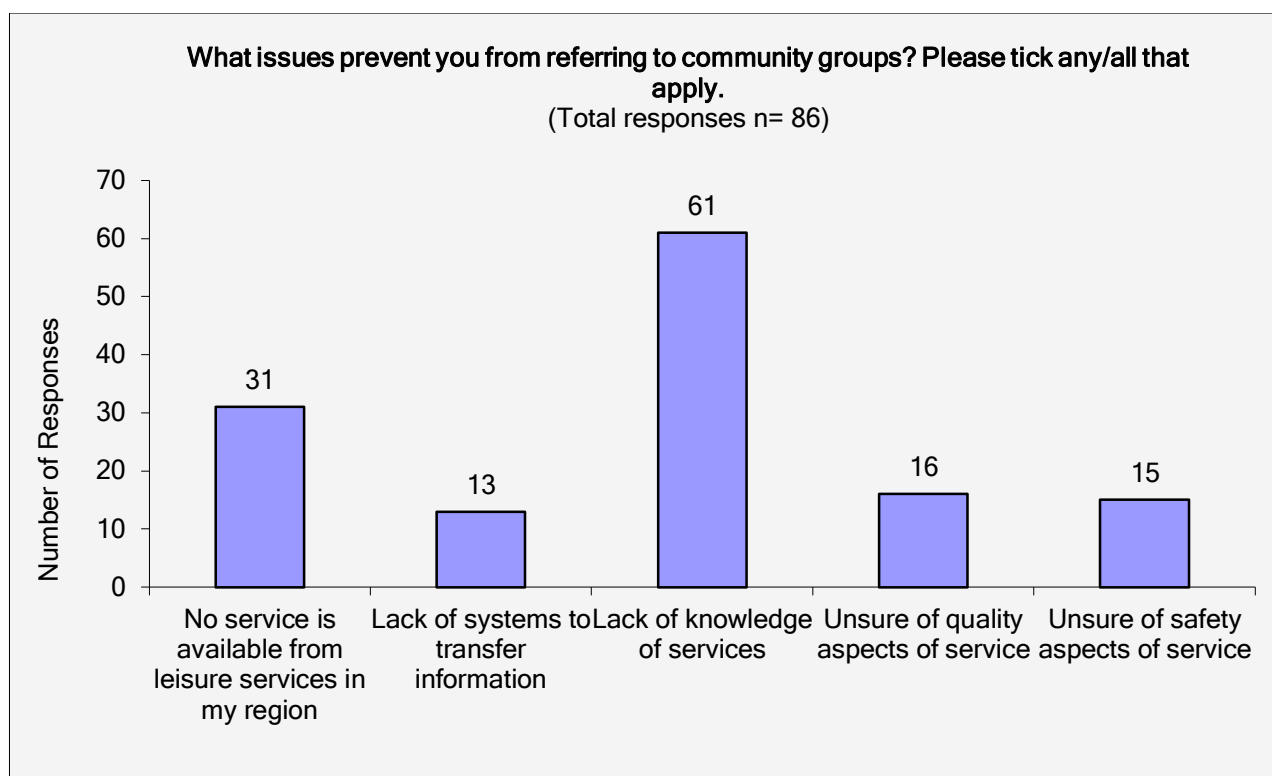
HCP primary reasons for not referring:

- lack of knowledge of services
- no service provision

GP primary reasons for not referring (total responses n= 70)

- lack of knowledge of services: 56% (n=31)
- no service in the community: 56% (n = 39)
- no service in leisure services: 44% (n=31)

From a HCP perspective, lack of knowledge of services in relation referral to community groups was more of an issue than when referring to leisure groups where lack of referral was reported to be almost equally due to lack of service provision (n=31) and lack of knowledge of services (n=30).



Other **barriers to referral and/or transfer of information**

From a referrer perspective, these included:

- lack of referral due to concerns regarding service quality and safety, e.g. instructors have appropriate training
- lack of systems to transfer information
- systems and procedures that prevent information transfer to non NHS agencies, e.g. IT systems and information transfer policies
- unsure of medico legal aspects of referral
- having to complete different referral forms for different providers
- having the appropriate form and contact to send the referral form to if no there is no single point of referral.

From a service provider perspective, barriers included:

- accessing electronic referral forms: some providers reported having to go to an NHS venue to access referrals due to confidentiality policies.

Referral, self-referral and signposting

In terms of referral to EM classes (leisure provided, e.g. gym/circuit type classes), it appeared that service delivery models with referral integral to the process were most widely used, and this is the recommendation in many standards and guidelines (see Appendix 7, 8, and 9). In some regions signposting (making service users aware of services, but not directly referring) was the

strategy to circumnavigate some of the barriers. Signposting to other PA interventions, e.g. walking, and non-PA services, e.g. support groups, were often seen, particularly in areas with good partnership working and peer support.

Referral and self-referral options were often inconsistent within and across regions and conditions. The value of self-referral from a service user perspective is in engaging with services independently. Some services are newly established and can only be accessed by HCP referral. If you have a LTC and/or completed rehabilitation prior to the scheme existing, accessing this can be challenging. You may not know the services exist and if you do, you may not know if or how you can access and indeed be able to access it depending on the referral process in the region. The challenge of self-referral from a service provider perspective is ensuring that the self-referrer with a LTC is safe to exercise and thus having the appropriate screening tools in place to ensure this. Another issue is also ensuring the workforce have appropriate skills, knowledge and expertise to tailor exercise for any of the possible LTC that may present.

Recommendations in relation to referral or signposting

Signposting or referral to groups by HCPs would be dictated by the remit and delivery of exercise within these groups to align with professional standards, e.g. referral would require the delivery of exercise by the relevant groups to be aligned with professional standards. This was the consensus reached by the PARC Advisory sub group. This was based on evidence from PARCS:

- i) the framework for exercise referral currently in delivery in Wales identified by BHF PARCS scoping and a national approach to training and as part of the wider exercise referral work
- ii) CHSS scoping of service in Scotland
- iii) key strategic drivers including the shift of care to the community and the integration of health and social care
- iv) expert opinion (from the Advisory Sub Group membership)
- v) the needs of all partners (represented on the Sub and wider Advisory Group)

For full details, see Appendix 8.

Single point of referral

The majority of Health Boards (13 out of 14) have no single point of referral across the Health Board region, six out of 14 have a regional referral point (CHP, Leisure or Local Authority). Four Health Boards have a referral point or co-ordinator in one or some geographical locations only. These Boards cover large geographical areas and are in rural/semi-rural regions.

Having multiple referral points (people, providers and location), with differing referral procedures, often combined with various pathways for specific conditions, were all reported to be barriers from a referrer perspective. Examples of this are multiple referral forms for different providers in geographical regions, so the referrer needs the appropriate referral form but must send it to the right person, assuming they are aware the service exists and who the referral contact is. This often leads to no referral occurring. Having a single referral point/service co-coordinator appears effective in addressing lack of knowledge of services from the referrer perspective: it simplifies

the referral process and leads to a more effective pathway. Having a single pathway for all LTC is also helpful.

Often it may be challenging, or not feasible to have a single point of referral. Reasons for this include: large geographical regions, different service structures, differing referral pathways and procedures, differing service provider agencies and roles. Solutions evidenced in this scoping include having a regional point of referral and having a single point of access, e.g. the MCN website. Another emerging solution explored as part of the project was the SCI Gateway. SCI Gateway is designed as a national portal for clinical communications between and within Healthcare organisations and has been developed by National Information Systems Group (NISG) as a cornerstone product of the eHealth Strategy in Scotland. Meetings as part of this project suggested the SCI may be expanded to other include social care and other agencies.

Service co-ordinators

Service co-coordinators were mainly leisure employed and often the service co-ordinator and the single point of referral were one and the same role. These roles often had multiple other roles, including managing and delivering services. In urban areas there was more than one service co-coordinator, with an overall management lead. There were various ways of approaching the role of the service co-coordinator from a condition specific perspective or more widely seen as a service co-originator for an exercise referral/LTC referral scheme. Some NHS professionals had the service co-ordinator role – this was often seen in rural areas and in areas lacking leisure service provision. Limitations of having a single service provider e.g. leisure, as service coordinator was lack of signposting to other menu-based options across the community and third sector. This could be due to lack of knowledge of services and relationships, with other providers and concerns regarding quality assurance. The impact for service users was not being offered services that could be of benefit and other community and third sector groups were lacking in referrals, making sustainability an issue.

Inconsistency in pathways

“Key essentials would be a good referral pathway for specific condition... and also general LTC and a directory of what is available in each area”

HCP

There are differences in pathways to EM often both within and between Health Board regions. Exercise referral generic and exercise referral for LTC and cardiac, were evidenced as most available, with stroke least. Cardiac conditions, traditionally having a long term maintenance approach (Phase IV), embedded in the pathway which may explain this being one of the most well reported condition specific pathways.

Importance of clinical rehabilitation and rehabilitation integration

“Patients from... rehabilitation are given opportunity to be referred on to a long term maintenance classes which are generally held in same location and the hour before our rehabilitation classes and they can commence [on] completion of rehabilitation”

Rehabilitation integration was evidenced by PARCS BHF (Wales) and CHSS as important to the pathway, in achieving a seamless transition and increasing likelihood of attendance to EM. Strategies around this include:

- offering PR and CR in community based venues
- offering PR and CR in the same venue as exercise maintenance
- the exercise maintenance specialist instructor/peer attending clinical rehabilitation sessions and promoting exit strategy
- EM session taking place one hour preceding /following clinical rehabilitation.

From a service user perspective this then appears as a continuation of their journey, with the support of peers and professionals with whom the service user has already developed a relationship. The service user is often introduced to a social network that can facilitate attendance at EM, e.g. peers providing transport.

A major barrier to a seamless transition is when clinical rehabilitation is inconsistently provided, this was particularly apparent for PR. The scoping identified that in one Health Board region PR had no funding and there was no PR available, and two other Health Board regions had only short term funding for PR. Delivery of rehabilitation, particularly PR and CR, was identified in some areas as catalyst to establishing EM services in local communities.

Key message

Rehabilitation and rehabilitation integration is a key link in the pathway to exercise maintenance.

Recommendations in relation to single point of referral and pathways

This PARCS framework for the **ideal framework for transition from health to community based activity in the prevention and management of chronic conditions** addresses these issues of single point of referral and pathways. This framework was agreed by the sub group and was subsequently endorsed by the wider PARCS Advisory Group. This was based on evidence from PARCS:

- the framework for exercise referral currently in delivery in Wales identified by BHF PARCS scoping and a national approach to training and as part of the wider exercise referral work
- CHSS scoping of service in Scotland
- key strategic drivers including the shift of care to the community and the integration of health and social care
- expert opinion (from the Advisory Sub Group membership)
- the needs of all partners (represented on the Sub and wider Advisory Group).

For full details, see Appendix 9.

3) IMPACT – HEALTH AND ECONOMICS

“I have been closely involved in many projects over many years that sought to develop and enhance.... services and adherence. Until the MCN and Health Board fully funded a comprehensive staff and service delivery programme, things were always piecemeal and temporary. This seems to me to be the biggest driver in long term successful services”

HCP

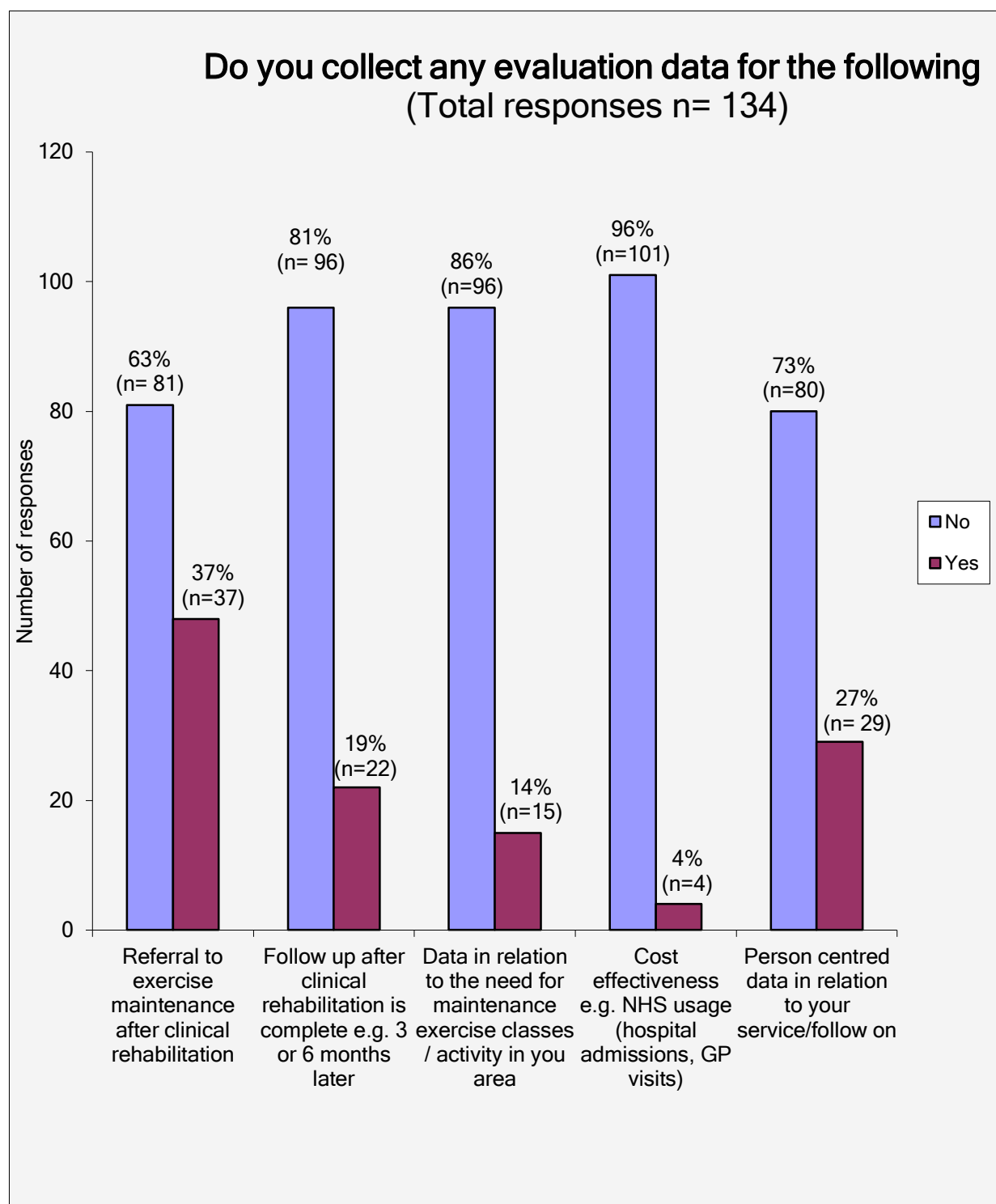
Measuring impact

Data collection is inconsistent in terms of collection, collation and the role or service undertaking this. There are often inconsistencies within Health Board regions as well as between regions. Thus makes measuring and demonstrating impact challenging. Standardisation of data collection is was a key issue with different partners and stakeholders often requiring different data sets to demonstrate impact. Consistency in data collection is needed to demonstrate clinical and cost effectiveness.

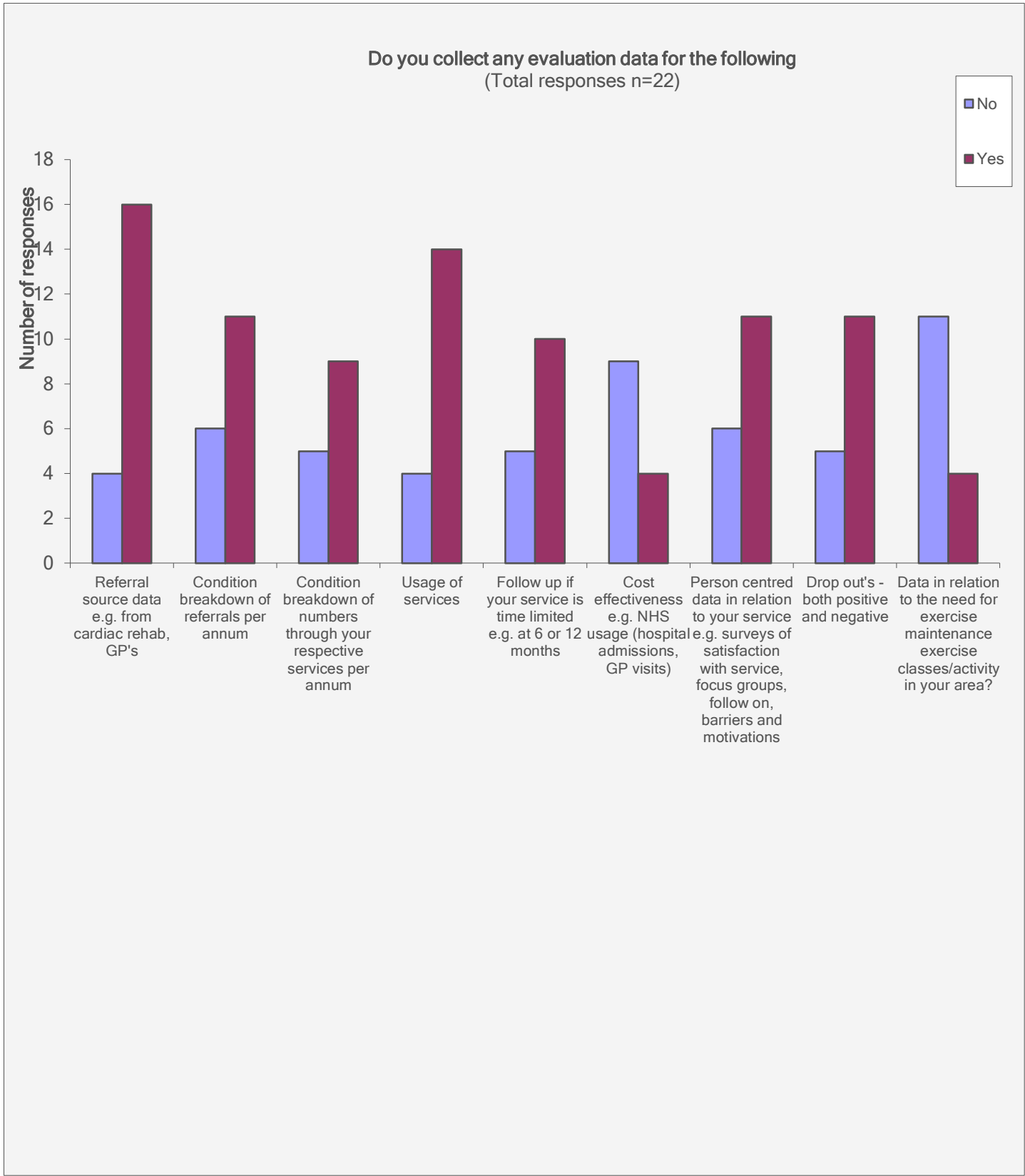
From the surveys

- **HCP reported, 62.79% – 96.19%, did not collect data** in relation to exercise maintenance, in response to: do you collect any evaluation data for referral to exercise maintenance, need for services, follow up, cost effectiveness and person centred data (total n=134) (see graph on next page)
- **Leisure services** reported: overall the response to this was poor (n=22), data collection appeared **inconsistent with most responses to collection of usage and attendance**

HCP responses to:



Leisure services responses to:



From the overview profiles and meetings

Often services collected data in relation to their service, e.g. rehabilitation, data was collected over the period of rehabilitation. Once rehabilitation was delivered, data collection stopped. This was noted in other services. Leisure services reported collecting more data than HCP in relation to EM. In many areas, detailed data was often kept by the individual leisure provider or service. There appeared to be no central mechanism for collating data nationally and often within regions. Resources to collect and collate of data were a barrier including staff time and administrative support for this.

Lack of standardisation of data collected often related to the lack of standardisation of data collected on the referral forms. The scoping showed different referral forms within and between regions. Reasons for this included different service providers, and each provider had often agreed the content of referral forms with many different refers and then produced databases around this.

Funding

Funding for instructor training shows variation and inconsistencies of funding streams. Often short term funding only is needed to meet training costs. Approaches to this are often fragmented, i.e. individual providers training instructors. Health Board or CHP wide approaches via collaborative working groups appear to maximise resources (see instructor training sections above for more detail).

Funding streams for service delivery show a large variation, often with variations /inconsistencies of funding streams from statutory bodies for service provision. The third sector was often a key partner or provider. Integrated partnership funding is seen in well-established schemes with a large reach. Some services are self-sustaining once established. Leisure reported to be the primary provider of funding (See Appendices 4 and 5). Funding for Leisure Services provision was often short term which prevented service development, affected staff recruitment, training and retention and data collection.

PERSON-CENTRED

SERVICE USER PERSPECTIVE IMPACT AND KEY MESSAGES FOR DELIVERY

Impact from a service user perspective was evidenced by both service users, HCP and GPs (see Appendices 4 and 5). Impact of exercise groups for service users from a HCP perspective (both HCP and GP surveys) included benefits in health and wellbeing, and the facilitating and supporting the health promotion message.

The full details of service user engagement can be found in Appendices 4, 5, 6 and 10, including extrapolation of existing data (Appendix 11).

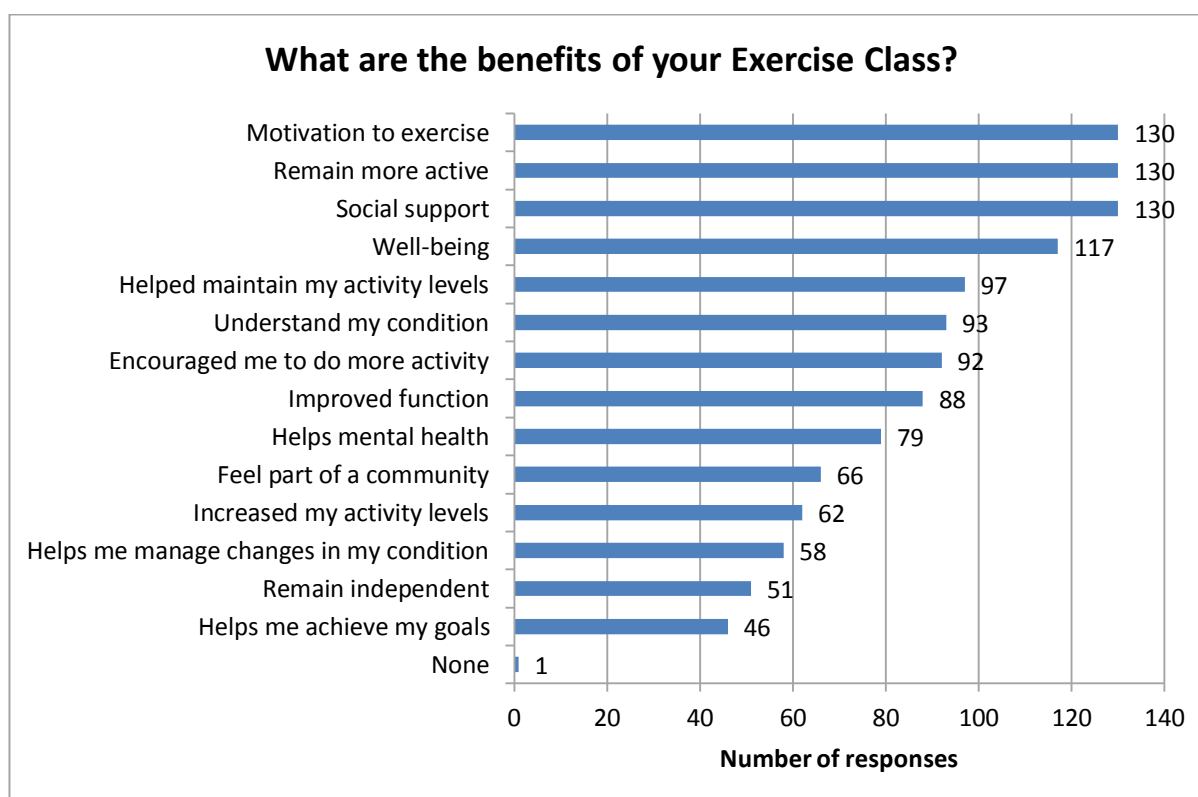
The Service User Advisory group considered the PARCS BLF and CHSS work (see Appendix 10) and identified that the social interaction and peer support were key. The key messages they wished to be presented were:

Health Impact

- **Achievement of physical activity targets of service users attending an exercise maintenance group:** 76% (n=165) meet physical activity targets compared to national averages of 15% for chest, heart and stroke conditions
- **Exercise group linked to improvement in condition:** 76% (n=165) report feeling their condition has improved since joining the exercise group
- **Benefits of the exercise class:** the key benefits were social support (n=130/222), motivation to exercise (n=130/222) and remaining more active (n=130/222)
- **Potential link to reduced hospital admissions:** 74% (n=165) of service users reported having no hospital admissions in the last year.

The benefits of being part of an exercise group from service users of CHSS-affiliated groups were multiple (see Appendices 4 and 5). Some of these groups were part of partnership service delivery, e.g. with leisure and local authority, NHS and some groups were independent.

Physical, social, psychological, self-management and societal benefits of exercise group were the main reported benefits of exercise group – (in order of prevalence) social support, remaining more active, motivation to exercise, improved wellbeing, maintaining activity levels, understanding their condition, encouragement to do more activity, improved function, improved mental health and feeling part of a community. Similar benefits were reported from support groups in terms of physical, social, psychological, self-management and societal.

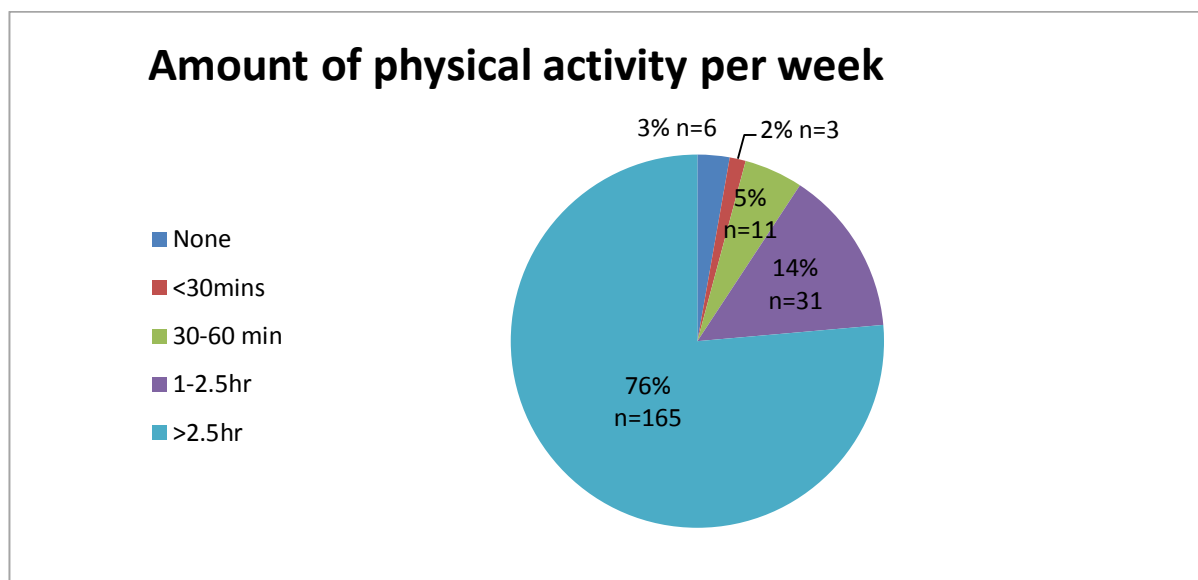


Physical benefits

Service users in CHSS-affiliated exercise/support groups (self-reported)

- **physical activity targets³ achieved:** 69% (n=124) meet physical activity targets compared to national averages of 15%

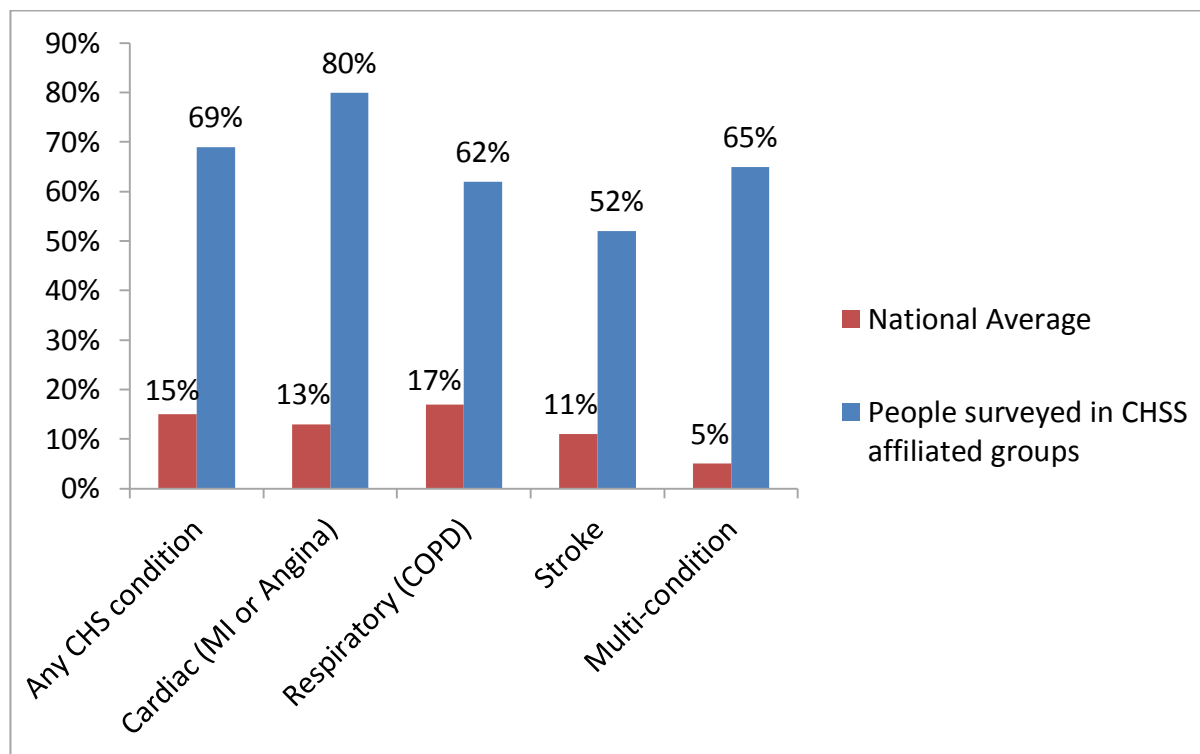
CHSS service users in affiliated groups (exercise and support group) responses to the question: Physical activity includes walking, active household chores, and sport and leisure activity. How much time do you spend doing these activities in one week? Various options were offered ranging from none to 2.5 hours. The national figures used for comparison were from the Scottish Health Survey (SHS) questionnaire which asks about four broad types of activity: activity at home (housework, gardening, DIY); walks of 15 minutes or more; sports and exercise activities, and activity at work. For each of these types of activity, questions are asked to establish the frequency, duration and intensity of activity in the four weeks prior to interview. Both the PARCS and the SHS questionnaires were self-reported PA.



³ Adults should accumulate (build up) at least 30 minutes of moderate activity on most days" (Let's make Scotland more active: a Strategy for Physical Activity, physical activity task force (2003) <http://www.scotland.gov.uk/Resource/Doc/47032/0017726.pdf>). „Adults aged 18–64 should do at least 150 minutes of moderate-intensity aerobic physical activity throughout the week or do at least 75 minutes of vigorous-intensity aerobic physical activity throughout the week or an equivalent combination of moderate- and vigorous-intensity activity. The recommendations listed above are applicable to the following health conditions: cardiorespiratory health (coronary heart disease, cardiovascular disease, stroke and hypertension); metabolic health (diabetes and obesity); bone health and osteoporosis; breast and colon cancer and depression". „The evidence is currently insufficiently precise to warrant separate guidelines for each specific disease". „Adults aged 65 years and above should do at least 150 minutes of moderate-intensity aerobic physical activity throughout the week or do at least 75 minutes of vigorous-intensity aerobic physical activity throughout the week or an equivalent combination of moderate- and vigorous intensity activity". „The recommendations listed above are applicable to the following health conditions: cardio-respiratory health (coronary heart disease, cardiovascular disease, stroke and hypertension); metabolic health (diabetes and obesity); bone health and osteoporosis; breast and colon cancer and prevention of falls, depression and cognitive decline'. (World Health Organisation Global Recommendations on Physical Activity for Health (2010), http://whqlibdoc.who.int/publications/2010/9789241599979_eng.pdf?ua=1) See also Appendix 2.

Comparison of the amount of physical activity per week of those attending CHHS-affiliated exercise group compared with the national averages, by condition.

(National averages from Scottish Health Survey combined results compiled by Public Health and Sport Analytics service, the Quality Unit Scotland, on request of PARCS project manager)



- **the exercise group was an important contributor to physical activity and improvement of condition:** the exercise group was the second largest reported type of physical activity people were partaking in after walking and 76% (n=136) report feeling their condition has improved since joining exercise group. Groups were also linked to preventing deterioration of health.

“I don't think I would be as fit as I am if I didn't go to the class each week”

“Without [the exercise group] I don't think I would have survived long. They have opened my eyes to what exercise can do to improve my health and wellbeing”

“I feel the benefit of taking part and it encourages me to take further independent exercise. Extremely valuable service and I intend using it regularly”

“The class has made me do exercise I would otherwise not have done. Through attending the class I have now taken up golf which I play twice a week”

Social benefits

The social aspect of groups was of primary importance in terms of social interaction and support. This included encouraging and enabling people to attend classes, helping them to stay active and helping support each other through various stages of a long term condition. The groups promoted and enabled social interaction and addressed social isolation.

“Before I heard of [exercise group] I never went anywhere, I sat at home, did no exercise. Now I get out at least once a week for exercise and company of other people I never knew and we have a laugh and days out through the year and at Christmas”

“I am now oxygen dependent, and have been for past two years. I have someone from the support group who picks me up so I can attend. As I am in the end stages of COPD I cannot do very much but attending the... group helps and I have made friends there”

“The social interaction is wonderful, also helpful to hear others” experiences. I look forward to my class every week”

Psychological

Psychological aspects included motivation to exercise, positive effect on mental health and wellbeing and reduced fear associated with exercise and activity, as well as improved confidence

Mental health:

“In general very beneficial to my physical and mental welfare”

Motivation:

“Motivated to attend weekly to socialise and exercise”

“I feel the exercise group is very important if it wasn't available my health and fitness would deteriorate. It motivates me to carry on walking and to keep active”

“Firmly convinced of the benefits of exercise for all. Exercise within a group makes it easy to keep going even when sometimes you might feel like having a night off”

Fear/confidence:

“It has helped me to do more without getting worried about getting out of breath. It has helped me control my breathing better and know my limitations”

“I was unsure what I could physically do without (in my mind) disturbing the stent!”

Self-management

The groups were reported as integral to enabling self-management, including improving knowledge in relation to their condition and how to manage it.

“I feel better awareness is a priority to help patients to help themselves”

“The NHS staff referred us to the group and it has given a sense of involvement in self-management of condition, up to date information on COPD and a wonderful routine... with the knowledge that we are all in the same boat with great emotional support. Life-changing”

“I have learned so much about my condition from our group”

Societal benefits

Many people reported becoming involved in these groups and as result of this wanting to „give back“ and become more involved in their community often through volunteering and supporting others.

“I have gone on to do voluntary work in seated exercise classes for the frail and the elderly. Also assist in classes doing exercises for patients with MS, stroke sufferers and COPD. Doing these classes has given me a new lease of life, seeing the improvement in their wellbeing is my way of saying a huge thank you to the doctors, nurses and physiotherapy staff for their care and attention”

“For my heart condition I feel a lot better... I will always have a condition and need to take medication. My osteoporosis causes me more pain and inactivity. I have a good group who help a lot. I still like to do my bit of volunteering and help others less fortunate”

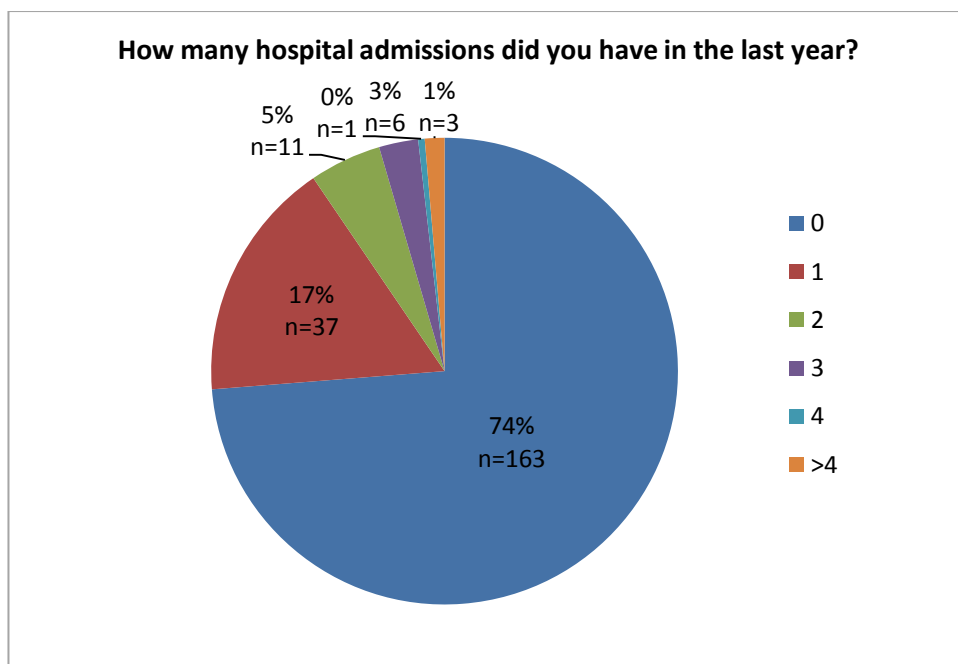
Attendance/Adherence

Attendance /adherence was high with the majority being members of exercise group for more than three years (56% n=100).

Economic impact

Hospital admissions

Data collected suggests that attendance at exercise/support groups may be linked with hospital admissions. 74% (n=163) reported not attending hospital in the last year.



The data collected on self-reported admissions (related to their condition) by exercise maintenance groups' service users was compared with national-level admissions data from ISD (2011)^{4, 5} in the PARCS economic report (see Section E).

Table 2 – National data on admissions, bed days and patients derived from ISD data tables (referenced above) for calendar year 2012

Condition group	Admissions	Patients	Admitted patients as		Mean bed days per admission	Mean admissions per patient
			% of total prevalence	Total bed days		
CHD	24897	19911	5.021%	113493	4.6	1.250
COPD	18904	12163	10.488%	144389	7.6	1.554
Stroke	7899	7607	6.530%	202767	25.7	1.038

Self-reported data on admissions from the 221 PARCS survey respondents attending a CHSS-affiliated exercise group (n= 181) support group (n= 106) (majority reported engagement in varied PA, a small number reported they were non-active, n=6) showed an average numbers of admissions per respondent as follows:

- Cardiac conditions: 0.38
- COPD: 0.42
- Stroke: 0.76

The breakdown by condition of those that had not had a hospital admission in the previous year: 78% of respondents with cardiac conditions, 67% of respondents with respiratory conditions and

⁴ Cardiac and Stroke data taken from ISD Table: Number of bed days, admissions and patients for selected conditions, NHS Scotland, Calendar Year 2011.

⁵ COPD data taken from ISD Table: Total and average number of admissions and bed days for COPD, NHS Scotland, Calendar Year 2011.

60% of respondents with stroke conditions. However it is important to note that the national admissions data also includes initial and acute events and is actual admissions, whereas many of the survey respondents had been living with their condition for a number of years and self-reported. Nonetheless this small scale dataset does offer positive indications of the role of exercise maintenance in reducing admissions and this area would benefit from further investigation. Rigorous economic analysis was outwith the scope of this project and the scoping undertaken so far highlights the need for a rigorous, comprehensive cost-effectiveness analysis.

The physical activity message – who, where, how

The message from service users was that that the majority were told about and understood the importance of physical activity but that support to be active in their community was what they required. The importance of the HCP in delivering this message was important to the individual.

- **Brief intervention/physical activity message was achieved:** 86% (n=180) were told about the importance of physical activity
- **HCPs were important in delivering the physical activity message:** physical activity message delivered by physiotherapist (n=117), nurse (n=107), GP (n=93) and hospital doctor (n=76), support group (n=53) self-management (myself) (n= 59)
- **Clinical rehabilitation, self-referral and routine appointments** were important for information about exercise maintenance/classes. Information about exercise class delivered at cardiac rehabilitation (n=110), pulmonary rehab (n= 25), self-initiated (n=26), routine appointment (n=18).

Key Issues from a service user perspective

HCP involvement/ importance of rehabilitation

The role of the HCP in encouraging, supporting and enabling follow on activity was important.

“I believe that if the rehabilitation team had not told me of the groups and encouraged me to take part I would have struggled to find out about alternatives myself. I also believe that I wouldn't feel better and may in fact have had further complications”

“All were recommended to me by rehab nurses and by the physiotherapists who were brilliant and very encouraging”

Peer support

Social and peer support throughout the journey was again very important. This peer support included forming relationships during rehabilitation which continued into the community, visits to rehabilitation to encourage further attendance, helping one another in terms of transport and support when there was a change in an individual's health. Another factor was being able to talk to people who had been through similar events and had similar conditions.

“Knowing that you are not alone is a great support. We all support one another”

“Talking to other people with similar problems is one of the most helpful things about the group”

“A representative from the class came and talked about it during cardiac rehab. A leaflet and contact details were provided. I am greatly indebted to all parties concerned”

Access

Local access was a key theme; the service being offered locally and the ability to get there transport and parking at the venue were factors.

“Access to activity groups in this area is very easy”

“I have to take a bus to meetings and there is no bus home until two hours after the meeting. Sometimes I can now get a lift home. I would rather go to an exercise group where I live”

“Exercise groups are pretty well known to local residents but everyone at these classes has the common issue with transportation to and from them”

Knowledge of services

Lack of knowledge of services was a key issue, even in regions of good service provision, and greater awareness from HCP was noted as ways to improve service delivery.

“I believe that patients are not made aware enough about what exercise groups are available. Likewise more could be done to inform patients about support groups which are relevant to them. I have personally found both of the above to be very beneficial”

“I saw a leaflet about the [exercise group] classes and made enquiries about joining. I feel that information on exercise classes should be given greater prominence and be funded by the area health authority”

“I feel better awareness is a priority to help patients to help themselves”

“After this rehab it was suggested that I continue with follow-on classes on cardiac exercise”

Tailored supervised exercise by qualified staff

The ability to have exercise tailored to the needs of the individual was very important, as was the knowledge and support of the instructor and the feeling that exercising was in a „safe“ environment.

“The instructor is knowledgeable and understands all our problems”

“Gave me the confidence and encouragement to exercise in a safe environment. Having a medically qualified physio/instructor is essential”

“Provides guidance and is knowledgeable on our conditions and encourages us to push for better results, all to our gain”

“I would love to join an exercise class where the leader understands my needs”

Transition to follow-on in the community

The move from NHS services e.g. clinical rehabilitation to follow-on physical activity/exercise services and achieving a seamless transition was varied. From the survey the majority of service users reported an easy transition. However this may reflect the fact that they are indeed service users and many reported actively seeking opportunities and groups. From meetings as part of the project with service users and potential service users (see Appendix 6) in areas with an established service in place, the „seamless transition“ to follow-on services was easy; for others in areas with varied or lack of service provision, this often led to a delay or lack of uptake. The length of time was also important as if you had a condition for a longer time, follow on services may not have been available when you were having treatment.

“It was always a natural progress from rehab to [follow on exercise group] but sadly does not seem to be the norm now”

“I had physio for three months following my stroke, but never attended, nor know of, any exercise groups”

“In 1990 when I was diagnosed I got six weeks at a pulmonary class, after that there was nothing in this area. Over the years things got better... Sports centres started letting pulmonary people attend whereas before they would not let us in the door. More classes started...support groups sprang out of these classes. I have tried to take an active part in what has gone on and hope what is still to come”

“I have no issues with my treatment and subsequent support activities offered. Everything has been first class and professionally administered throughout. Classes offered locally, very well run and attended. Local fitness facilities also offered via NHS, professional again. Excellent services provision if taken up as offered”

Tackling health inequalities, deprivation areas and ethnic groups

As part of the project, two meetings took place to address health inequalities. One was a meeting with people who had completed pulmonary rehabilitation in an area of social deprivation which was also rural and another with an ethnic group (see Appendix 6). Key issues from these groups were around access. One example was an individual with a respiratory condition whose oxygen only had a one hour life span. He lived in a rural community, with no service provision so to travel to the nearest town with a service was a one hour trip each way. This was not possible in terms of the oxygen supply but also due to the fatigue involved in travelling to a class, as well as partaking in it. Although this man wanted to be active and be part of a group, his condition and lack of service provision made this impossible. Other findings were similar to service user surveys in terms of knowledge of services, tailoring of exercise, and the importance of peer support in follow up.

From the women's ethnic group, similar themes were identified in terms of HCP support, tailored exercise and the social aspect. Specific issues were around social support within the community after illness – this is offered by the family and extended community and thus the ideal would be to deliver the service, exercise, education and support for self-management, in a way that works with this existing support network, by bringing the service to the community in a culturally sensitive manner. Again key issues and lessons learnt from previous initiatives were that a collaborative approach, sustained funding and delivery, tailored exercise led by a specialist instructor and local access delivered within the community and at a community venue, incorporating social support, were important.

OBJECTIVE 3 – EXPLORATION OF INNOVATIONS AND TECHNOLOGY SUMMARY

- Scope innovations and technologies available/emerging
- Identify relevant innovations/technology for exercise maintenance/physical activity opportunities

Methods: Meetings and scoping as detailed above, internet searches and networking, attendance at relevant conferences/launches throughout the duration of the project.

Results: Innovations and the use of technology can address some of the issues and barriers the project has identified and related projects that support the multi-intervention approach including self-management. Key projects/resources were identified by the PARCS project. Further details of these and potentially others will be available in the PARCS resource, which follows this report. There is a need to develop telehealth/care applications to promote PA in individuals with cardiac, stroke and/ or respiratory conditions.

Key messages from innovation and technology

- take the service to the service user
- innovations and technology an address barriers in particular access and knowledge of services
- there is a need to develop telehealth/care applications to promote PA in individuals with cardiac, stroke and/ or respiratory conditions

INCLUSIVE ACCESS to EM service

Innovations in service delivery – targeting hard to reach groups

Tackling health inequalities - deprivation

- **GGC: Silver Deal** is a partnership between Glasgow Housing Association and Glasgow Life that provides free regular, coach-led physical activity and arts sessions in GHA Sheltered Housing Complexes www.paha.org.uk/CaseStudy/silver-deal-active
- **Xcite (West Lothian Leisure)**: instructors deliver classes in community venues, e.g. working men's clubs in ex- mining communities/

Tackling health inequalities - those housebound and carers of those with LTC

- **Angus, Tayside: Be Active... Live Well**, a programme of activities for people with a LTC, a partnership organisation between Angus Cardiac Group (CHSS-affiliated), Angus Council's Leisure Services, Angus Community Health Partnership, Angus Chronic Obstructive Pulmonary Disease (COPD) Groups, Volunteer Gold and the Angus Carers' Centre in collaboration with Angus Care and Repair. The programme is not time limited. There is also delivery in care homes by trained care home staff for seated exercise. They have also facilitated access to exercise classes for carers, to exercise with individuals with LTC conditions. This gives carers the opportunity to exercise and social support and support the person they are caring for to exercise.
- **SCI Gateway** is designed as a national portal for clinical communications between and within healthcare organisations and has been developed by National Information Systems Group (NISG) as a cornerstone product of the eHealth Strategy in Scotland. Meetings as part of this project suggested the SCI gateway may be expanded to include other social care and other agencies <http://www.nisg.scot.nhs.uk/currently-supporting/sci-gateway>

Telehealth and technology

ACCESS to PA and EM

- **NHS Lanarkshire and Glasgow University, Podcasts for EM**, a partnership with NHS MCN and an academic institution. Research started for multiple sclerosis and is now expanding to looking at podcasts for COPD. Contact: Lorna.Paul@glasgow.ac.uk
- **World Walking** is virtual walking designed as a simple, free and fun way to keep active <http://worldwalking.org/>

There is a need to develop telehealth/care applications to promote PA in individuals with cardiac, stroke and/or respiratory conditions

ACCESS and KNOWLEDGE of services

- **Living It Up:** a £10m digital health, care and wellbeing project with connections to information and services in the community. Living it Up aims to help in the design and development of ways in which local services can be delivered digitally, to provide tailored advice on improving and managing health, care and wellbeing, and to ensure technology matches an individual's needs and interests with professional information, local services, and beneficial activities and events in their community. <http://www.sctt.scot.nhs.uk/living/>
<https://portal.livingitup.org.uk/>
- **ALISS:** a community-driven initiative which makes it easy to find and point to local online information about keeping well. The focus is helping people to live better with long term health conditions, providing tools and frameworks, and working with communities to build infrastructure together. The [ALISS Engine](#) links up current data and ideas from people living with LTC. ALISS is currently working towards a new national set of links that can be used by all, to provide better, more tailored local information and create new self-management information services
- **Active Scotland** enables people to be active in their local area or across Scotland. This includes: sports centres, community halls, parks, gyms, climbing walls, woodlands, swimming beaches, national cycle routes.
- **NHS 24, Health Advice on digital TV:** NHS 24 offers a digital channel to improve people's access to health information and advice. The channel is available through Freesat, Sky and Virgin and gives access to health advice and information on local services. Apps are also available. This aims to improve access to health information for those without home internet access often people from deprived communities and older people.

The national initiatives, Living It Up, Active Scotland and ALISS, are now harmonising. Some information/databases are still developing in relation to local access for those with LTC. It is hoped that a further PARCS Phase 2, subject to future funding, would allow the local initiatives and groups identified in the PARCS scoping to be added to these databases.

ACCESS to REHABILITATION which is key in pathway to EM

- **NHS Ayrshire and Arran:** PR which has links with maintenance, delivered electronically. www.sctt.scot.nhs.uk/programmes/community/home-based-health-monitoring/copd/
- **NHS Tayside (and other regions):** remote PR
<http://www.sctt.scot.nhs.uk/archive/health/remote-pulmonary-rehabilitation/>
- **Activate Your Heart®** is an online cardiac rehabilitation programme that has been designed by cardiac rehabilitation specialists and patients at the University Hospitals of Leicester NHS Trust. The aim of the programme is to help those people who have had a recent cardiac event or have an existing cardiac problem, manage their condition more

effectively. This is currently being piloted in two regions in Scotland lead by lead clinicians in NHS Lothian, NHS Forth Valley and Scottish Centre for Telehealth and Telecare (SCTT).

PATHWAY, single point of referral and data transfer

- SCI Gateway is designed as a national portal for clinical communications between and within healthcare organisations and may offer solutions for secure data transfer between agencies e.g. NHS and non NHS (e.g. leisure and other service providers).

As part of a multi -intervention approach that includes self-management

- **CHSS – My lungs, My Life** (in development) will be a free resource for individuals with COPD, adults with asthma and parents/guardians of children with asthma. This new website is being developed by Chest Heart & Stroke Scotland working in collaboration with the National Advisory Group for Respiratory Managed Clinical Networks (NAG), British Lung Foundation (BLF), the Scottish Government, the University of Edinburgh (technical partners), patients and parents. It is envisaged that „My Lungs, My Life“ will be a comprehensive resource that will help patients to undertake self-management. This will include a physical activity module.
- **CHSS – Self help 4 stroke:** a free stroke-specific, self-management online resource for people following stroke. The areas addressed are key topics that people following stroke have personally identified as important to them within their self-management. This will include a physical activity module. (In development, will be launched at the Scottish Stroke AHP Forum Conference in June 2015.)
<http://www.chss.org.uk/stroke/Selfhelp4stroke.php>
- **Sound Doctor Resource App** aimed at individuals with LTCs, including COPD, to help improve their quality of life. Health care professionals giving audio information and video clip including practical advice, includes physical activity.

Training for self-management and heart disease

- **COSMIC** training – Champions Of Self-Management and In Care, free training for service users and other stakeholders e.g. NHS HCPs and social care.
http://www.chss.org.uk/voices_scotland/cosmic
- **Heart E Project** – Heart Education Awareness Resource and Training through E-learning a free heart disease educational resource that health and social care professionals across Scotland can access http://www.chss.org.uk/education_and_training/heart_e.php

OBJECTIVE 4 - IDENTIFICATION OF RESOURCE NEED, SERVICE USER AND/OR SERVICE PROVIDER SUMMARY

Identification of primary resource need based on the all three strands of the project: PARCS CHSS, BHF and BLF

Methods:

Service user resource need: Identification of need for a resource from a service user perspective. This was based on CHSS scoping and meetings with service users detailed earlier. The PARCS Service User Advisory Group was then consulted (see Appendix 10) regarding PARCS qualitative work and the PARCS scoping findings. This group reached consensus on recommendations regarding a resource need from a service user perspective.

Service provider resource: Identification of need for a resource from a service provider perspective. This was based on CHSS, BHF and BLF scoping. The PARCS Advisory Group was then consulted and reached consensus on recommendations regarding a resource need.

Results: The PARCS Advisory Group considered that the primary need was a service provider resource.

Resource need from service user perspective

It is not necessary to have more information on the benefits of exercise; rather the need is for details of local facilities/opportunities and support around this

- **A web-based resource, with sustained funding**, which acts as a repository of information with a person to facilitate and maintain/update this (although this may not be suitable for all).
- **Tailored professional local support** for people with complex needs e.g. stroke, ideally one-to-one support, so that individual conversations can happen, either with a person who is the single point of referral/service co-ordinator or with another person with appropriate knowledge to signpost/access relevant services.

Resource need from a service provider perspective

- **Production of service provider resource** to support service delivery for LTC PA/EM in the community.

The PARCS Advisory Group reached consensus that the primary need was a service provider resource aimed at all potential service providers in relation to service delivery (including NHS, leisure, third sector and partnerships). Due consideration was given to both resource needs and findings of PARCS CHSS, BHF and BLF scoping. The rationale for this was

that a resource for service providers addressing service delivery had potential to address the tailored local support need identified by service users and potentially the scoping of local services as part of PARCS could potentially link with other national resource initiatives.

Outcome: BHF to lead on development of the resource, with some content linked and/or generated by the wider scoping undertaken and outputs of the three charities.

OBJECTIVE 5 – SUMMARY OF IDENTIFICATIONS OF GOOD PRACTICE MODELS, CRITICAL SUCCESS FACTORS AND PERSON CENTRED PATHWAY

- a) **Identify good models of practice** in differing geographical areas of Scotland – urban, semi-rural, rural
- b) **Identify critical success factors** in relation to NHS quality strategy for service delivery of EM
- c) **Person-centred pathway** to maintenance in the community for LTC, based on user need

Methods:

Points a) and b) were generated by the Project Manager based on the scoping (methods and findings detailed in objective 2. This included visits to different geographical (urban, rural and semi-rural) Health Board regions and meetings with various stakeholders within these regions.

Point c): initial service user group meeting (n= 8) to develop pathways, a further group (n= 14) looked at these pathways and provided further feedback. These meetings with cross sections of service users at the beginning of the project, in differing geographical regions, were largely opportunistic and aligned with other areas of work the charity was involved in. A table to summarise this work can be found in Appendix 11. These pathways were then provided to the BLF for their qualitative work. A subsequent single pathway was developed by the BLF qualitative work and the Service User Advisory Group was consulted regarding this and recommendations in relation to this made. This pathway was then provided to the BHF for use.

Results/Outcomes: Good models of practice, critical success factors and a person centred pathway were produced and provided to the BHF, with subsequent adaption for the target audience for the resource.

- a) **Identification of good models of practice** in differing geographical areas of Scotland – urban, semi-rural, rural and island Board with detailed schematics of these good practice models produced. Key elements were identified and anonymised models incorporating the key elements for the respective geographical regions were produced. These schematics were then provided to BHF. The BHF project lead adapted these for the PARCS resource in order to harmonise with overall findings of the three strand PARCS project (CHSS, BHF and BLF) and to ensure user friendliness for the cross sector target audience (see Appendix 12).
- b) **Critical success factors produced** for EM to align with the NHS quality strategy in differing geographical areas of Scotland – urban, semi-rural, rural. Key elements were

identified and generic critical success factors were produced incorporating the key findings. These **critical success factors** schematics were then provided to BHF. The BHF project lead adapted/simplified these for the PARCS resource in order to harmonise with overall findings of the 3 strand PARCS project (CHSS, BHF and BLF) and to ensure user friendliness for the target cross sector target audience for the resource (see Appendix 13).

- c) **Person centred pathway produced** to maintenance in the community for LTC, from a service user perspective. The BHF project lead adapted these for the PARCS resource in order to harmonise with overall findings of the 3 strand PARCS project (CHSS, BHF and BLF) and to ensure user friendliness for the target cross sector target audience for the resource (see Appendix 14)

Good practice models

Good practice models identified included one large urban area which included a standardised delivery of services via a generic long term conditions approach across the Health Board region. This service was well established with a large reach, with a collaborative approach to delivery, funding and governance, specialist instructors trained across condition areas delivering tailored exercise at different functional levels and menu-based options. This region also offers integration with rehabilitation being delivered in community and leisure venues with follow on classes linking to this. HCP were also providing support to instructors in relation to initial training and continuous professional development. Also available within this region are initiatives to address hard to reach groups e.g. deprivation by taking the service to the service user. There were other urban areas which also had good practice models and key elements of good practice.

A semi-rural model was identified in a region where there were large towns and other areas which were more rural. This model again has a generic long term conditions approach across the Health Board region. This service was well established with a large reach with a collaborative approach to delivery, funding and governance, a single point of referral/service co-ordinator, specialist instructors training across condition areas and delivering tailored exercise at different functional levels, and menu-based options. This region also offers integration with rehabilitation being delivered in venues with follow on classes linking to this. HCP were also providing support to instructors in relation to initial training and continuous professional development. In both these regions leisure was the service provider, in partnership with the NHS and other stakeholders. Both regions had initially delivered a condition specific model for various conditions and evolved to offer a generic approach.

A rural model was identified in one community health partnership (CHP) region, although this was not an isolated example as a CHP in a different geographical region was also identified. This model has a collaborative approach to delivery, governance approach and funding, a service co-ordinator and specialist instructors training across condition areas delivering tailored exercise at different functional levels and a menu-based options with integrated third sector and peer support. This group was initially a person-centred initiative in partnership with the third sector (CHSS) and NHS staff, delivering cardiac specific classes. Again this evolved into a generic long term conditions model in response to service user need. This region also offers integration with rehabilitation, with peer visits to clinical rehabilitation. Also available within this region are initiatives to address hard to reach groups including carers and those in care homes, by facilitating carers to exercise with the person they care for and delivery of exercise in care homes via staff with appropriate training.

One island board was identified as a good model of practice in offering services for cardiac and stroke. These services has a large reach, with service co-ordinators for these conditions, a collaborative approach to delivery and funding and specialist instructors training across condition areas delivering tailored exercise. This is integrated with rehabilitation with an exercise after stroke course offered as part of the pathway for those with stroke, which is initially HCP lead with continuation into leisure.

“...Very keen that we support the local hospital to continue on from medical treatment to life-long management of exercise. This is delivered through exercise specific classes and a good working relationship with medical staff to find out level of conditions and find the correct pathway to take the customer out of the hospital and into a leisure environment...

Usage continues to grow due to the excellent relationship between NHS Shetland and Shetland Recreational Trust. The customers are probably our „most grateful“ for the services we provide as it not only improves their physical abilities but opens a pathway for social interaction. This is essential for good quality of life - they have the challenges, we don't!”

Service provider, island board

All models incorporated all or some of the identified key elements of service delivery which included:

Key elements of service delivery

- Single point of referral/service co-ordinator within the CHP or local authority region
- Governance via a multi-agency group, e.g. MCN or multi-agency working
- Integration with clinical rehabilitation
- Specialist instructor led classes
- Tailored exercises which were function based and offered at different levels e.g. seated exercise to moderate circuit level
- Linkage with other menu-based options under the umbrella of self-management, including physical activity e.g. walking groups and other options such as support groups and, where services were time limited an exit strategy to ongoing self-management (PA and other support)
- Pathways that included referral from the health interface including primary, secondary care and self-referral and screening
- Peer support

ADDITIONAL OBJECTIVES

As part of the project it became apparent that key issues needed to be addressed in order to make recommendations, therefore further objectives were identified, as detailed in the table below:

OVERVIEW OF ADDITIONAL OBJECTIVES ACHIEVED
Objective 6: Produce a proposed framework for transition from health to community based activity in the prevention and management of chronic conditions that can be recommended to SGHD
Objective 7: Address issue of instructor training and reach conclusions and recommendations for SGHD

OBJECTIVE 6
Produce a proposed national framework for transition from health to community based activity in the prevention and management of chronic conditions

Method: The PARCS Advisory Sub group consisted of NHS: MCN manager, HCP-physiotherapists, Health Scotland, academic institution (professorial lead), also a representative of the Scottish Stroke Allied Health Professions Forum (SSAHPF), Academic and Register of Exercise Professionals/Skills Active representative, Leisure, and third sector: CHSS and BHF. This group was consulted in relation to a proposed framework for transition from health to community based activity in the prevention and management of chronic conditions in Scotland.

Discussions around the proposed framework were based on the framework for exercise referral currently in delivery in Wales identified by BHF PARCS scoping and as part of the wider national exercise referral work (i.e. England, Wales and parts of Scotland). The proposed framework was discussed in relation to the transition from health to community based physical fitness and activity, rather than solely an exercise referral context. The proposed framework in Scotland should align with the strategic drivers of shift of care to the community and the integration of health and social care. Discussion focused on if and how the Wales framework could be modified for use across Scotland to integrate and not exclude existing varied service delivery, from all sectors, identified within the PARCS Scotland scoping. Good practice models that demonstrate how various Health Boards are delivering this service already were agreed should be included in the report to SGHD, to give Health Boards an understanding of how delivery is currently implemented. Full details of this meeting and the spectrum of issues discussed that surround this framework can be found in Appendix 8.

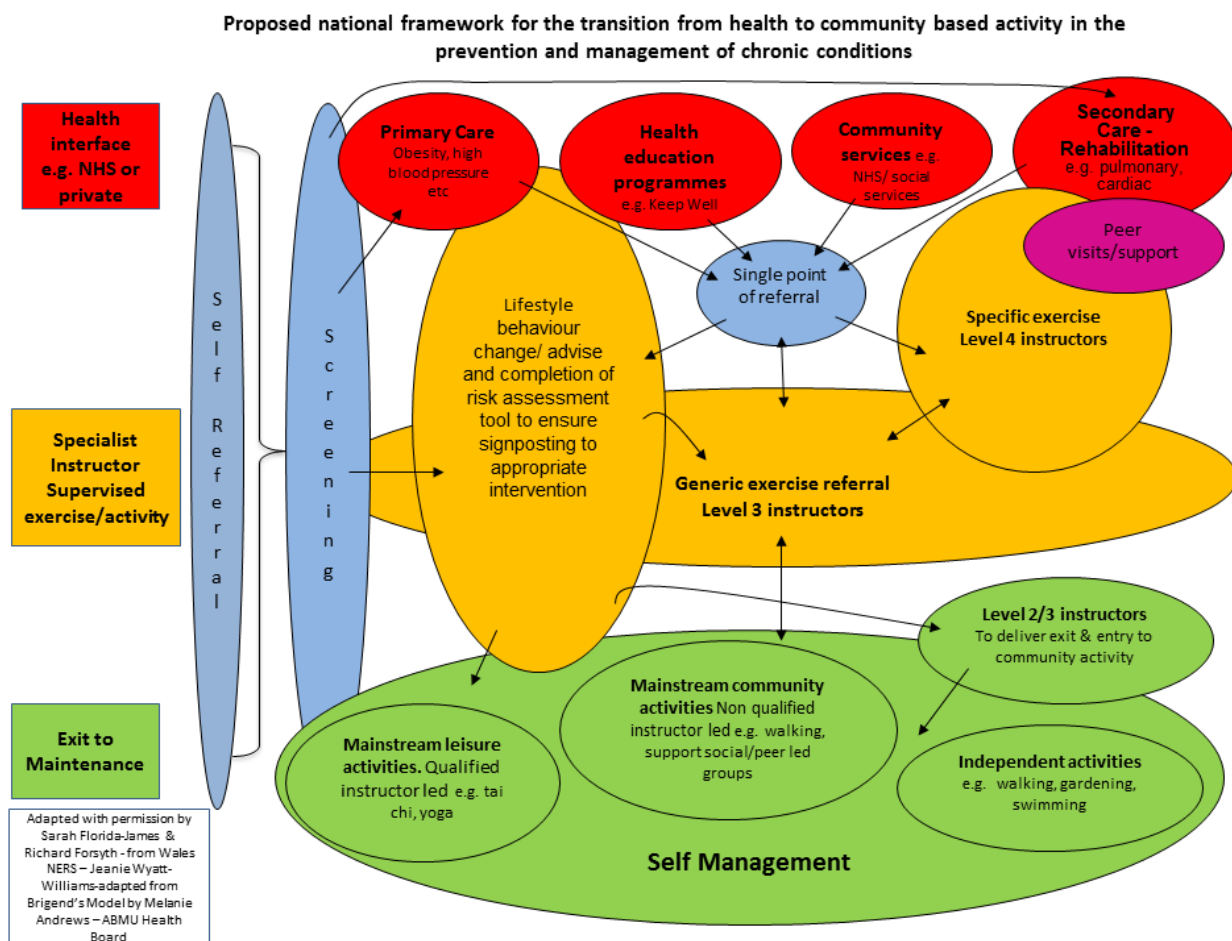
Results:

- **Consensus was reached for the proposed national framework** for transition from health to community based activity in the prevention and management of chronic conditions (see below and Appendix 9)
- **Consensus was reached in relation to the skills, knowledge and expertise needed at each tier** (see below and Appendix 8 and 9)

Recommendations to the SGHD in relation to the framework

- 1) **Recommend to SGHD to use this agreed proposed framework for transition from health to community based physical activity in the prevention and management of chronic conditions (See Appendix 9)**
- 2) **Recommend that SGHD present the proposed framework to Health Boards in relation to the transition from health to community based physical activity in the prevention and management of chronic conditions. This will enable Health Boards to identify where any gaps in the service in their region exist.**

FRAMEWORK FOR SERVICE DELIVERY IN THE PREVENTION AND MANAGEMENT OF CHRONIC CONDITIONS



Ideal framework for the transition from health to community based activity in the prevention and management of chronic conditions

Basis for the framework

As part of the PARCS project, the British Heart Foundation (BHF) conducted an evaluation of frameworks and systems for current service delivery for exercise referral and ongoing physical activity after formal clinical rehabilitation. This evaluation focused on those with long term conditions, primarily cardiac, respiratory and stroke. The proposed framework for Scotland is based on the framework for exercise referral currently in delivery in Wales, the National Exercise referral framework. The Welsh National Exercise Referral Schemes (NERS) was identified by BHF PARCS project (see Section D) scoping as part of the wider national exercise referral work (i.e. England, Wales and parts of Scotland). There is also wider work in relation to exercise referral which key leads are currently concurrently working on within the UK and Canada.

The Welsh NERS scheme (see Section D) provides a national approach to training specialist instructors (level 4⁶) across a variety of conditions, including cardiac (n=137), stroke (n=40) and respiratory (n=90), a standardised single point of referral, one national and 22 regional co-ordinators, standardised pathways and interventions that link with rehabilitation, multifaceted model of delivery (including professional and peer support) and defined exit strategies.

Adaption of the framework for Scotland

The Wales framework was adapted for use across Scotland to integrate and not exclude existing varied service delivery from all sectors, identified within the PARCS Scotland scoping. This was adapted in consultation with the PARCS Advisory Sub Group and endorsed by the wider PARCS group (See Appendix 8).

The proposed framework relates to the transition from health to community based physical fitness and activity, rather than solely an exercise referral context. The proposed framework in Scotland aligns with the strategic drivers of shift of care to the community and the integration of health and social care.

The agreed proposed framework shows all of the different tiers with a clear distinction between tiers and the level of training within these tiers, so that the Health Board can see their own gaps. The ideal framework incorporates the Skills Active National Occupational Standards (NOS) for exercise referral (L3) and for specialist exercise referral (L4)⁷. The proposed framework relates to the transition from health to community based physical fitness and activity, rather than solely in an exercise referral context. The ideal framework in Scotland aligns with the strategic drivers of shift of care to the community and the integration of health and social care.

The modification of the framework for Scotland was in relation to implementation, but not a modification where national duty of care (for patients/service users) and established professional minimum standards, qualifications and training pathways (instructors) are concerned i.e. National

⁶ **Register of Exercise Professionals (REPs)** is an independent, public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REP's provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards. **DEFINITION OF REPS LEVEL 3:** The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions this includes respiratory conditions, e.g. asthma and chronic obstructive pulmonary disease (COPD), musculoskeletal conditions, cardiovascular conditions, hypertension, hypercholesterolaemia, psychological/mental health conditions, metabolic/immunological conditions e.g. diabetes type 1 and type 2 and obesity. **DEFINITION OF REPS LEVEL 4:** The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the effects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease. <http://www.exerciseregister.org/resources/exercise-referral>

⁷ See also Appendix 9 ref 1

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009671; <http://nos.ukces.org.uk/Pages/index.aspx>;

Occupational Standards (NOS). The National Quality Assurance Framework and the new Professional and Operational Standards have both been developed in partnership with the medical defence unions, i.e. Medical and Dental Defence Union (MDDU) of Scotland and England in relation to self-referral and screening.

Good models of practice

Good practice models demonstrating how various Health Boards are delivering this service are also included in the PARCS CHSS report, to give Health Boards an understanding of how delivery is currently implemented.

Skills, knowledge and expertise needed at each tier (see framework diagram)

Level 4 for specialist exercise delivery framework (see diagram, specialist instructor supervised exercise delivery tier)

Level 4: the standards at level 4 have been written to outline the knowledge and skills required to work safely with patients with often chronic and complex medical conditions

(<http://www.exerciseregister.org>)

Level 4: Specialist Exercise Referral instructors (Skills Active & Register of Exercise Professionals, REP) category for exercise professionals within the specialist exercise delivery framework (see diagram, specialist exercise delivery tier)

Definition of Level 4: the knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions.

Specialist Exercise Delivery Tier

Ideally this could incorporate the concepts of exercise referral schemes run by L3 Exercise Referral Instructors in areas where this service exists.

At present instructor training within Level 4 has 10 different components including NOS and qualifications in:

Level 4
Cardiac Disease
Falls Prevention
Stroke
Back Pain
Mental Health
Chronic Respiratory Disease
Cancer Rehabilitation
LTNC
Long term Neurological conditions
Obesity/Diabetes
Accelerated Rehabilitation (military only)

(<http://www.exerciseregister.org/about-reps/reps-entry-qualifications>)

It is acknowledged that for stroke there is a different training programme with a different provider, content and qualification that is recognised by REPS at level 4.

Training across long term conditions (LTC)

The PARCS Scotland scoping of the training level in specialist instructors identified that Level 4 across Scotland is varied and there is a fragmented approach to delivery of this training.

The PARCS Advisory group were consulted regarding the priority training areas for chronic conditions and although cardiac conditions, falls and stroke presented the greatest risk for an exercise related adverse event; these conditions may be a starting point for training delivery. **The ideal training would cover all conditions** (e.g. neurological/neuromuscular, metabolic, musculoskeletal, etc.) **to allow delivery of a generic class** i.e. one that would meet the need of a range of service users with LTC existing from (and, whenever the need arose back to) specialist exercise pathways.

Description of the Framework

The framework provides a multi intervention approach including professional and peer support.

Health Interface tier (red)

Ideally there should be multiple entry point into services.

Health interface: this includes NHS services or private provider equivalent

All sectors should be addressing lifestyle factors including physical activity either as strategies for: primary prevention (screening and identification of individuals at risk) or secondary prevention (for those with established disease).

Primary care: e.g. GPs and specialist nurses working largely in the community. In relation to LTC, the regular reviews often scheduled with primary care should be used as opportunities to discuss lifestyle issues including physical activity.

Health education programmes: such as „Keep Well“, largely involved in primary prevention.

Community services: both NHS and social services in line with health and social care integration.

Secondary care: involved in the treatment and management of those with ill health including those having falls and LTC e.g. pulmonary conditions. This includes rehabilitation such as cardiac rehabilitation (CR), stroke rehabilitation and pulmonary rehabilitation (PR).

Specialist Instructor Supervised Exercise/Activity tier (amber)

Lifestyle behaviour change/advice and completion of risk assessment tool to ensure signposting to appropriate intervention:

It is helpful to have discussions with service users to support behaviour change and ensure potential risks are addressed of particular importance for those with LTC considering undertaking exercise/PA. This can be approached in different ways dependent on regional infrastructure. This would ideally be started by HCPs within the health interface tier and be evident throughout the tiers. Some regions offer specific support in relation to this examples are, lifestyle advisors within primary care, and instructors within Leisure Services offering one-to-one support for behavioural change. This can range from one off support and referral/signposting or regular follow up throughout a longer period, e.g. between three and 12 months.

Specialist exercise instructors level 4

Specialist instructor skills, knowledge and expertise and definitions around the different levels of instructor are detailed in the section above.

Again different approaches to delivery include, specialist/level 4 instructors working alongside HCPs to deliver rehabilitation programmes such as cardiac and pulmonary rehabilitation. Specialist/level 3 and 4 instructors delivering physical activity/exercise maintenance classes can be employed by different providers (e.g. Leisure, third sector, private sector) or self-employed, and in deliver classes in various community venues.

The Exit to Maintenance tier (green)

This tier encompasses the principles of self-management and offers a person centred approach to delivery including menu based options:

- 1) Mainstream leisure activities
- 2) Community activities
- 3) Individual activities
- 1) Mainstream leisure activities

This could incorporate a wide range of physical activities, e.g. yoga, tai chi.

- 2) Mainstream community activities

This could incorporate a wide range of physical activities including walking, and non-physical activities including social and peer support groups, cultural activities.

- 3) Independent activities

This could incorporate a wide range of physical activities including walking, gardening, and swimming.

Quality assurance and duty of care within this tier

It is important to clarify those referring into these options the differences in insurance and quality assurance and personal responsibility between the qualified instructor and non-instructor led options, in relation to the standards of supervision and exercise delivery.

Qualified instructor lead options

The qualified instructor lead options would be delivered by instructors with the specialist skills knowledge and expertise detailed in the section above.

This could include mainstream L2/3 instructors or continuing at specialist L4 instructor dependant on the assessed need of the individual and the service offered in the regions, e.g. some regions offer a specialist L4 instructor non time limited.

Non-qualified instructor led

This could include a variety of peer, volunteer, carer, led activity.

Peers/volunteers could have often undergone training to deliver an activity e.g. Path for All Walk leader training, completed a specific course e.g. seated exercise e to deliver the respective activity; this is not always the case.

Guidance for service users

All options 1-3 listed above would ideally include guidance for service users with LTC when they are choosing a group, which may include a disclaimer. This guidance could include:

- a checklist for the person exercising which offers practical guidance when choosing a group
- appropriate details of the group e.g. whether this is peer or qualified instructor led

Pathways within the framework

It is intended that there is fluidity and flexibility within the individual's pathway to respond to service user need, e.g. in cases of change in condition, represented by the double headed arrows. The pathway is also intended to facilitate ongoing communication between all stakeholders.

Rehabilitation integration

Rehabilitation integration was evidenced by PARCS BHF and CHSS as important to the pathway, in achieving a seamless transition and increasing likelihood of attendance to exercise maintenance. Strategies around this include PR and CR in community based venues, offering Pr and CR in the same venue as exercise maintenance, the exercise maintenance specialist instructor attending clinical rehabilitation sessions and promoting exit strategy, exercise maintenance session taking place one hour preceding /following clinical rehabilitation.

Referral and signposting

Signposting or referral to groups by Health Care Professionals would be dictated by the remit and delivery of exercise within these groups to align with professional standards.

Self-referral, screening and screening tool

The framework offers the option of self-referral; an appropriate screening process and tool would be a specific requirement for a self-referral pathway. This would ensure both the appropriate required liaison with the individual's general practitioner and the self-referrer's safety. This screening process would be an essential gateway to the appropriate tier within this framework. The screening process is intended to be helpful (i.e. match each individual with their most appropriate physical activity) to make it enjoyable as well as safe. The internationally recommended and implemented Canadian Physiological Society's: *Physical Activity Readiness Questionnaire – Revised* (PARQR) was identified as the current appropriate pre-physical activity screening tool for use, until the updated 2012 PARQ+ is published in 2014. The BHF National Centre for Physical Activity at Loughborough University is completing its evaluation and customisation for the UK and Europe in collaboration with the Canadian Physiological Society. This updated screening tool involves an additional role by the instructor to reduce both the work for the GP and the number of inappropriate referrals.

Completion of the PARQR or PARQ+ by the self-referrer/potential service user can be undertaken within a health care or non-health care setting, e.g. leisure, with initial screening within the remit of an appropriately qualified instructor. If appropriate the screening tool should then be forwarded to the GP and the self-referrer advised of this. The GP must acknowledge the appropriateness of the self-referrer to participate in the session as per the MMDU stipulation (see section 1, paragraph 2 above). The outcome of the GP review should be communicated to the self-referrer, by either the GP or the potential service provider e.g. leisure.

Single point of referral

Having multiple referral points (people, providers and location), with differing referral procedures, often combined with various pathways for specific conditions can be barriers from a referrer perspective. Examples of this are multiple referral forms for different providers in geographical regions, so the referrer needs the appropriate referral form but must send it to the right person, assuming they are aware the service exists and who the referral contact is. This often leads to no referral occurring. Having a single referral point/service co-coordinator appears effective in addressing lack of knowledge of services from the referrer perspective – it simplifies the referral process and leads to a more effective pathway. Having a single pathway for all LTC is also helpful.

Often it may be challenging, or not feasible to have a single point of referral. Reasons for this include: large geographical regions, different service structures, differing referral pathways and procedures, differing service providers' agencies and roles. Solutions evidenced in this PARCS scoping include having a regional point of referral and having a single point of access, e.g. the MCN website. Another emerging solution explored as part of the project was the SCI Gateway. SCI Gateway is designed as a national portal for clinical communications between and within Healthcare organisations and has been developed by National Information Systems Group

(NISG) as a cornerstone product of the eHealth Strategy in Scotland. Meetings as part of this project suggested the SCI may be expanded to other include social care and other agencies.

Peer support and visits

Ideally peer support would be offered across all tiers from health interface to exit and maintenance, good practice examples are reported in the PARCS scoping. A key transition area is from clinical rehabilitation to maintenance, e.g. cardiac rehabilitation (CR) and pulmonary rehabilitation (PR). Visits by peers to clinical rehabilitation, often within the education component of this, were reported to be very influential in uptake of services as relationships and contacts are made.

References

1. http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009671;
2. <http://nos.ukces.org.uk/Pages/index.aspx>;
3. <http://nos.ukces.org.uk/Pages/results.aspx?u=http%3A%2F%2Fnos%2Eukces%2Eorg%2Euk&k=exercise%20referral#Default=%7B%22k%22%3A%22exercise%20referral%22%2C%22r%22%3A%5B%7B%22n%22%3A%22RefinableString00%22%2C%22t%22%3A%5B%22%5C%22%2C%22%82%2C%22%82536b696c6c73416374697665%5C%22%22%5D%2C%22o%22%3A%22and%22%2C%22k%22%3Afalse%2C%22m%22%3Anull%7D%5D%7Dhttp://www.exerciseregister.org/resources/exercise-referral>

OBJECTIVE 7

Address issue of instructor training and make recommendations for SGHD

Method: The PARCS Advisory Sub group consisted of NHS: MCN manager, HCP physiotherapists, Health Scotland, academic institution (professorial lead) also a representative of the Scottish Stroke Allied Health Professions Forum (SSAHPF), Academic and Register of Exercise Professionals/Skills Active representative, leisure, and third sector: CHSS and BHF. This group was consulted in relation to an ideal framework for transition from health to community based activity in the prevention and management of chronic conditions in Scotland.

A generic modular course was identified as being available in England, at Middlesex University; this is a well-established course at undergraduate level. Several others in England are in an embryonic state. In addition, there are important relevant developments by the British Association

of Sport and Exercise Sciences (BASES) to consider. Consensus was reached that Scottish academic institutions should consider developing similar generic training potentially within a professional pathway for exercise instructors which aligns with National Occupational Standards.

Whilst this standardisation of generic training is in development, good practice models that demonstrate how various Health Boards are delivering services currently should be given to Health Boards to give an understanding of how service delivery is currently implemented (see Appendix 8).

Results:

- **Consensus was reached that a recommendation should be a ‘generic’ LTC specialist instructor course covering all core principles and conditions at Level 4 Specialist Exercise. A standardised national approach, for specialist instructor training across Scotland, available and delivered within Scotland, would be the ideal.**

Recommendations to SGHD in relation to instructor training:

Recommend to SGHD a standardised national approach to specialist exercise instructor training. A generic (LTC) instructor training is recommended based on existing qualification pathways; current best evidence and practice should be available and delivered within Scotland. Future work to take this forward would involve Scottish academic institutions and partner organisations developing and delivering this generic training for specialist instructors.

ADDITIONAL UNFORESEEN BENEFITS OF PARCS PROJECT

- **Improved knowledge** in relation to EM in Scotland, amongst various stakeholders
- **Influencing local policy and service delivery**
- **Sharing/spread of good practice** by PARCS project manager facilitating networking

Methods: Promotion of PARCS project at national conferences, surveys to different stakeholders as detailed in objective 2, presentations/workshops by PARCS project manager to clinicians (respiratory, cardiac, stroke), other stakeholders (e.g. physical activity specialists, Leisure Services and academics) and networking

Improved knowledge

Various stakeholders have a greater awareness of issues in relation to delivery, e.g. specialist instructor training and good models of practice, verified by feedback from individuals and various working groups.

Influencing local policy and service delivery

MCN managers and clinicians having greater awareness of services and service providers in their region has led them in some cases to start to address implementation by working in partnership. Other regions have started to identify gaps in service and implementation needs locally. Feedback from different geographical regions indicated that they would value a resource (post) to facilitate and support implementation.

Sharing/spread of good practice

„Buddying“: clinicians/other partners making contact/visiting good practice models in different geographical locations in Scotland has been facilitated by the PARCS project manager. This has been based on the project manager's knowledge gained of services over the 22 months of the project including models of practice, regions with solutions to specific „gaps“ and different approaches to delivery.

References for CHSS PARCS full report

- 1) http://www.who.int/topics/physical_activity/en/
- 2) Mead, G., van Wijck, F. (Eds) (2013) Exercise and fitness training after stroke: a handbook for evidence based practice. Churchill Livingstone
- 3) Improving the Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan PDF 11 [PDF, 444.7 kb:
03 Dec 2009]<http://www.scotland.gov.uk/Resource/Doc/294270/0090939.pdf>
- 4) World Health Organization (1993) Needs and action priorities in cardiac rehabilitation and secondary prevention in patients with CHD. Geneva: World Health Organization.
Available from http://whqlibdoc.who.int/euro/-1993/EUR_ICP_CVD_125.pdf
- 5) Mead, G., van Wijck, F. (Eds) (2013) Exercise and fitness training after stroke: a handbook for evidence based practice. Churchill Livingstone.
- 6) National Institute for Health and Clinical Excellence. Chronic obstructive pulmonary disease. Management of chronic obstructive pulmonary disease in adults in primary and secondary care (partial update). 2010.
<http://www.nice.org.uk/nicemedia/live/13029/49397/49397.pdf> (accessed May 2013)
- 7) [http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publicationsandstatistics/P
ublications/PublicationsPolicyAndGuidance/DH_4009671;](http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009671;)
[http://nos.ukces.org.uk/Pages/index.aspx;
http://nos.ukces.org.uk/Pages/results.aspx?u=http%3A%2F%2Fnos%2Eukces%2Eorg%2Euk&k=exercise%20referral#Default=%7B%22k%22%3A%22exercise%20referral%22%C%22r%22%3A%5B%7B%22n%22%3A%22RefinableString00%22%2C%22t%22%3A%5B%22%5C%22%2C%22o%22%3A%22and%22%2C%22m%22%3Anull%7D%5D%7D](http://nos.ukces.org.uk/Pages/index.aspx;http://nos.ukces.org.uk/Pages/results.aspx?u=http%3A%2F%2Fnos%2Eukces%2Eorg%2Euk&k=exercise%20referral#Default=%7B%22k%22%3A%22exercise%20referral%22%C%22r%22%3A%5B%7B%22n%22%3A%22RefinableString00%22%2C%22t%22%3A%5B%22%5C%22%2C%22o%22%3A%22and%22%2C%22m%22%3Anull%7D%5D%7D)
- 8) <http://www.exerciseregister.org/resources/exercise-referral>
- 9) [http://www.exerciseafterstroke.org.uk/resources/Exercise After Stroke Guidelines.pdf](http://www.exerciseafterstroke.org.uk/resources/Exercise_After_Stroke_Guidelines.pdf)

APPENDIX 1 – PARCS OBJECTIVES, METHODS AND OUTCOMES

OVERVIEW OF KEY OBJECTIVES	METHODS	KEY OUTCOMES/RESULTS
<p><u>Objective 1</u></p> <p>Review the evidence in relation to the project</p>	<p>Identify of key literature – academic/ professional guidelines and strategies</p>	<p>Key strategies</p> <ul style="list-style-type: none"> • NHS Quality Strategy • 2020 Vision Route Map • Heart Disease Improvement Plan • Stroke Improvement Plan <p>Key evidence</p> <p>LTC have a high prevalence, with almost half the Scottish population effected, cardiovascular and respiratory diseases are amongst the most prominent</p> <p>Cardiovascular and respiratory diseases have place a huge economic burden on NHS services</p> <p>Physical activity is of benefit for individuals with cardiac, stroke and respiratory conditions (COPD)</p> <p>Individuals with cardiac, respiratory (COPD) and stroke in Scotland are well below PA targets</p> <p>Cardiac and pulmonary rehabilitation are clinically effective and cost effective</p> <p>Individuals with these conditions largely do not maintain physical activity after NHS rehabilitation</p> <p>Global strategies, national strategies and clinical guidelines advocate ongoing/long term PA/ exercise for individuals with these conditions</p> <p>Cardiac and pulmonary rehabilitation are clinically and cost effective</p> <p>Maintenance exercise/PA for COPD is effective in the short and medium term for exercise capacity, with a lack of evidence for the long term</p> <p>Exercise after stroke is beneficial at improving function</p> <p>Exercise after stroke services in Scotland – lack of current service provision and service development in needed to ensure equity</p>

		<p>Optimal PA/ exercise maintenance interventions are likely to include exercise training, with self management and behaviour change supported by professionals and peers</p> <p>Barriers to exercise maintenance:</p> <ul style="list-style-type: none"> ○ Access – availability of groups and transport ○ Motivation <p>Benefits of exercise maintenance:</p> <ul style="list-style-type: none"> ○ Advocated by service users ○ Social support influences PA and increases motivation to exercise <p>Enablers</p> <ul style="list-style-type: none"> ○ Professional support ○ Social interaction and peer support ○ Follow up/ongoing communication between individuals/service users and professionals
<p><u>Objective 2</u></p> <p>Produce overview profiles for 14 Health Board regions across Scotland in relation to exercise maintenance/ physical activity opportunities</p>	<p>SURVEYS</p> <p>Managed Clinical Networks n = 11/14 responded to the initial survey with 13/14 responding to the draft overview profiles</p> <p>HCPs n= 274 „hits“</p> <p>GPs n= 146 „hits“</p> <p>Service Users n= 221 responses</p> <p>Service Providers n= 40 „hits“</p> <p>MEETINGS with service providers/ stakeholders in service provision n= 63</p> <p>HCP – n= 42 (35 face to face, 7 telecoms)</p> <p>Leisure services n= 20 (face to face, 7 telecoms)</p>	<p>SERVICE DELIVERY</p> <p>Availability of EM services is varied throughout Scotland ranging from minimal service/establishing service in 3 Health Board Regions (all rural), to well established, with menu based options, in some or all CHP regions, in 4 Health Boards.</p> <p>Generic models of delivery for LTC have evolved in well established delivery models (urban, semi rural and rural) from condition specific delivery. This generic LTC encompasses cardiac, stroke and respiratory and other conditions and is based on functional ability rather than the condition. These often offer menu based options.</p> <p>Specialist instructor training, large variation in skill set in terms of numbers, and levels of expertise of specialist trained instructors (for LTC) .This ranged from i) Health Boards regions that had no instructors trained at a level able to deliver classes for LTC ii) Health Board regions that had some instructors trained in relation to specific condition delivery (e.g. cardiac) but not across all conditions (the majority of Health Boards). 4 Health Boards had a cross section of training across the spectrum of LTC. 3 out of 4 Boards had achieved this by NHS „in house training“ within their respective regions.</p> <p>Collaborative partnership working and working groups involving all stakeholders for service delivery and governance appear effective.</p>

	<p>Local Authority n= 1 MEETINGS with service users /potential service users total with LTC n= 33 (included areas of social deprivation and ethnic minority group)</p> <p>IDENTIFICATION & EXTRAPOLATION OF EXISTING DATA</p> <p>Post Pulmonary Rehab Data x 4 regions</p> <p>Pilots of community exercise for stroke programmes x 2 regions</p> <p>Academic research funded by CHSS into optimising engagement into Physical Activity after Stroke x 1 region</p> <p>Leisure services evaluations x 4 regions</p> <p>Person centred groups evaluations in conjunction with HCP or Academic institutions x 2 regions</p>	<p>PATHWAY JOURNEY</p> <p>Effective referral and signposting are key- barriers to this are lack of knowledge from referrers e.g. GPs and HCPs and/or lack of availability of services to refer to.</p> <p>No single point of referral - Majority have no single point of referral across the Health Board (13 out of 14). 6 out of 14 have a regional (CHP, Leisure or Local Authority) referral point. 4 Health Boards have a referral point or co-ordinator in one or some geographical locations only areas of the Health Board region lacking this. These Boards cover large geographical area and are in rural/semi rural regions. This importance of the referral point is in relates to the key issue of lack of knowledge of services by the referrer. Having a referral point/co-coordinator appears effective in addressing this</p> <p>Inconsistency in pathways –Differences in pathways to EM both within and between Health Board regions. Cardiac and exercise referral appear as most well established/available, stroke least.</p> <p>Importance of clinical rehabilitation overall, and the delivery of this in the community, particularly Pulmonary and Cardiac Rehabilitation</p> <p>ECONOMICS/IMPACT</p> <p>Data collection inconsistent – in terms of collection, collation and the role or service undertaking this. There are often inconsistencies within Health Board regions as well as between regions.</p> <p>Funding for instructor training - large variation - regional variations/inconsistencies of funding streams. Often short term funding to meet training costs. Approaches to this are often fragmented i.e. individual providers training staff.</p> <p>Funding streams for service delivery - large variation – regional variations/inconsistencies of funding streams from statutory bodies for service provision. Integrated partnership funding is seen in well established schemes with a large reach. Some are self sustaining once established.</p> <p>Person Centred Impact</p> <p>Achievement of physical activity targets of service users attending an exercise maintenance group: 76% (n=165) meet physical activity targets compared to national averages of 15% for Chest, Heart and Stroke conditions</p>
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		<p>Exercise group linked to improvement in condition: 76% (n=165) report feeling their condition has improved since joining the exercise group</p> <p>Benefits of exercise class: motivation to exercise, remain more active and social support</p> <p>Potential link to reduced hospital admissions: 74% (n=165) of service users reported having no hospital admission in the last year</p>
<p><u>Objective 3</u></p> <p>Identify relevant innovations/technology for exercise maintenance/physical activity opportunities</p>	<p>Meetings as detailed above, internet searches and networking, attendance at relevant conferences/launches throughout the duration of the project</p>	<p>Telehealth</p> <p>Podcasts for delivery of home based exercise for long term conditions, academic research in partnership with Lanarkshire MCN. Protocol for COPD underway</p> <p>Telehealth for Pulmonary rehabilitation with a relationship to post rehab physical activity</p> <p>Telehealth option for delivery of Cardiac Rehabilitation (Activate your Heart)</p> <p>Living It Up Project – connections to information, products & services in the community</p> <p>ALISS – resource with information and services for LTC</p> <p>Active Scotland – resource of activities and activity venues throughout Scotland</p> <p>CHSS – Self management for COPD and asthma - My lungs, My life and self management for stroke - online service user resources</p> <p>NHS inform in deprived area</p> <p>Sound Doctor – England – Resource for those with LTC</p> <p>Innovations</p> <p>To address health inequalities, access and knowledge of services identified</p>
<p><u>Objective 4</u></p> <p>Identification of resource need, service user and/or</p>	<p>Identification of resource need - based on findings of project and discussion with service user advisory group</p>	<p>Resource need from service user perspective It is not necessary to have more information on the benefits of exercise; rather the need is for details of local facilities/opportunities.</p>

<p>service provider</p>	<p>Identification of service provider resource – based on the data/meetings undertaken from PARCS CHSS and linking with PARCS BHF and BLF work</p>	<p>1) A web-based resource, with sustained funding for this, which acts as a repository of information with a person to facilitate and maintain/update this. Although this may not be suitable for all.</p> <p>2) Tailored local support –for people with complex needs e.g. stroke, ideally 1:1 support, so that individual conversations can happen, either with a person who is the Single point of Referral/service co-ordinator or with another person with appropriate knowledge to signpost/access relevant services.</p> <p>Production of service provider resource for LTC PA in the community – for action by BHF as part of project</p>
<p><u>Objective 5</u></p> <p>i) Identify good models of practice in differing geographical areas of Scotland – urban, semi-rural, rural</p> <p>ii) Identify critical success factors in relation to NHS quality strategy</p> <p>iii) Person centred pathway to maintenance in the community for LTC, based on user need</p>	<p>Synthesis of data surveys and meetings and visits as detailed in objective 2</p> <p>ii) Synthesis of data surveys and meetings and visits as detailed in objective 1</p> <p>Initial service user focus group n= 8 to develop pathway</p> <p>Further focus group n= 12 to feedback</p> <p>After BLF qualitative work complete and pathway adapted discussion with service user advisory group on pathway and their recommendations adapted</p>	<p>Diagrammatic representation of good practice models produced for provided to BHF for adaption by BHF project lead in the PARCS resource</p> <p>Critical success factors produced in line with NHS strategy provided to BHF for adaption by BHF project lead in the PARCS resource</p> <p>Work on service user pathway provided to British Lung Foundation strand prior to their qualitative PARCS work</p> <p>Finalised pathway provided to BHF for use/ adaption by BHF project lead in the PARCS resource</p>

Additional Objectives/Outcomes as a result of from key issues identified throughout the duration of the project.

OVERVIEW OF KEY OBJECTIVES	METHODS	OUTCOME/RESULTS
<p><u>Objective 6</u> Produce an ideal framework for transition from health to community based activity in the prevention and management of chronic conditions framework for delivery</p>	<p>PARCS Advisory Sub group – with NHS- MCN manager, HCPs, Physiotherapists, Health Improvement, Register of Exercise Professionals/Skills Active Representative, Leisure and third sector- CHSS and BHF consulted on:</p> <p>Identify key models of delivery structures/ framework and discuss adaption for the Scottish context, based on models out with Scotland and PARCS findings</p>	<p>Consensus reached on an ideal framework for transition from health to community based physical activity in the prevention and management of chronic and recommendations agreed to be put to SGHD</p>
<p><u>Objective 7</u> Address issue of instructor training and reach conclusions and recommendations for SGHD</p>	<p>Identify of issues economic factors impacting on instructor training- cost of course for each specific condition</p> <p>PARCS Advisory Sub group – with NHS- MCN manager, Health Care Professionals – Physiotherapists, Health Improvement, Register of Exercise Professionals/Skills Active Representative, Leisure and third sector- CHSS and BHF</p>	<p>Consensus reached on recommending to SGHD a standardised national approach to specialist instructor training</p>

<p>To improve knowledge of current service delivery of exercise maintenance in Scotland – amongst various stakeholders</p>	<p>Promotion of PARCS project</p> <p>Surveys as detailed above</p> <p>Presentations/workshops by PARCS project manager to: clinicians – respiratory and cardiac, other stakeholders - physical activity and Leisure</p>	<p>MCN managers and clinicians have greater awareness of services in their region. Some regions have started to address implementation or implementation needs locally and work by working in partnership. Feedback from regions that they would value a resource (post) to facilitate this implementation</p> <p>Various stakeholders have greater awareness of issues and good models of practice – verified by feedback from working groups and individuals</p> <p>Sharing/spread of good practice „buddying“ – clinicians and partners making contact/ visiting good practice models in different geographical locations in Scotland, facilitated by PARCS project manager sharing contact details and models</p>
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APPENDIX 2 – REVIEW OF THE EVIDENCE IN RELATION TO THE PROJECT

Summary table of evidence review (full text below the table)

OVERVIEW OF KEY OBJECTIVES	METHODS	KEY OUTCOMES/RESULTS
<p><u>Objective 1</u></p> <p>Review the evidence in relation to the project</p>	<p>Identify of key literature – academic/ professional guidelines and strategies (for</p>	<p>Key strategies</p> <ul style="list-style-type: none"> • NHS Quality Strategy • 2020 Vision Route Map • Heart Disease and Stroke Disease Improvement Plans <p>Key evidence</p> <p>LTC have a high prevalence, with almost half the Scottish population effected, cardiovascular and respiratory diseases are amongst the most prominent</p> <p>Cardiovascular and respiratory diseases have place a huge economic burden on NHS services</p> <p>Physical Activity is of benefit for individuals with cardiac, stroke and respiratory conditions (COPD)</p> <p>Individuals with cardiac, respiratory (COPD) and stroke in Scotland are well below PA targets</p> <p>Cardiac and pulmonary rehabilitation are clinically effective and cost effective</p> <p>Individuals with these conditions largely do not maintain physical activity after NHS rehabilitation</p> <p>Global strategies, national strategies and clinical guidelines advocate ongoing/long term PA/ exercise for individuals with these conditions</p> <p>Cardiac and pulmonary rehabilitation are clinically and cost effective</p> <p>Maintenance exercise/PA for COPD is effective in the short and medium term for exercise capacity, with a lack of evidence for the long term</p> <p>Long term PA activity is advocated in guidelines for cardiac conditions. Emerging evidence that multi intervention follow up appears effective in maintaining PA/exercise, but further research is needed</p>

		<p>Strong evidence that exercise after stroke is beneficial at improving function</p> <p>Exercise after stroke services in Scotland – lack of current service provision and service development in needed to ensure equity</p> <p>Optimal PA/ exercise maintenance interventions are likely to include exercise training, with self management and behaviour change supported by professionals and peers</p> <p>Barriers to exercise maintenance:</p> <ul style="list-style-type: none"> ○ Access – availability of groups and transport ○ Motivation <p>Benefits of exercise maintenance:</p> <ul style="list-style-type: none"> ○ Advocated by service users ○ Social support influences PA and increases motivation to exercise <p>Enablers</p> <ul style="list-style-type: none"> ○ Professional support ○ Social interaction and peer support ○ Follow up/ongoing communication between individuals/service users and professionals
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APPENDIX 2 - FULL TEXT EVIDENCE IN RELATION TO THE PROJECT

Introduction/ Background

In Scotland, 46% of adults had a long-term condition in 2012⁽¹⁾

Summary of Long Term Conditions (LTC) Evidence

- **LTC have a high and increasing prevalence in Scotland, particularly in the elderly**
- **Cardiovascular and respiratory diseases are amongst the most prominent LTC**
- **There has been an increased prevalence of cardiovascular vascular disease and asthma. There was a downward trend in the incidence of coronary heart disease**
- **LTC have a major impact on personal and social health well being, as well as wider societal impact**
- **LTC, in particular cardiovascular disease and chronic obstructive pulmonary disease, have a major impact on costs for health service provision**
- **Physical activity positively contributes to the prevention and management of over 20 chronic conditions, including CHD**

Long Term Conditions

Long-term conditions (LTC), often referred to as chronic diseases, last a year or longer, limit what a person can do and may require ongoing medical care (2). While many serious long term conditions are present, diabetes, cardiovascular disease (CVD) and respiratory diseases together are a significant health burden in Scotland, and globally (3).

Prominent long term respiratory diseases are asthma and chronic obstructive pulmonary disease (COPD). Asthma has changeable and recurring symptoms of breathlessness, wheezing, coughing and chest tightness. COPD, another chronic lung condition, is characterised by restricted airways leading to breathing difficulties, persistent coughing and abnormal sputum production (4). Historically COPD has also been referred to as chronic bronchitis or emphysema.

The largest contributors to CVD are ischemic heart disease (IHD) or coronary heart disease (CHD) and stroke, both of which have been identified as clinical priorities for the NHS in Scotland (5). „Coronary heart disease is a disease of the blood vessels supplying the heart muscle“ (6). „Heart attacks and strokes are usually acute events and are mainly caused by a blockage that prevents blood from flowing to the heart or brain. The most common reason is a build-up of fatty deposits on the inner walls of the blood vessels. Strokes can be caused by bleeding from a blood vessel in the brain or by blood clots“ (6)

LTC, Impact for Health Care Provision for in the UK

Throughout the UK it is estimated that people with a LTC:

- account for 80% of all GP consultations
- are twice as likely to be admitted to hospital
- stay in hospital disproportionately longer
- account for over 60% of hospital bed days (7)

LTC in Scotland

There is a significant impact on Scottish society in terms personal, social and economic costs of LTC (8). In Scotland the established links with deprivation and age are also significant; this is of particular importance in relation to health inequalities and the ageing population (8).

LTC Prevalence in Scotland

The most commonly reported long-term conditions for men and women (aged 16 or above) in 2012 were: musculoskeletal conditions (18% prevalence), heart and circulatory conditions (including CVD conditions) (13%), endocrine and metabolic conditions (including diabetes) (9%), and conditions related to the respiratory system (including asthma and COPD) (8%)

<http://www.scotland.gov.uk/Publications/2013/09/3684/12>

In Scotland, one third of adults had a limiting LTC in 2012 ⁽⁹⁾

- It is estimated that 2 million people in Scotland have at least one LTC (8)
- Along with the 46% of adults with a LTC, one third of adults had a limiting LTC in 2012 (1)
- There was also a significant increase in the prevalence of LTCs in adults between 2008 and 2012 (from 41% to 46%) (1)
- At age 75 and over, 79% of men and 76% of women reported the presence of a LTC in 2012 (1)

Respiratory Disease

Asthma

- The proportion of adults with doctor-diagnosed asthma has increased from 11% to 17% in 2012 (1)

COPD

- 4.8% reported that a doctor had diagnosed them with the condition in 2012; there had been an increase in this figure from 3.8% in 2008 (1)
- 7.8% of men aged 75 and over and 10.7% of women of this age had doctor-diagnosed COPD in 2012 (1)

Cardiovascular Disease

In Scotland, one in six adults had a CVD condition in 2012 ⁽¹⁾

- There was a rise in the proportion of adults (aged 16 to 64) with cardiovascular disease (CVD) (from 8.7% to 10.8%) between 1995 and 2012 (1)
- CVD prevalence increased with age (from 4.6% among those aged 16-24 to 45.8% for those aged 75 and above) (1)
- 2.8% of adults reported they had had a stroke in 2012 (1)
- IHD and stroke prevalence in adults has not varied significantly since 1995 (1)
- The number of new cases of CHD (incidence) has decreased over the past decade. The age and sex standardised incidence rate decreased from 361.7 per 100,000 in 2003/04 to 262.8 in 2012/13, a decrease of 27.3% (9)

LTC – impact and costs for healthcare provision in Scotland

In Scotland, LTC account for 80% of all GP consultations ⁽¹⁾

- Long-term respiratory conditions and CVD all place significant demands on the NHS in Scotland

COPD

- Breathing difficulties associated with COPD are a major cause of repeat hospital admissions in Scotland (10)
- The estimated cost to NHS Scotland of treating COPD is £98.5 - £100 million (1,10). This is an underestimate of the total costs as it does not incorporate costs from social, third sector and family and carers, due to the lack of data. Also only one prescribed medicine is used in this calculation (11)
- £1,036 is the average cost per patient with COPD, suggesting the severity of those with this condition (11)
- The annual cost of managing a patient at each stage of COPD: severe - £1,307.25, moderate - £308, mild - £150 (11)

CVD

- £146 million spent on hospital cardiology services in 2010/11 (12)
- £167 million spent on drugs for treating heart disease and stroke in the community in 2010/11 (12)
- £43 million spent on statin (atorvastatin) for cardiovascular disease, the highest spend on any single drug in the community (12)

- Increase of 61% in the number of GP prescriptions for cardiovascular disease, from 15.3 million in 2000/01 to 24.7 million in 2010/11. (12)
- 47,900 estimated hospital discharges involving CHD, roughly 33% of which were the result of emergency admission in the year ending March 2010 (9)
- There has been a general downward trend in hospital discharges for CHD over the last 10 years (9)
- 660,000 General Practice consultations for heart disease annually (12)
- „60,000 bed days a year could be released as a direct result of avoiding CVD admissions, with associated cost savings of £20 million from fewer in-patient stays. The cost of managing CVD (unstable angina, acute MI and reinfarction and other IHD, HF and stroke was 380,000 bed days and £125 million“ (13)

The PARCS project has focused on community based exercise maintenance for those with LTC, primarily cardiac, respiratory and stroke.

“Physical activity has been identified as positively contributing to the prevention and management of over 20 chronic conditions, including CHD” (WHO - 2)

Summary of Physical Activity (PA) Evidence for LTC

- PA positively contributes to the prevention and management of over 20 chronic conditions
- 2,447 people in Scotland die prematurely each year due to physical inactivity
- Targeting PA is recognised globally as a best buy intervention
- Physical activity has a long term effect on all LTC
- Interventions to target risk factors and specific functional difficulties are likely to be effective in overall management

”

Physical activity has been identified as positively contributing to the prevention and management of over 20 chronic conditions, including CHD ⁽¹⁴⁾

Physical Inactivity is currently described as a pandemic, and the fourth leading cause of death worldwide (15). „It is estimated by the World Health Organisation that around 3% of disease burden in developed countries is caused by physical inactivity, and over 20% of heart disease and 10% of stroke in developed countries is due to physical inactivity“ (14).

Physical Activity and Chronic Disease in Scotland

Inactivity accounts for at least 2,500 deaths in Scotland each year. „Increased physical fitness would reduce premature death by 30% and can help prevent and treat more than 20 chronic diseases“ (14). 2,447 people in Scotland die prematurely each year due to physical inactivity. 2,162 deaths are from CHD (42% of total CHD deaths each year), 168 deaths from stroke (25% of total stroke deaths each year)“ (16).

Economic case for exercise based management of disease

In 1994 exercise prescription/promotion was described, in the prevention of CHD, as a best buy in public health (17). More recently (2011) the World Health Organisation and the World Economic Forum identified interventions to target physical inactivity in its best buy interventions (18).

In Scotland, if the goal for reducing inactivity levels over the next five years is achieved (that is, a 1% change per year), deaths due to inactivity could fall by 157. Yearly hospital admissions for CHD and stroke would also fall by an estimated 2,231 cases and the possible yearly cost savings to the NHS, as a consequence, is estimated at £3.5 million. These estimates, although cautious, align with other economic benefit studies of physical activity (19).

Physical activity/exercise based management of disease

Extensive evidence confirms the benefits of physical activity/exercise in the management of disease processes including respiratory and cardiovascular conditions (20). Physical activity can also reduce the risk of heart disease and stroke by 20-35% (20).

Physical Activity/ Exercise Based Management of Long Term Conditions (LTC)

Systematic reviews show that physical activity appears to have a positive long-term influence on all LTC including coronary heart disease, diabetes, Alzheimer's and dementia (21) and heart disease and COPD (22).

Evidence on the overall care of patients with multimorbidity is limited, despite the prevalence of multimorbidity and its impact on patients and healthcare systems. Interventions to date have had differing effects; they are more likely to be more effective if targeted at risk factors or specific functional difficulties. A need exists to clearly identify patients with multimorbidity and to develop cost effective and specifically targeted interventions that can improve health outcomes (23).

Physical Activity/ Exercise Based Management of Respiratory Disease/ COPD

Less than 2 hours of physical activity per week is a significant predictor of hospitalizations in patients with severe COPD

Summary Physical Activity for COPD Evidence

- Physical activity levels are reduced in those with COPD, 83% do not meet PA targets
- Physical inactivity is the strongest predictor of mortality
- Pulmonary rehabilitation (PR) including an exercise component is recommended as 'gold standard' for COPD
- PR is clinically and cost effective
- Physical activity decline after PR with PA levels back to pre pulmonary levels in 6 to 24 months
- PA
 - has a positive effect on functional capacity
 - reduces the likelihood of hospital admissions and other co-morbidities
 - is linked with reduced shortness of breath and improved quality of life
- Long term exercise maintenance (EM) is recommended in numerous guidelines as an aim and outcome from PR
- EM increases PA and in the short and medium term (3-6 months) is effective in improving exercise capacity, long term evidence is inconclusive due to heterogeneity of studies and lack of robust and longitudinal studies
- Qualitative/person centred data, there are multiple barriers to engagement, the benefits of maintenance are endorsed and key enablers are tailored supervised exercise from professionals and social interaction/peer support.

Physical Activity levels in those with COPD

- **83% of those with COPD do not meet PA targets (24)**

Physical activity is reduced in those with COPD (25, 26) and mild COPD reduces exercise capacity and ability to perform daily physical activities (27), illustrating the need for early intervention. De-conditioning and declining physical activity accelerates the progression of COPD (27). However physical activity does not correlate to the severity of the disease (28, 29). 30 minutes/day is recommended for COPD (American College of Sports Medicine, ACSM), 150 minutes/week (WHO 2010).

How physical activity can benefit COPD

Recent guidelines for PA evidence the benefits of PA for those with COPD (30) (see list below):

Functional capacity:

- Low levels of physical activity are associated with a low FEV1 (Forced Expiratory Volume)
- Physical activity reduces FEV1 decline and therefore slows disease progression
- Higher FEV1 values are associated with 30 min of walking every day
- Reduced physical activity can occur in COPD patients with minimal abnormality in FEV 1

Exacerbations and hospital admission:

- Patients who are more active are less likely to be admitted to hospital
- Less than two hours of physical activity per week is a significant predictor of hospitalisations in patients with severe COPD

Dyspnoea (shortness of breath):

- Increased physical activity is associated with reduced symptoms of dyspnoea

Co-morbidities

COPD patients who report lower levels of physical activity have more co-morbidities

- **Only 6% of COPD patients do not have co-morbidity, with the average patient having 3.7 conditions including COPD**
- COPD patients who report lower levels of physical activity have more co morbidities (cardiac dysfunction, diabetes, joint problems, osteoporosis, CHD, cataracts and glaucoma) than those with moderate or high levels of physical activity

Mortality

- Physical activity is the strongest predictor of all-cause mortality in patients with COPD.

Quality of life

- There is a strong association between levels of physical activity and quality of life.

Pulmonary rehabilitation

Pulmonary rehabilitation (PR) can be defined as „an interdisciplinary programme of care for patients with chronic respiratory impairment that is individually tailored and designed to optimise each patient's physical and social performance and autonomy. Programmes comprise of individualised exercise programmes and education"(31).

PR key messages

Pulmonary rehabilitation programmes are clinically effective and cost effective

PR is effective at:

- improving health and quality of life
- reduces length of hospital stay
- reducing the number of hospital re-admissions for people with COPD (31,32)

The National Institute for Health and Clinical Excellence (NICE):

- supports the use of PR programmes in a variety of settings, including the community
- has made a case for commissioning PR
- states that all those with COPD who are suitable should receive PR (31, 32)

The latest Cochrane review of Pulmonary Rehabilitation for COPD (33) included 23 randomised controlled trials (RCTs) and concluded that pulmonary rehabilitation was effective at relieving dyspnoea, fatigue and improving function and patients' sense of control over their condition. These improvements were clinically significant. This study emphasised that rehabilitation was exercise training for at least four weeks with or without education and/or psychological.

The Cochrane review of Pulmonary Rehabilitation following exacerbations of COPD (34) concluded from nine trials (n=432) of moderate methodological quality that pulmonary rehabilitation is **highly effective and safe intervention** which **reduces hospital admissions** and **improves health related quality of life** for patients who have had an exacerbation of COPD. The review only included trials that involved some type of exercise program.

The Global Initiative for Chronic Obstructive Lung Disease (GOLD) report 2013 (35) sites the level of evidence for PR as level A from well designed RCTs with a consistent pattern of findings of substantial numbers in substantial studies (the highest level possible).

Strong evidence for the benefits of PR in:

- Improving exercise capacity
- Decreasing breathlessness
- Improving quality of life
- Decreasing hospital admissions and days in hospital
- Decreasing anxiety and depression
- Improving recovery after hospitalisation

Cost effectiveness of PR for COPD

The LTC audit (2007) (11) states that „If there was around a 60% uptake among moderately severe COPD patients this would amount to 35,976 people. The cost per patient of pulmonary rehabilitation is £725.31, £26.1 million. PR has been shown to improve participants' quality of life. There is evidence that it saves four bed days in hospital over the following year at £195 per bed day – a total of £780 per patient, amounting to £28.1 million overall. This is not a direct saving but would free up beds for other patients". One study in 2010 evaluated the effect of PR delivered post COPD exacerbation. It showed a reduction in re-admissions of 26%, with cost effectiveness demonstrated (36).

Physical activity and maintaining the benefits post PR

Guidelines acknowledge the decline in function and health status following PR (37). There is strong evidence (well conducted meta-analyses, systematic reviews of RCTs, or RCT with a low risk of bias) that the benefits of pulmonary rehabilitation are even greater from programmes with

duration of more than three months, although the cost benefits would require further evaluation (37).

Post PR PA

- PA following rehab - insufficient overall (38)
- Return to pre-pulmonary levels - within 6 to 24 months (39,40,41)

IMPACT

- Maintaining the benefits of PR in relation to prognosis, exacerbations, exercise capacity, and quality of life (42,43)
- Retention of PA – improves health status and reduces hospital admissions (44, 45)

One systematic review showed that longer duration pulmonary rehabilitation programs appear to have a more favourable effect on health-related quality of life in individuals with COPD (46).

Evidence for physical activity/exercise based management (exercise maintenance) of respiratory disease/ COPD

Guidelines recommend that:

‘All patients completing PR should be encouraged to continue to exercise beyond the programme’ (37). This is based on level A evidence (at least one meta-analysis, systematic review, or randomised controlled trial (RCT) rated as 1++ and directly applicable to the target population or a systematic review of RCTs or a body of evidence consisting principally of studies rated as 1+ directly applicable to the target population and demonstrating overall consistency of results).

„Patients graduating from a PR programme should be provided with opportunities for physical exercise beyond their rehabilitation programme’ (37)

In relation to PR, it is questionable whether short-term increases in activity levels will be maintained in most participants unless the program features a formal long-term component (47). „More studies are needed to determine effective delivery models for maintenance exercise following a PR programme. This might include the use of telehealth technologies” (37).

A truly successful pulmonary rehabilitation entails implementing physical activity maintenance (38)

Evidence summary for exercise maintenance

Supervised exercise programs:

- **significantly increase physical activity levels**
- **after PR appear to be more effective than usual care for preserving exercise capacity in the medium term**
- **the evidence for longer term benefit (after PR) is inconclusive due to lack of evidence**

Key Messages

- **The optimal maintenance exercise program for individuals with COPD remains to be defined**
- **It is likely that the optimal maintenance intervention encompasses a combination of exercise training and self-management interventions aimed at promoting and sustaining behavioural change**
- **A combined approach to COPD intervention**
 - **improves quality of life**
 - **improves exercise capacity**
 - **reduced hospital admissions**
 - **reduced hospital days per person**
 - **long term inconclusive due to insufficient evidence**

As exercise maintenance was the key focus of this project the research was examined for each condition area respiratory, cardiac and stroke in more detail.

Systematic Reviews

There are two Cochrane systematic reviews, one is currently in the protocol stage, investigating maintenance rehabilitation for COPD (48), the results of this are yet to be published. This will investigate a maintenance programme, defined as including: refresher courses, telecommunication based interventions, home visits, and support group attendance and local gymnasium based classes. It will include programmes occurring in the home, community and hospital setting and range in frequency and duration of contact (48).

The second Cochrane review investigated the integrated disease management (IDM) interventions for patients with chronic obstructive pulmonary disease (see details in the table below), in a variety of settings, with exercise the dominant component in studies encompassed within the review. The study concluded that:

Integrated disease management (IDM) in COPD, with exercise components within studies:

- improved disease-specific quality of life and exercise capacity
- reduced hospital admissions
- Reduced hospital days per person.
- there was insufficient evidence to disprove or confirm long term effectiveness

There are two other systematic reviews of relevance. One investigated supervised exercise programs after pulmonary rehabilitation in individuals with COPD (46) (see table below for details). The authors concluded that supervised exercise programs after PR appear to be more effective than usual care for preserving exercise capacity in the medium term (six months). Longer term benefit is inconclusive due to lack of evidence. The optimal maintenance exercise program for individuals with COPD remains to be defined. Most of the studies in the review had only an exercise intervention. The authors proposed in line with other research that is a more wide-ranging rehabilitation approach, with ongoing health mentoring, could have been more effective at influencing outcomes. The authors advocate, from this review and in comparison with other research, that the likelihood is, the optimal maintenance intervention encompasses a combination of exercise training and self-management interventions aimed at promoting and sustaining behavioural change. This aligns with other research, evidenced earlier, that without compliance with a maintenance programme improvements will diminish with time and the best approach to maintaining programme adherence requires further investigation.

Another systematic review (50) concluded that evidence demonstrated that supervised exercise training may give a significant increase in physical activity in people with COPD. They recommended extending the intervention period for those who experience an acute exacerbation of their disease. They again identified the need for further research to evaluate the effect of physical activity on patients with COPD. Other research advocates that future efforts should be made to establish uniform guidelines to ensure that community based exercise training programs for COPD patients are scientifically rigorous and cost-effective.

Evidence summary of key systematic reviews for exercise maintenance in COPD

Evidence Summary	Evidence Source	SIGN level of Evidence
<p>Integrated disease management interventions for patients with chronic obstructive pulmonary disease (49)</p>	<p>Cochrane systematic review</p> <p>26 RCTs</p> <p>N=2997</p> <p>Mild, moderate and severe 3- 24 months follow up</p> <p>Interventions: integrated disease management (IDM) program - a program of different components of care in which different health care providers are co-operating and collaborating to provide efficient and good quality care,</p> <p>Including exercise, self management, education, follow up</p> <p>IDM exercise was most dominant component (13 studies), followed by Self management (5 studies)</p> <p>Studies in primary, secondary and tertiary care</p>	<p>1 ++</p> <p>High to moderate methodologically quality</p>
<p>Supervised exercise programs after PR in COPD (46)</p> <ul style="list-style-type: none"> • appear to be more effective than usual care for preserving exercise capacity in the medium term (6 months) • Longer term benefit is inconclusive due to lack of evidence • There was no difference for quality of life 	<p>One systematic review</p> <p>7 RCTs</p> <p>N=619</p> <p>Moderate to severe COPD</p> <p>6 and 12 month follow up</p> <p>Supervised exercise training</p> <p>Interventions: comparing post-PR maintenance with post-PR usual care, providing the initial and maintenance programs included supervised exercise training</p> <p>Usual care:</p> <p>Maintenance: Outpatient-, community-, or home-based maintenance that included directly supervised exercise after PR with or without education and</p>	<p>1- (Meta analyses, systematic reviews with a high risk of bias)</p>

	<p>psychological support</p> <p>Lack of blinding in some studies</p> <p>Some studies potential for bias</p> <p>(Beaucamp et al 2013)</p>	
<p>Effect on exercise training on physical activity levels in COPD (50)</p> <p>Overall, there was a significant positive effect on physical activity after supervised exercise activity- significant but small increase</p>	<p>One systematic review :</p> <p>7 studies, 2 RCTs, 5 single interventions</p> <p>N=472</p> <p>Moderate to severe COPD</p> <p>Interventions: Supervised exercise training with a duration range from 6 weeks to 6 months</p> <p>Control groups, where present, included a general exercise programme, counselling and pedometer in addition to exercise</p> <p>Quality of studies assessed using recognised scales/tools</p>	<p>1+</p> <p>(Well conducted meta-analyses, systematic reviews, or RCTs with a low risk of bias)</p>

Another systematic review looked at determinants and outcomes of physical activity in patients with COPD. They concluded that there is poor evidence about determinants of physical activity, including the impact of treatment. This review did not consider the type of exercise, duration of the intervention programme or the training intensity applied, so therefore the relation to this project for exercise maintenance is questionable (52).

Person-centred data/qualitative evidence

Summary of qualitative evidence

One qualitative study investigated individuals with COPD (n=12) attending a maintenance community programme, for at least six months, intended to maintain exercise capacity and quality of life following PR (53). The key themes identified were:

- attendance issues these included, exacerbations, fatigue, transportation and weather
- benefits of the programme, the participants endorsed the after PR programme
- perceived issues/problems of the programme and recommendations for improvement

The conclusion was that minimally supervised community-based programs with access to a case manager may provide a useful approach in improving adherence to exercise.

Another study investigated EM, with the aim to understand perception and perspectives on elements of success in sustaining long term exercise in individuals (n=11) with COPD (54). Key themes were identified:

- awareness and acknowledgement of the disease
- the manner and empowering skills of the therapist
- perception of the exercise programme
- ongoing support in maintenance

Key messages were the following factors were important:

- guidance of a therapist (physiotherapist or instructor) with extensive knowledge of exercise for patients with COPD – tailoring of exercise
- social interaction/peer support in the exercise setting
- ongoing communication between patients and practitioners across an entire continuum of care
- availability and continuity of the programme.

The conclusion was that more focus should be on the link between PR programs and follow-up programmes.

Service Delivery models outwith Scotland

The most feasible and cost effective approach of maintenance interventions appears yet to be identified in future research. Looking at service delivery in other European countries in the Netherlands, the Royal Dutch Society for Physical Therapy (KNGF), Dutch Asthma Foundation

(Nederlands Astma Fonds), and Netherlands Organization for Applied Scientific Research (TNO) have devised a physical activity program for COPD patients. This program involves participation (individual or in a group) in tailored physical activities, sports, and leisure activity. Peer contact plays a central role in maintaining improved physical activity behaviour. These programs are supervised by physiotherapists qualified in COPD rehabilitation. These Dutch guidelines identify that:

Dutch physical therapy guidelines for individuals with COPD

Main aspects of aftercare:

- Long term adherence will improve when patients continue to practice in group sessions and select forms of physical activity they enjoy.
- Scheduling regular check-ups during after-care increases the patient's motivation to maintain the behavioural change and the state of health achieved.

Conclusion of evidence summary for COPD

In conclusion there are multi factorial components inherent with individuals with COPD and therefore disease management has to address this.

- Physical activity is reduced in those with COPD
- Physical activity/exercise benefits those with COPD
- PR, the exercise component being imperative, is seen as a gold standard treatment for this condition and is clinically effective and cost effective
- The gains from PR are often not maintained
- Supervised exercise maintenance programs are beneficial in the short to medium term, 3-6 months, in increasing PA, exercise capacity
- More longitudinal studies are needed into the long term outcomes of maintenance in order to reach definitive conclusions
- The optimal maintenance intervention would appear to be a integrated approach both in terms of: 1) the content encompassing a combination of exercise training and self-management interventions, aimed at promoting and sustaining behavioural change, 2) the support required both professional and peer support

Qualitative/person-centred data – key issues identified:

Barriers

- Access – both availability and transport
- Attendance issues – due to exacerbations, fatigue and weather

Benefits – the benefits of maintenance are endorsed

Enablers

- Tailored supervised exercise from professionals with knowledge of COPD
- Social interaction and peer support
- Ongoing communication and support across the whole pathway of care between professionals and individual

Physical activity levels in those with heart disease

88% of those with ischemic heart disease *do not* meet physical activity targets ⁽²⁴⁾

Some studies show that individuals who participate in cardiac rehabilitation programmes do not maintain an exercise regimen. Evidence shows that at six months only 30-60% of individuals report regular exercise (55-57).

Benefits of PA for those with heart disease

These are incorporated within the cardiac rehabilitation section below.

Evidence for physical activity/exercise based management of cardiac conditions in a clinical (NHS) setting

Cardiac rehabilitation is one of the most clinically and cost effective interventions in CVD management ⁽⁵⁸⁻⁶²⁾

Cardiac Rehabilitation

The WHO definition of cardiac rehabilitation is: “the sum of activities required to influence favourably the underlying cause of the disease, as well as the best possible, physical, mental and social conditions, so that they (people) may, by their own efforts preserve or resume when lost, as normal a place as possible in the community. Rehabilitation cannot be regarded as an isolated form or stage of therapy but must be integrated within secondary prevention services of which it forms only one facet” (63).

SIGN 57 guidelines state that “structured exercise as a therapeutic intervention is central to cardiac rehabilitation” and “daily exercise should also be encouraged as part of an active living philosophy” (64).

SIGN 57 (64) gave an evidence level of A (High quality meta-analysis, systematic reviews of RCTs or RCTs with a very low bias risk) for:

- Exercise training should form a core element of cardiac rehabilitation programmes
- The formal exercise component of cardiac rehabilitation should be offered at least twice a week for a minimum of eight weeks evidence

Other national clinical guidelines and quality standards in relation to particular cardiac conditions (NICE CG48, NICE CG94, NICE CG108 and NICE QS9) and NHS improvement evaluations in relation to CR (65) recommend CR/ increased uptake of CR based on research evidence demonstrating positive impact which includes:

Benefits of CR

Reduces:

- Cardiac mortality by 26% (66)
- Morbidity
- Unplanned admissions by 28 -56% (67-69)

Improves:

- Quality of life
- Functional capacity

Supports:

- Early return to work
- The development of self-management skills

SIGN 57 (64) also states that:

- Cardiac rehabilitation is both safe and cost effective.
- Cardiac rehabilitation (CR) should not be regarded as an isolated form or stage of therapy, but be integrated within secondary prevention services.

Risks;

Cardiovascular non-fatal and fatal events are very low, being 1/50,000 and 1/750,000 person hours of supervised exercise or 1 sudden death per 15 000 to 18 000 participants. (70). the potential benefits of exercise far outweigh the risks (30).

Four stages of CR

Historically there were four recognised phases of CR, detailed below.

SIGN 57 (64) states:

Phase 1 – inpatient stay or change in condition. „This stage could include a admission for myocardial infarction, onset of angina, any emergency hospital admission for coronary heart disease (CHD), cardiac surgery or angioplasty, or first diagnosis of heart failure.“

Phase 2 is the early post discharge period. This stage is „a time when many patients feel isolated and insecure. Support can be provided by home visiting, telephone contact, and by supervised use of the Heart Manual. This manual is a self-help programme for patients recovering from a heart attack that has been shown to reduce anxiety, depression and hospital readmission rate.“

Phase 3 structured exercise programme „with educational and psychological support and advice on risk factors has historically delivered in a hospital setting it is now recognised that both components can be undertaken safely and successfully in the community. A menu based approach recognises the need to tailor the delivery of services to the individual, and is likely to include specific education to reduce cardiac misconceptions and encourage smoking cessation and weight management; vocational rehabilitation to assist return to work or retirement; and referral to a psychologist, cardiologist, or exercise physiologist.“

Phase 4 - the long term maintenance of physical activity and lifestyle change. „Available evidence suggests that both must be sustained for cardiac benefits to continue. *Membership of a local cardiac support group, which involves exercise in a community centre such as a gym or leisure centre, may help maintain physical activity and behavioural change*’.

Although the SIGN 57 guidelines update is at present in development, a core competencies approach is now being advocated. Modern CR is menu-based and patient-centred, and provides a pathway across the seven stages from diagnosis to long term management.

British Association for Cardiovascular Prevention and Rehabilitation (BACPR) 7 core competencies (71) are:

1. Health behaviour change and education
2. Lifestyle risk factor management
 - physical activity and exercise
 - diet
 - smoking cessation
3. Psychosocial health
4. Medical risk factor management
5. Cardioprotective therapies
6. Long-term management
7. Audit and evaluation (BACPR 2012)

Evidence for physical activity/exercise based management - exercise maintenance

SIGN 57 (64) give an evidence level B (well conducted meta –analysis, systematic reviews, or RCTs with a low risk of bias) for

- „People with stable coronary disease should be encouraged to continue regular moderate intensity aerobic exercise“

SIGN 57 (64) recommend:

- Exercise: regular low to moderate intensity exercise (3-5 times per week)
- Self help groups should be encouraged and enabled to use the same evidence-based approach to cardiac rehabilitation advocated for professionally led programmes
- For HCP to advocate that if the benefits of exercise are to be maintained then exercise must continue long term
- Sources of local community support available should be discussed, e.g. nurse counsellor, supervised use of the Heart Manual, GP, primary care secondary

prevention clinic, self-help groups

- The importance of ongoing contact with health care professionals should be reinforced

Long term follow up

Guidelines on physical activity levels post CR

SIGN 57 (64) states that:

‘Meta analysis of exercise-based cardiac rehabilitation trials has shown that the greatest benefits associated with exercising for 12 weeks or longer. If the benefits of exercise are to be sustained, moderate physical activity should continue long term, but this proves difficult for most people with coronary disease once supervision is withdrawn. Some people may devise their own exercise programmes, or return to previous sports, join a self help group or a sports centre, or use walking-based home exercise programmes. Others prefer formal, class-based cardiac exercise programmes. There is no good evidence that any one of these options is better than any other, so the choice should be determined by patient preference. Clearly it is helpful if as many options as possible are available locally’.

Evidence base for maintenance

Cochrane and other reviews

No Cochrane systematic reviews investigated exercise maintenance or phase 4 interventions. Relevant systematic reviews include:

Home based versus centre based cardiac rehabilitation: a Cochrane systematic review and meta-analysis (72). Outcomes were reported at 12 months for the majority of studies and some up to 24 months. CR was of duration 1.5 to 6 months. All programmes included exercise, centred based being typically cycle and treadmill exercise; home based walking with some type of specialist nurse or exercise instructor support. Both home and centred based were equally effective at improving clinical and health related quality of life outcomes, with no reported difference in outcomes at 3-12 (short term or 24 months).

One other systematic review of physical activity intervention studies after cardiac rehabilitation was identified (73). This review looked at interventions to maintain or increase physical activity after CR. Studies with cognitive interventions (self efficacy, barrier management and problem solving) reported conflicting results, whereas studies with behavioural interventions (self monitoring, prompting goal setting and feedback) and combinations interventions reported more consistent positive findings. Limitations were the lack of quality of studies in both design and measurement. It was concluded that more robust research is needed to understand physical activity behaviour related change after CR.

The majority of reviews have focused on adherence either during or after CR. A Cochrane systematic review investigated promoting patient uptake and adherence in CR (74). 10 studies were identified, 7 evaluating interventions to increase adherence. No meta-analysis was possible due to heterogeneity of studies. 2 or 7 studies targeting increased adherence had a significant effect. There was no reporting of data on mortality, morbidities, cost or health care utilisation in any of the studies. This review is of particular interest to the current project due to the duration of studies. This included studies that investigated uptake of adherence, defined as uptake which varied from the first session of CR, to uptake of CR at 12 months, and variations in between. There was large heterogeneity in the types of interventions, with the inclusion of supervised and unsupervised exercise. Some studies had interventions that included exercise post CR. The duration of CR follow up was between 2- 14 months. The conclusions suggested that interventions to increase the uptake of cardiac rehabilitation can be effective. There was some evidence to suggest that interventions involving motivational communications, telephone calls and home visits may be effective in increasing uptake of cardiac rehabilitation, and also the use of liaison nurses to support coordination of care. The barriers to uptake and adherence in cardiac rehabilitation were considered to be multi factorial and reasons for non-participation may vary between individuals. The conclusion was that interventions targeting patient identified barriers i.e. an individually tailored approach, may increase probability of success. Further robust research is required.

Another review investigated barriers to participation and adherence to cardiac rehab programs (75). This review cited literature that only one third of those attending CR are *maintaining exercise attendance after 6 months*. *Barriers to participation and adherence to CR programs included: lack of referral by physicians, associated illness ,specific cardiac diagnoses, reimbursement, self-efficacy, perceived benefits of CR, distance and transportation, self-concept, self-motivation, family composition, social support, self-esteem and occupation*. Factors associated with non adherence included: being older, female gender, less formal education, perceiving the benefits of CR, having angina, physically active and being less physically active during leisure time. There were issues in objectively measuring adherence to unstructured, non-hospital based programs and further research was needed. *Many of the studies were methodologically poor, with very few controlled, randomized studies, suggesting caution in relation to the findings. Key issues were objectively measuring adherence to unstructured, non-hospital-based programs*.

Another review investigated the correlates of exercise of CHD patients in all CR spectrums to address different levels of influence on exercise (76). This review included 121 studies, with 32 different correlates of exercise and 25 217 participants. Six areas were related to exercise: self-efficacy, health status, intention, perceived control, beliefs/benefits and previous physical activity. Other issues that also related to exercise were perceived barriers, attitude, action planning,

gender and employment status. It was concluded that many of the variables related to exercise may be could be changed through the development and implementation of appropriately tailored interventions.

In relation to heart failure another systematic review of controlled studies investigated what strategies were effective for exercise adherence in heart failure (77). Nine randomised controlled trials were identified, with 3,231 participants. Positive outcomes resulted with short-term interventions such as exercise prescriptions, goal setting, feedback and problem-solving. However, longer-term maintenance of exercise was more problematic. Addressing self-efficacy in relation to exercise was considered a particular area for consideration.

Based on the evidence from the above reviews it would appear that follow up interventions composed of exercise/behaviour change were effective in the either the medium (6 months) and in some studies in the long term (>12 months) at maintaining/improving the benefits of CR. The barriers to adherence are multi factorial and tailored approached incorporating exercise and behavioural change support/follow up may be of benefit.

Other recent studies, including randomised control trials (RCT) and controlled trials which have specifically looked at long term EM (> 12 months and up to 5 years)

One RCT investigated maintenance of exercise after Phase II Cardiac Rehabilitation (78). They investigated a home-based intervention to support exercise maintenance among participants (n=130) who had completed Phase II cardiac rehabilitation. Data was collected over a five-year period. Participants were randomized to an exercise counselling /maintenance counselling group (n=64) or contact control group (n=66). The maintenance counselling group participants received a six-month program of exercise counselling delivered via telephone, with printed materials and feedback. The maintenance counselling group reported significantly higher participation in exercise and physical functioning than the contact control group at 12 month and increased the probability of participants" exercising at or above physical activity guidelines. The authors concluded that a telephone-based intervention can help maintain exercise, and improve physical functioning.

Another randomised control study looked at lifestyle intervention programme in patients with Coronary Heart Disease (n=197), compared with usual care with follow up after two years (79). The intervention was multi factorial addressing diet, regular exercise, smoking cessation, psychological support and education (including group meetings) delivered by nurses. Usual care was follow up in the outpatient clinic. Participants in the lifestyle intervention group showed significant improvement in dietary, exercise and smoking habits when compared with usual care.

Other studies have investigated methods to improve maintenance of exercise after CR. This has included comparing usual care or to a group counselling sessions (80). Participants in the usual care group were 76% more likely than those in the intervention group to stop exercising after 12 months. Another study (81) compared two, in-person exercise consultations and two support phone calls compared to a control, this showed maintenance of self-reported exercise but not differential fitness outcomes (peak oxygen uptake, V02) at 12 months in the intervention compared with the control group. Another compared participants (enrolled in CR) who were offered pedometer-based intervention plus four behavioural counselling telephone calls, over 18

weeks, compared with a control group (82). At six months, minutes of physical activity, number of activity sessions, (including walking sessions) increased significantly in the intervention compared with the control group. There were no significant group differences in cardio-respiratory fitness. Another study compared the effects of using a diary of physical activities and quarterly group exercise sessions with usual care at 12 months after either in or outpatient CR (83). 73% of the intervention group reported regular physical activity compared to 40% in the usual care group.

Another study (participants n=31) investigated various aspects of follow up including standard care with regular testing, home based and centre based programmes on various lifestyle factor including lipids, body compositions and exercise (objectively tested) after centre based CR (84). All groups showed improved/maintained function, blood lipids and body weight/composition at 12 months.

One observational study of long term exercise maintenance after CR (n=109) investigated participants post acute myocardial infarction after CR, comparing a five-month MDT CR programme intervention that included exercise, to a non exercise group (85). At six months EM was at >82% in the exercise group. EM high levels remained high at 18 months and may be one of the factors relating to quality of life and objective physical activity levels. Limitations of the study were there relatively small sample size and lack of randomisation.

Another observation study investigated the effects of a five year follow up of a community based phase 4 programme (86). This study looked at those with acute myocardial infarction (n=143) who had completed cardiac rehabilitation. Three groups were then followed: those who took up phase 4 rehabilitation, those offered who declined and those not offered phase 4 rehabilitation due to lack of availability locally. Risk factor profile, self-reported exercise and quality-of-life scores were assessed in all patients. BMI showed no change in the accepted group, with a significant increase between pre and five-year levels in the „declined“ group and the „not offered“ group. For quality of life scores there was a significant improvement in all groups. All groups showed an improvement in quality of life scores following phase 3, which showed a trend towards significance. Both the „accepted“ and „not offered“ groups maintained this improvement, the „declined“ group returned to baseline. For exercise levels all groups had similar exercise levels initially and all showed significant improvements after phase 3, with deterioration over five years. This decline in exercise was significant in the „declined“ group and shows a trend in the „not offered“ group. The authors concluded that there were observable benefits in participating in long-term phase 4 cardiac rehabilitation, although it was acknowledged that this was a small single centre study and whether the benefits seen can be ascribed directly to phase 4 cardiac rehabilitation further research with a different study design would need to address.

The limitation of these studies are acknowledged, some being RCTs and others controlled studies, whilst two were observational studies, and the quality of evidence has not been fully evaluated as part of a systematic review process. From the studies above there appears to be emerging evidence that follow up incorporating professional support (both in person or telephonic) group exercise to address behavioural change and/or exercise issues appear effective in maintaining physical activity and exercise in individuals with cardiac conditions.

Person-centred/qualitative evidence

Two qualitative review articles were identified as relevant. The first review conducted a qualitative synthesis of factors influencing maintenance of lifestyle behaviour change in individuals with high cardiovascular risk (87). The aim was to clarify factors thought to influence maintenance of changed healthy lifestyles, from the individual's perspective. Twenty two studies were included. The most commonly reported influences were those relating to social support (formally or informal), beliefs (about the self or the causes and management of poor health, and the value of maintaining lifestyle behaviours), and other psychological factors (attitude, thinking and coping styles, and problem solving skills). Physical activity was the most commonly investigated behaviour but overall, the main barriers and facilitators related to a range of behaviours. Interrelationships between factors of „social support“, „education and knowledge“, and „beliefs and emotions“ were all considered key themes. The authors concluded factors that influence lifestyle change are also central for maintaining healthy behaviour. Thus addressing barriers and facilitators within lifestyle support programmes are of value in the longer-term.

The second review article investigated conducted a systematic review article of qualitative papers to explore barriers and enablers to physical activity among individuals with heart failure (HF) (88). Synthesis of results from the 20 studies identified four main themes: Changing self/body, negative emotional response, adjusting to altered status, and interpersonal influences. How individuals responded to their diagnosis and altered physical status correlated to their activity levels, as did the degree of support to exercise coming from family, friends, and professionals. These findings link to behavioural change philosophies. The authors concluded that behavioural change may be useful for developing interventions to support individuals with HF in undertaking and maintaining regular PA/exercise patterns.

Two other single studies were identified which were of relevance. One primarily qualitative study conducted in Grampian was an evaluation of Phase 4 classes (89). Questionnaires were sent to attendees who participated in the classes, and ex-attendees that had attended phase 4 classes but now did not. Various aspects of the experience and perceptions were explored. Attendee comments and key data were around the: „high benefit“ of the classes 89% (n=282), exercise (47%), social aspects (47%) and wellbeing (6%) (n= 300 respondents provided 530 comments) were the key themes identified in relation to what they liked about the class. There was good attendance, with 4.7 attendances (average) per month (n=319) and sustained attendance, 3.32 years was the average membership with the group providing the classes (n=319). For ex attendees (n= 203 or which n=68 provided below data, average time since last attendance 15 months) reasons why they no longer attended responses (n=68) were illness/other conditions (n=18), Work/other commitments (n=18) and suitability (time) /access (n=10). Positive drop outs/ reasons for not attending were attendance at exercise elsewhere (e.g. other groups, classes or independently) A key message overall was that follow up was important.

One study focused on participation in community based EM programs after completion of hospital based CR programmes (90). This was a mixed methods study (surveys and focus groups) with 81 respondents. This was in Scotland, in Argyll and Clyde NHS region. The focus groups identified that support during the transition to EM was a key issue. Respondents proposed facilitators to achieve a seamless transition, this included: personal contact from

service providers to service users, peer support and integration of community based cardiac rehabilitation and EM sessions; to give the opportunity try sessions. The conclusion was that the use of community based exercise maintenance programmes was influenced by multiple factors including views of exercise, confidence, and suitability of the exercise programme to the participant.

Overall Summary of Cardiac Evidence

- CR is clinically effective and cost effective
- Long term PA/exercise is part of the recommended in guidelines as part of the pathway and exit strategy from CR
- Good quality evidence that people with stable coronary disease should continue regular PA/exercise and that it is safe (delivered appropriately)
- Studies show PA exercise levels are not maintained post CR
- Adherence to CR exercise component is multi-factorial
- Individualised tailored approaches may lead to success in adherence to CR
- Some reviews and emerging evidence that multi intervention follow up support, in terms of PA/exercise and behavioural change appear effective in maintaining PA/exercise, but further research is needed
- Qualitative evidence shows that barriers and facilitators are multi factorial to maintaining PA and behavioural change. Key aspects/themes identified are social support, knowledge and education and beliefs and attitude

Physical activity levels after stroke

89% of those with stroke living in Scotland do not meet physical activity targets ⁽²⁴⁾

Physical activity levels after rehabilitation remain below recommended levels for health and wellbeing at three and six month time post stroke (91). Improvements in physical and functional improvements gained from organised programmes, are lost at follow up (three months) (92) Stroke survivors spend an average of 81% per 24-h day in sedentary behaviour at one, six and twelve months post stroke (93). This is particularly relevant to community dwelling stroke survivors, who remained highly sedentary a year after stroke, independent of their functional ability (93).

Guidelines for exercise after stroke

Evidence based guidelines advocate PA/exercise after stroke, based on a robust evidence base (94) (95)

SIGN guidelines 108

SIGN 108 – Management of patients with Stroke or TIA (94)

Exercise

- „Lifelong participation in programmes of exercise after stroke should be encouraged”

Physical Activity after Stroke

‘The guidelines recommend that services need to be available in the community to encourage people with stroke to engage in physical activity’. They acknowledge that „currently, partnerships are developing between NHS Boards and the leisure industry”.

They also reference that social aspects are important: „It is also important for service providers to consider the psychosocial aspects of physical activity. Evidence from qualitative studies suggests that people with stroke undertaking exercise may benefit from the social aspects of the service.”

In terms of how to deliver, further work is needed: „It needs to be acknowledged that not every person with a stroke who would benefit from an increase in physical activity wishes to participate in exercise training classes. Therefore, to increase the level of physical activity after stroke in a manner that is safe, effective, and enjoyable for participants, further research is required into barriers and motivators for physical activity, in order to inform the development...”

„This evidence is recognised by clinical guidelines which recommend long-term participation in PA after stroke because of its potential impact in reducing risk of cardiac events, diabetes depression, obesity, and recurrent stroke . Thus there is an evidence-based consensus that after stroke people should engage in long-term PA behaviour as part of, and as follow up to, rehabilitation”.

Physical activity and exercise after stroke – evidence of benefits

Cochrane reviews

There are four key recent Cochrane systematic reviews.

The initial review of interest was conducted in 2009 and investigated physical fitness training after stroke (96) which showed that cardio respiratory training can improve walking. This was followed by a review of all trials of exercise that included all variables (e.g. exercise mode and type of delivery) (97). This systematic review of physical fitness training for stroke patients included 32 RCTs with 1414 participants, most ambulant at more than 1 month post stroke. They concluded that cardio respiratory training increased walking speed and exercise capacity; for resistance training there was insufficient data. Physical fitness training was safe (incidences of adverse outcomes: five in 1414 deaths, four in 1414 cerebrovascular events or cardiovascular events). The authors concluded there was sufficient evidence to incorporate CR training involving walking within post stroke rehab programmes.

The review from 2009 was updated in 2013 (98) and addressed fitness training after stroke, including evaluation of if this reduced death, dependence, and disability and also sought to determine the effects of training on physical fitness, mobility, physical function, quality of life, mood, and incidence of adverse event. 45 trials, involving 2188 participants, were identified which were composed of cardiorespiratory (22 trials, 995 participants), resistance (eight trials, 275 participants), and mixed training interventions (15 trials, 918 participants).

It was concluded that cardiorespiratory training decreased disability after stroke and may enhance mobility and balance. There was sufficient evidence to include cardiorespiratory and varied training, involving walking, within post-stroke rehabilitation programs to improve walking; this may also improve balance. There was insufficient evidence for resistance training. Further research is required in relation to the ideal content of the exercise prescription and to determine long-term benefits.

Another review (99) focused on a circuit class therapy for improving mobility after stroke. This involved six trials of 292 participants, long term stroke survivors living in community or receiving in patient treatment, able to walk 10 metres unassisted. They concluded that circuit training therapy was safe and effective in improving mobility for people after moderate stroke and may reduce in-patient stays

Based on the evidence above the most beneficial exercise prescription and the timescales for delivering exercise training require further investigation. There was consensus that delivering exercise training after stroke improved function and links with guidelines that this should be part of the ongoing care (95). There is evidence that group circuit training is effective in improving functional outcomes after stroke. In addition group exercise is also likely to be more cost effective (100), though more specific evidence is required. It should also be considered that other research has shown that advice only is reported to unlikely to be sufficient to change behaviour after stroke (101). Investigations into the effectiveness of multi factorial lifestyle interventions for increasing exercise in individuals post stroke requires further research. One study showed that a 12 month complex lifestyle intervention including, smoking cessation, reduction in alcohol intake, maintaining an appropriate body mass index and taking exercise reduced risk factors and increased physical activity in stroke survivors (102).

Evidence in relation to current service delivery of exercise after stroke services

One study (103) conducted a survey of community exercise programmes for stroke survivors in Scotland. They conducted a web-based survey which was emailed to health, leisure service and stroke charity contacts in Scotland with email and telephone follow-up to non-respondents. The overall response rate was 64% (230/361). A total of 14 Exercise after Stroke services were identified, the majority of which were run by charity collaborations (7/14), followed by leisure centre services (4/14) and health services (3/14). The conclusion was there was a shortage for stroke specific services, and service development in relation to instructor training and referral pathways was required to enable individuals with stroke to access services.

Person centred/qualitative data

There were two systematic reviews identified. One systematic review focused on perceived barriers and motivators to physical activity after stroke (Nicolson et al 2012) of 174 stroke patients from five qualitative studies and one quantitative study with only two studies reporting motivators and two reporting barriers. Barriers were lack of motivation, environmental factors (e.g. transport), health concerns and stroke impairments; motivators (most commonly reported) were social support and the need to be able to perform activities of daily living. The conclusion was that the development of tailored interventions targeting barriers and facilitating perceived motivators to increase and maintain stroke survivors' physical activity were needed.

Morris et al (2012) conducted a structured review of the importance of Psychological and Social Factors in Influencing the Uptake and Maintenance of Physical Activity after Stroke. They identified 20 studies from 19 publications, one RCT and 10 qualitative studies. barriers and/or motivators were self-efficacy, perceived confidence, and ability to perform PA, PA beliefs both positive and negative influenced PA behaviour, social support, family support and ability to participate in group exercise, related to PA behaviour after stroke, and fear and anxiety. Enablers were the role HCP professional, role of exercise instructor and their level of knowledge and expertise. Group exercise had a positive influence on PA, particularly groups where social aspects (friendships and camaraderie) were encompassed and peer support was greatly valued.

The barriers and motivators are multi factorial. Key barriers were motivation, access, health concerns and poor functions. Key motivators were social aspects/support, especially in the group exercise context (having a positive effect on PA) and enablers included social and professional support. Tailored interventions to address the multi factorial barriers/issues may be useful to maintain or increase physical activity.

Summary of Evidence for Stroke

- **PA is not maintained after clinical rehabilitation and those with stroke are largely inactive**
- **There is good quality evidence that PA/exercise after stroke has a beneficial impact on function**
- **Exercise after stroke is recommended by guidelines and is safe (delivered appropriately)**
- **Current service delivery in Scotland, there is a lack of services and service development is needed**
- **Person centred/qualitative data, shows barriers and motivators are multi factorial, professional and social/peer support are important**
- **Tailored interventions to address the multi factorial barriers/issues may be useful to maintain or increase physical activity**

EVIDENCE BASE REFERENCES

- 1) Scottish Health Survey (2012) <http://www.scotland.gov.uk/Publications/2013/09/3684>
- 2) Improving the Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan PDF 11 [PDF, 444.7 kb: 03 Dec 2009] <http://www.scotland.gov.uk/Resource/Doc/294270/0090939.pdf>
- 3) Lozano, R. et al. (2012). Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: a systematic analysis for the Global Burden of Disease Study 2010. *The Lancet* Vol 380. Issue 9859: 2095-128.
- 4) *Chronic Obstructive Pulmonary Disease (COPD)*. Factsheet No.315. World Health Organization, 2012. :<http://www.who.int/mediacentre/factsheets/fs315/en/>
- 5) *Better Heart Disease and Stroke Care Action Plan*. Edinburgh, Scottish Government, 2009 <http://www.scotland.gov.uk/Resource/Doc/277650/0083350.pdf>
- 6) WHO - <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/cardiovascular-diseases/cardiovascular-diseases2/definition-of-cardiovascular-diseases>
- 7) Chronic disease management. A compendium of information, Department of Health, May 2004.
- 8) Improving the Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan. Edinburgh: Scottish Government, 2009. www.scotland.gov.uk/Publications/2009/12/03112054/11
- 9) Information services division (ISD) Heart Disease Statistics Update Year Ending 31 March 2013 Publication date – 28 January 2014 <http://www.isdscotland.org/Health-Topics/Heart-Disease/Publications/2014-01-28/2014-01-28-Heart-Disease-Report.pdf>
- 10) *Clinical Standards for Chronic Obstructive Pulmonary Disease Services*. Edinburgh: NHS Quality Improvement Scotland, 2010. http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/copd_implementation/copd_clinical_standards.aspx
- 11) Managing long term conditions, Audit Scotland 2007, http://www.audit-scotland.gov.uk/docs/health/2007/nr_070816_managing_long_term.pdf
- 12) Cardiology services, prepared for the Auditor General for Scotland February 2012 http://www.auditscotland.gov.uk/docs/health/2012/nr_120223_cardiology_km_bw.pdf
- 13) Management of coronary heart disease a national clinical and resource impact assessment, 2007 <http://www.sign.ac.uk/pdf/chdaudit.pdf>
- 14) *The world health report 2002* http://whqlibdoc.who.int/publications/2010/9789241599979_eng.pdf?ua=1

- 15) *Lancet* (2012) *Pandemic of physical inactivity- Global action for Public Health*
[http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(12\)60898-8/fulltext#article_upsell](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)60898-8/fulltext#article_upsell)
- 16) Getting Scotland fit would increase life expectancy by almost a year. (Annual report of Chief Medical Officer – Health in Scotland 2011- transforming Scotland's Health)
<http://www.scotland.gov.uk/Publications/2012/12/7521>
- 17) Morris, J (1994). Exercise in the prevention of coronary heart disease: Today's best buy in public health. *Medicine and Science in Sport and Exercise*, 26, 807-814.
- 18) From burden to best buys WHO (2011)
http://www.who.int/nmh/publications/best_buys_summary.pdf
- 19) Let's make Scotland more active a Strategy for Physical Activity, physical activity task force (2003) <http://www.scotland.gov.uk/Resource/Doc/47032/0017726.pdf>
- 20) Exercise for life - Physical activity in health and disease. Recommendations of the Sport and Exercise Medicine Committee Working Party of the Royal College of Physicians June 2012 <http://www.rcplondon.ac.uk/sites/default/files/documents/exercise-for-life-final.pdf>
- 21) Miriam Reiner, Christina Niermann, Darko Jekauc and Alexander Woll Reiner et al. *BMC Public Health* (2013). Long-term health benefits of physical activity – a systematic review of longitudinal studies, 13:813. <http://www.biomedcentral.com/1471-2458/13/813>
- 22) Chad KE, Harrison EL, Reeder BA, Marshall SC (2005) Home versus centred based physical activity programs for older adults. Ashworth NL, Cochrane review [Cochrane Database Syst Rev](#). 2005 Jan 25;(1):CD004017.
- 23) Smith S, Soubhi H, Fortin M, Hudson C, Dowd T. Managing patients with multi morbidity: systematic review of interventions in primary care and community settings. *BMJ*. 2012 Sep 3;345:e5205. doi: 10.1136/bmj.e5205.
- 24) Scottish Health Survey combined results (2008-2011). Compiled by Public Health and Sport Analytical Services, The Quality Unit Scottish Government on request by PARCS project manager.
- 25) Johnson- Warrington, Harrison S, Mitchell K, Steiner M, Morgan M, Singh, S (2014). Exercise Capacity and Physical Activity in Patients With COPD and Healthy Subjects Classified as Medical Research Council Dyspnea Scale Grade 2. *Journal of Cardiopulmonary Rehabilitation and Prevention*, 34:150-154
- 26) Dyer, C. Harris, N, Jenkin, E, Langley-Johnson C, Lewis R, Taylor G, Gruffydd-Jones K (2013) Activity levels after pulmonary rehabilitation – what really happens? *Physiotherapy* 93, 228–232
- 27) Maltis, F. (2013) Exercise and COPD: therapeutic responses, disease-related outcomes, and activity-promotion strategies [Phys Sportsmed](#), Feb; 41(1):66-80. doi: 10.3810/psm.2013.02.2001.

- 28) **Vorrink S, Kort S, Trooster T and Lammers JW (2011)** Level of daily physical activity in individuals with COPD compared with healthy controls. *Respiratory Research* 2011, **12:33** doi:10.1186/1465-9921-12-33
- 29) Watz, H, Waschki, B, Meyer T and Magnussen H (2008) Physical activity in patients with COPD. *European Respiratory Journal*. Published online doi: 10.1183/09031936.00024608 **February 1, 2009** vol. 33 no. 2 **262-272**
- 30) Physical Activity and long term conditions a guide for GPs. Intelligent Health <http://www.intelligenthealth.co.uk/wp-content/uploads/2013/03/MBM-Booklet.pdf>
- 31) National Institute for Health and Clinical Excellence. Chronic obstructive Pulmonary disease: management of chronic obstructive pulmonary disease in adults in primary and secondary care. Update guideline. London: National Institute for Health and Clinical Excellence 2010. URL: <http://guidance.nice.org.uk/CG101/>
- 32) National Institute for Health and Clinical Excellence. Pulmonary rehabilitation service for patients with COPD. London: National Institute for Clinical Excellence; 2006 URL: www.nice.org.uk/media/63F/4D/PulmonaryRehabCommissioningGuide.pdf/English
- 33) Lacasse Y, Goldstein R, Lasserson TJ, Martin S, (2009) Pulmonary rehabilitation for chronic obstructive pulmonary disease (Review) <http://www.update-software.com/pdf/CD003793.pdf>
- 34) Puhan MA, Gimeno-Santos E, Scharplatz M, Troosters T, Walters EH, Steurer J.(2011) Pulmonary rehabilitation following exacerbations of chronic obstructive pulmonary disease. *Cochrane Database Syst Rev*. 2011 Oct 5; (10):CD005305. doi: 10.1002/14651858.CD005305.pub3.
- 35) Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease: GOLD http://www.goldcopd.org/uploads/users/files/GOLD_Report_2013_Feb20.pdf
- 36) Seymour JM, Moore L, Jolley CJ, Ward K, Creasey J, Steier JS (2010). Outpatient pulmonary rehabilitation following acute exacerbations of COPD. *Thorax*; 65(5):423-428
- 37) British Thoracic Society Guidelines on pulmonary rehabilitation in adults (2013) <https://www.brit-thoracic.org.uk/document-library/clinical-information/pulmonary-rehabilitation/bts-guideline-for-pulmonary-rehabilitation/>
- 38) Bourbeau, J (2010) Making pulmonary rehabilitation a success in COPD. *Swiss Medical Weekly*, 140:w13067
- 39) Ries AL, Kaplan RM, Myers R, et al. Maintenance after pulmonary rehabilitation in chronic lung disease (2003). *Am J Respir Crit Care*;167: 880–888
- 40) Brooks D, Krip B, Mangovski-Alzamora S (2002) The effect of post rehabilitation programmes among individuals with chronic obstructive pulmonary disease. *Eur Respir J*; 20: 20–29.
- 41) Troosters, T, Gosselink, R, Decramer, M (2000) Short- and Long-term Effects of Outpatient Rehabilitation in Patients with Chronic Obstructive Pulmonary Disease: A Randomized Trial *Am J Med*. 109:207–212. Q 2000 by Excerpta Medica, Inc

- 42) Weiner, P, Magadle R, Beckerman M, Weiner, M and Berar-Yanay, N (2004) Maintenance of inspiratory muscle training in COPD patients: one year follow-up. *10.1183/09031936.03.00059503 ERJ* **January 1**, vol. 23 no. 1 **61-65**
- 43) Foglio K, Bianchi L, Ambrosino N. (2001) Is it really useful to repeat outpatient pulmonary rehabilitation programs in patients with chronic airway obstruction? A 2-year controlled study. *Chest*, Jun; 119 (6):1696-704.
- 44) Moullec G, Ninot G, Varray A, Despla J, Hayot M, Prefaut C. (2008) An innovative maintenance follow-up program after a first inpatient pulmonary rehabilitation. *Respiratory Medicine* 102, 556–56
- 45) Cockram J, Cecins N, Jenkins S (2006) Maintaining exercise capacity and quality of life following pulmonary rehabilitation. *Respirology*. 2006 Jan; 11(1):98-104.
- 46) Beauchamp MK, Janaudis-Ferreira T, Goldstein RS, Brooks D (2011) Optimal duration of pulmonary rehabilitation for individuals with chronic obstructive pulmonary disease - a systematic review. *Chron Respir Dis.*; 8(2):129-40. doi: 10.1177/1479972311404256.
- 47) Casaburi, R (2011) Activity Promotion: A Paradigm Shift for Chronic Obstructive Pulmonary Disease Therapeutics *Am Thorax Soc Vol 8*. pp 334–337, 2011
DOI: 10.1513/pats.201101-001RM. Internet address: www.atsjournals.org
- 48) Yorke J, Rochnia N, Walters S, Dugdill L, Vestbo J, Calverley P (2010) Maintenance rehabilitation for chronic obstructive pulmonary disease (Protocol). *Cochrane Database of Systematic Reviews Issue 11*. Art. No.: CD008837. DOI: 10.1002/14651858.CD008837.
- 49) Kruis AL, Smidt N, Assendelft WJJ, Gussekloo J, Boland MRS, Rutten-van Mölken M, Chavannes NH (2011). Integrated disease management interventions for patients with chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews, Issue 11*. Art. No.: CD009437. DOI: 10.1002/14651858.CD009437.
- 50) Ng LW, Mackney J, Jenkins S, Hill, K (2012) Does exercise training change physical activity in people with COPD? A systematic review and meta-analysis. *Chronic Respiratory Disease* **February 2012** vol. 9 no. 1 **17-26**
- 51) Amin S, Abrazado M, Quinn M, Storer, T, Tseng CH, and Coope, CB. A controlled study of community-based exercise training in patients with moderate COPD. *BMC Pulmonary Medicine* , 14:125 <http://www.biomedcentral.com/1471-2466/14/125>
- 52) Gimeno-Santos E, Frei A, Steurer-Stey, C de Batlle, J. Rabinovich, RA, Raste, Y, Hopkinson, NS, Polkey MI, van Remoortel, H, Troosters, T, Kulich, K, Karlsson, N, Puhon, MA, Garcia-Aymerich, J Gimeno-Santos E. Determinants and outcomes of physical activity in patients with COPD: a systematic review. *Thorax* 2014; 0:1–9. doi:10.1136/thoraxjnl-2013-204763
- 53) Desveaux L, Rolfe D, Beauchamp M, Goldstein R, Brooks D (2014) Participant experiences of a community-based maintenance program post-pulmonary rehabilitation. *Chron Respir Dis.*; 11 (1):23-30. doi: 10.1177/1479972313516880
- 54) Hellem E, Bruusgaard KA, Bergland A. (2012) Exercise maintenance: COPD patients' perception and perspectives on elements of success in sustaining long-term exercise. *Physiother Theory Pract*. 2012 Apr; 28(3):206-20. doi: 10.3109/09593985.2011.587502. Epub 2011 Abstract

- 55) Ades PA, Savage PD, Tischler MD, Poehlman ET, Dee J, Niggel J. (2002) Determinants of disability in older coronary patients. *American Heart J*; 143 (1):151–6.
- 56) Bock BC, Carmona-Barros RE, Esler JL, Tilkemeier PL. (2003) Program participation and physical activity maintenance after cardiac rehabilitation. *Behav Modif.*; 27 (1):37–53. [PubMed: 12587259]
- 57) Hellman EA. (1997) Use of the stages of change in exercise adherence model among older adults with cardiac diagnosis. *J Cardiopulm Rehabil*; 17(3):145–55. [PubMed: 9187980]
- 58) Unal B, Critchley JA, Fidan D, Capewell S. Life-years gained from modern cardiological treatments and population risk factor changes in England and Wales, 1981-2000. *Am J Public Health* 2005 Jan; 95(1):103-8.
- 59) 15. Department of Health. Commissioning Pack for Cardiac Rehabilitation. London: Department of Health; 2010. Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_117504.
- 60) National Institute for Health and Clinical Excellence. NICE CG48. *Secondary* prevention in primary and secondary care for patients following a myocardial infarction. London: NICE, May 2007. Available from: <http://www.nice.org.uk/CG48>.
- 61) National Institute for Health and Clinical Excellence. NICE CG94. Unstable Angina and NSTEMI: the early management of unstable angina and non-ST-segment-elevation myocardial infarction. London: NICE, March 2010. Available from: www.nice.org.uk/CG94.
- 62) National Institute for Health and Clinical Excellence. Commissioning a cardiac rehabilitation service. London: NICE, October 2011. Available from: www.nice.org.uk/usingguidance/commissioningguides/cardiacrehabilitation/cardiacrehabilitation.jsp.
- 63) World Health Organization (1993) Needs and action priorities in cardiac rehabilitation and secondary prevention in patients with CHD. Geneva: World Health Organization. Available from http://whqlibdoc.who.int/euro/-1993/EUR_ICP_CVD_125.pdf
- 64) <http://www.sign.ac.uk/guidelines/fulltext/57/>
- 65) Making the case for cardiac rehabilitation: modelling potential impact on readmissions. NHS Improvement <http://www.networks.nhs.uk/news/making-the-case-for-cardiac-rehabilitation-modelling-potential-impact-on-readmissions>
- 66) Taylor RS, Brown A, Ebrahim S, Jolliffe J, et al. (2004) Exercise-based rehabilitation for patients with coronary heart disease: systematic review and meta-analysis of randomized controlled trials. *Am J Med* 2004;116:682-92
- 67) Davies EJ, Moxham T, Rees K, Singh S, et al. Exercise based rehabilitation for heart failure. *Cochrane Database of Systematic Reviews*. 2010; Issue 4:Art. No. CD003331. DOI:10.1002/14651858.CD003331.pub3
- 68) Heran BS, Chen JM, Ebrahim S, et al. Exercise based cardiac rehabilitation for coronary heart disease. *Cochrane Database Syst Rev*. 2011 ;(7):CD001800.

- 69) Lam G, Snow R, Shaffer L, La Londe M, et al. The effect of a comprehensive cardiac rehabilitation program on 60-day hospital readmissions after an acute myocardial infarction. *J Am Coll Cardiol.* 2011; 57(14s1):E597-E597. DOI: 10.1016/S0735-1097(11)605974
- 70) Thompson PD , Franklin BA , Balady GJ, Blair SN, Corrado D, Estes NA III , Fulton JE, Gordon NF, Haskell WL, Link MS , Maron BJ, MittlemanMA , Pelliccia A, Wenger NK, Willich, SN, Costa F; American Heart Association Council on Nutrition, Physical Activity, and Metabolism; American Heart Association Council on Clinical Cardiology; American College of Sports Medicine. Exercise and acute cardiovascular events: placing the risks into perspective: a scientific statement from the American Heart Association Council on Nutrition, Physical Activity, and Metabolism and the Council on Clinical Cardiology. *Circulation.* 2007; 115: 2358–2368.
- 71) The BACPR Standards and Core Components for Cardiovascular Disease Prevention and Rehabilitation 2012 (2nd Edition)
http://www.bacpr.com/resources/46C_BACPR_Standards_and_Core_Components_2012.pdf
- 72) Taylor RS, Dalal H, Jolly K, Moxham T, Zawada A. Home-based versus centre-based cardiac rehabilitation. *Cochrane Database of Systematic Reviews* 2010, Issue 1. Art. No.: CD007130. DOI: 10.1002/14651858.CD007130.pub2.
- 73) Chase, J. D (2011) Systematic Review of Physical Activity Intervention Studies After Cardiac Rehabilitation. *Journal of Cardiovascular Nursing*, Vol 26, 5, 351-358
- 74) Davies P, Taylor F, Beswick A, Wise F, Moxham T, Rees K, Ebrahim S. Promoting patient uptake and adherence in cardiac rehabilitation (2010). *Cochrane Database of Systematic Reviews*, Issue 7. Art.No.:CD007131. DOI: 10.1002/14651858.CD007131.pub2.
- 75) Daly J, Sindone A P, Thompson DR, Hancock K., Chang E. and Davidson P. (2002), Barriers to Participation in and Adherence to Cardiac Rehabilitation Programs: A Critical Literature Review. *Progress in Cardiovascular Nursing*, 17: 8–17. doi: 10.1111/j.0889-7204.2002.00614.x
- 76) [Pettera](#), M, [Blancharda](#), C, [Kempa](#), KAR, Mazoff, AF, Ferriera, S.N (2009) Correlates of exercise among coronary heart disease patients: review, implications and future directions *European Journal of Preventive Cardiology* **October** vol. 16 no. 5 **515-526**
- 77) Tierney S, Mamas M, Woods S, Rutter MK, Gibson M, Neyses L, Deaton C (2012) What strategies are effective for exercise adherence in heart failure? A systematic review of controlled studies. *Fail Rev.* Jan; 17(1):107-15. doi: 10.1007/s10741-011-9252-4
- 78) Pinto, BM, Goldstein, MG, Papandonatos, GD, Farrell, N, Tilkemeier, P, Marcus, BH, and Todaro, JF (2011) Maintenance of Exercise After Phase II Cardiac Rehabilitation: A Randomized Controlled Trial . *Am J Prev Med.* September; 41(3): 274–283. doi:10.1016/j.amepre.2011.04.015
- 79) Vestfold Heart care Study Group (2003). Influence on lifestyle measures and five-year coronary risk by a comprehensive lifestyle intervention programme in patients with coronary heart disease. *Eur J Cardiovasc Prev Rehabil.* 2003 Dec; 10(6):429-37.

- 80) Moore SM, Charvat JM, Gordon NH, Pashkow F, Ribisl P, Roberts BL, Rocco M.(2006) Effects of a CHANGE intervention to increase exercise maintenance following cardiac events. *Ann Behav Med*; 31(1):53–62. [PubMed: 16472039]
- 81) Hughes AR, Mutrie N, MacIntyre PD.(2007) Effect of an exercise consultation on maintenance of physical activity after completion of phase III exercise-based cardiac rehabilitation. *European J Cardiovascular Prevention Rehabil*; 14:114–121.
- 82) Butler L, Furber S, Phongsavan P, Mark A, Bauman A. Effects of a pedometer-based intervention, on physical activity levels after cardiac rehabilitation: A randomized controlled trial. *J Cardiopulm Rehabil Prev*. 2009; 29(2):105–14. [PubMed: 19305235]
- 83) Arrigo I, Brunner-LaRocca H, Lefkovits M, Pfisterer M, Hoffmann A. Comparative outcome 1 year after formal cardiac rehabilitation: the effects of a randomized intervention to improve exercise adherence. *European J Cardiovascular Prev Rehab*. 2008; 15:306–311
- 84) Brubaker, P. H., Rejeski, W. J., Smith, M. J., Sevensky, K. H., Lamb, K. A., Sotile, W. M., & Miller, H. S. (2000). A home-based maintenance exercise program after centre-based cardiac rehabilitation: Effects on blood lipids, body composition, and functional capacity. *Journal of Cardiopulmonary Rehabilitation*, 20, 50–56
- 85) Izawa KP , Yamada S, Oka K, Watanabe S, Omiya K, Iijima S, Hirano Y, Kobayashi T, Kasahara Y, Samejima H, Osada N. (2004) Long-term exercise maintenance, physical activity, and health-related quality of life after cardiac rehabilitation. *Am J Phys Med Rehabil*. Dec; 83 (12):884-92.
- 86) Willmer, KA, Waite M. (2009) Long-term benefits of cardiac rehabilitation: a five-year follow-up of community-based phase 4 programmes. March, Volume 16, Issue 2 *Br J Cardiol* 2009; 16:73-77.
- 87) Murray J, Fenton G, Honey S, Bara AC, Hill KM and House, A (2013) .A qualitative synthesis of factors influencing maintenance of lifestyle behaviour change in individuals with high cardiovascular risk. *BMC Cardiovascular Disorders* 2013, 13:48 doi:10.1186/1471-2261-13-48.
- 88) Tierney S, Mamas M, Skelton D, Woods S, Rutter MK, Gibson M, Neyses L, Deaton C. (2011). What can we learn from patients with heart failure about exercise adherence? A systematic review of qualitative papers. *Health Psychol*. Jul; 30(4):401-10. doi: 10.1037/a0022848.
- 89) Evaluation of Phase IV commissioned by Grampian Cardiac Rehabilitation Association of exercise class members (Gray, 2010) (unpublished research- Robert Gordon University – Aberdeen)
- 90) Clark AM, Mundy C, Catto S, MacIntyre PD. (2011) Participation in community-based exercise maintenance programs after completion of hospital-based cardiac rehabilitation: a mixed-method study. *J Cardiopulm Rehabil Prev*. 2011 Jan-Feb;31(1):42-6. doi: 10.1097/HCR.0b013e3181f68aa6.

- 91) Moore SA¹, Hallsworth K, Plötz T, Ford GA, Rochester L, Trenell MI. (2013) Physical activity, sedentary behaviour and metabolic control following stroke: a cross-sectional and longitudinal study. [PLoS One](#). 2013;8(1):e55263. doi: 10.1371/journal.pone.0055263. Epub 2013 Jan 29
- 92) Touillet A¹, Guesdon H, Bosser G, Beis JM, Paysant J. (2010) Assessment of compliance with prescribed activity by hemiplegic stroke patients after an exercise programme and physical activity education. *Ann Phys Rehabil Med*. May;53(4):250-7, 257-65. doi: 10.1016/j.rehab.2010.03.005. Epub 2010 Mar 31.
- 93) Tieges Z, Mead G, Allerhand M, Duncan F, van Wijck F, Fitzsimons C, Greig C, Chastin S. Sedentary behaviour in the first year after stroke: a longitudinal cohort study with objective measures. (2014) *Arch Phys Med Rehabil*. 2014 Sep 11. pii: S0003-9993(14)01028-4. doi: 10.1016/j.apmr.2014.08.015.
- 94) <http://www.sign.ac.uk/guidelines/fulltext/108/>
- 95) Gordon NF, Gulanick M, Costa F, Fletcher G, Franklin BA, Roth EJ, Shephard T (2004) American Heart Association Council on Clinical Cardiology, Subcommittee on Exercise, Cardiac Rehabilitation, and Prevention; the Council on Cardiovascular Nursing; the Council on Nutrition, Physical Activity, and Metabolism; and the Stroke Council Physical activity and exercise recommendations for stroke survivors: an American Heart Association scientific statement from the Council on Clinical Cardiology, Subcommittee on Exercise, Cardiac Rehabilitation, and Prevention; the Council on Cardiovascular Nursing; the Council on Nutrition, Physical Activity, and Metabolism; and the Stroke Council. *Circulation*. 2004 Apr 27; 109(16):2031-41.
- 96) Saunders DH¹, Greig CA, Mead GE, Young A. (2009) Physical fitness training for stroke patients. *Cochrane Database Syst Rev*. Oct 7; (4):CD003316. doi: 10.1002/14651858.CD003316.pub3.
- 97) Brazzelli M, Saunders DH, Greig CA, Mead GE. Physical fitness training for stroke patients. (2011) *Cochrane Database of Systematic Reviews*, Issue 11. Art. No.: CD003316. DOI: 10.1002/14651858.CD003316.pub4.
- 98) Saunders DH, Sanderson M, Brazzelli M, Greig CA, Mead GE. (2013) Physical fitness training for stroke patients. *Cochrane Database Syst Rev*. 2013 Oct 21;10:CD003316. doi: 10.1002/14651858.CD003316.pub5.
- 99) English C, Hillier SL (2010) Circuit class therapy for improving mobility after stroke. *Cochrane Database Syst Rev*. 2010 Jul 7 ;(7):CD007513. doi: 10.1002/14651858.CD007513.pub2
- 100) [English CK](#), [Hillier SL](#), [Stiller KR](#), [Warden-Flood A](#). (2007) Circuit class therapy versus individual physiotherapy sessions during inpatient stroke rehabilitation: a controlled trial. [Arch Phys Med Rehabil](#). Aug; 88(8):955-63.

- 101) Boysen G, Krarup LH, Zeng X, Oskedra A, Kõrv J, Andersen G, Gluud C, Pedersen A, Lindahl M, Hansen L, Winkel P, Truelsen T; (2009) ExStroke Pilot Trial Group of the effect of repeated instructions to improve physical activity after ischemic stroke: a multinational randomised controlled clinical trial. *BMJ*. Jul 22; 339:b2810. doi: 10.1136/bmj.b2810.
- 102) Joubert J, Reid C, Barton D, Cumming T, McLean A, Joubert L, Barlow J, Ames D, Davis S. (2009) Integrated care improves risk-factor modification after stroke: initial results of the Integrated Care for the Reduction of Secondary Stroke model. *J Neurol Neurosurg Psychiatry*. Mar; 80(3):279-84. doi: 10.1136/jnnp.2008.148122. Epub 2008 Nov 14.
- 103) Best C, van Wijck F, Dennis J, Smith M, Donaghy M, Fraser H, Dinan-Young S, Mead GA (2012) A survey of community exercise programmes for stroke survivors in Scotland. *Health Soc Care Community*. Jul; 20(4):400-11. doi: 10.1111/j.1365-2524.2011.01043.x. Epub 2011 Nov 15.

APPENDIX 3 - PARCS Project Aims and Alignment to Government Strategies and Standards and Clinical Guidelines
(Compiled near commencement of project in January 2013)

Aim	Strategy, Standards and Guideline this relates to
<p>1) To assist the Scottish Government to deliver the best quality healthcare to the people of Scotland</p>	<p>NHS Quality Strategy 2010 <i>Person centred safe, effective, efficient, equitable and timely</i></p> <p>THE NHS Quality Outcomes Framework 2011/12– Domain 2, <i>Enhancing quality of life for people with long term conditions</i></p> <p><i>2.1 Ensuring people feel supported in managing their condition</i></p> <p>Better Health Better Care Action Plan 3.1 <i>Improving Quality</i></p> <ul style="list-style-type: none"> • Spread best practice in care for people with long term conditions • Bring a more systematic approach to clinical effectiveness <p>3.4 <i>Effectiveness, evidence based care</i></p> <p>Delivery Framework for Adult Rehabilitation Plan 4. <i>Comprehensive evidence based services – consistent with best practice</i></p>
<p>2) To contribute to the achievement of the Quality Ambitions by:</p> <p>a) developing a service based on user-articulated need and preference (Person-centred)</p>	<p>NHS Quality Strategy 2010 – Person centred</p> <p>NICE- CG138 – Patient experience in adult NHS services 1.3 <i>Tailoring health care service needs for each patient – listen to patient views and preferences</i> 1.5 <i>Enabling patients to actively participate in their care</i></p> <p>The 10 National Standards for Community Engagement</p> <p>Scottish Health Council – Participation Standard Healthcare Improvement Scotland – User involvement and Person Centeredness</p> <p>Heart and Stroke Action Plan</p> <p>4.33 <i>Improving patient experience of cardiac rehabilitation-MCNs encourage heart manual to ensure people receive structured information & mentoring/ „braveheart“</i></p> <p>Better Health Better Care Action Plan</p> <p>1.1 <i>Towards a mutual NHS – embedded patient experience information</i></p> <p>1.3 <i>Delivering Together – embedding patient experience data in NHS targets</i></p>

	<p>3.1 <i>Enable patients to be partners in their care</i></p> <p>Delivery Framework for Adult Rehabilitation Plan</p> <p>3. <i>Enablement and self managed care</i> – volunteer and specialist interest support groups involved in designing, evaluating and delivering services. Use of a buddy system explored.</p>
<p>2) To contribute to the achievement of the Quality Ambitions by:</p> <p>b) increasing focus on preventative services and interventions (Effective)</p>	<p>NHS Quality Strategy 2010 –Effective</p> <p>Heart Disease and Stroke Care Action Plan</p> <p>3.7 <i>Promoting healthy lifestyles</i> – all GPs and practice nurses to undertake training on brief intervention to help support lifestyle changes & a health promoting health service</p> <p>3.34 <i>Flexible and culturally sensitive programmes</i></p> <p>4.24 <i>Developing public access to defibrillation</i></p> <p>4.24 <i>Improving access to cardiac rehabilitation</i></p> <p>5.1 <i>Improving stroke services</i></p> <p>5.62 <i>Improve stroke research</i></p> <p>7.7 <i>Improving HD data collection</i></p> <p>SIGN 57 – Cardiac Rehab</p> <p><i>Phase 3</i> Exercise training/community setting</p> <p><i>Phase 4</i> Long term follow up in cardiac support group, which involves exercise in a community centre, leisure centre</p> <p>Self help groups should be encouraged and enabled to use the same evidence based approach to cardiac rehabilitation as advocated by professionally led programmes</p> <p>SIGN 108 – Management of Patient' with Stroke or TIA</p> <p>SIGN 118 – Stroke</p> <p>5.6 <i>Moving on after stroke</i> – support and voluntary services</p> <p>5.6.4 <i>Physical activity after stroke</i> – through stroke MCNs work with leisure industry to improve access to exercise and physical training for those with stroke</p> <p>Stroke Quality Standards</p> <p>7. <i>Ongoing Rehabilitation QS2</i> – active therapy for those with stroke as long as they continue to benefit from it</p>

	<p>Good Practice Guidelines for Exercise after Stroke</p> <p>NICE 101- Chronic Obstructive Airways Disease (COPD)</p> <p><i>Pulmonary rehabilitation for all those who need it</i></p> <p>Tailor the programme to individual needs, and include physical training,</p> <p>Hold pulmonary rehabilitation sessions at a practical time in a conveniently located, accessible building to increase concordance</p> <p>NICE 108 – Chronic Heart Failure</p> <p>Offer a supervised exercise base rehabilitation group for patients with heart failure</p> <p>NICE 48 – MI Secondary Prevention</p> <p>Patients should be physically active for 20- 30 minutes per day</p> <p>The benefit of exercise may be enhanced by tailored advice from a suitably qualified professional</p> <p>NHS QIS-Cardiac Heart Disease Clinical Standards</p> <p>3. <i>Regular HD updates</i> for staff – CPD</p> <p>BACPR - Standards and Core Competencies 2012</p> <p>Patients and their families should be signposted and encouraged.. to join local heart support and community exercise and activity groups</p>
<p>3) To develop partnership working between the statutory and voluntary sectors in order to improve the patient experience and achieve optimal use of resources and value for money</p>	<p>Heart Disease and Stroke Care Action Plan</p> <p>4.45 <i>Improving heart failure services</i> (support)</p> <p>5.12 <i>Raise public awareness of stroke</i> – local communication strategy</p> <p>NHS QIS-Cardiac Heart Disease Clinical Standards</p> <p>1.1 <i>Pt information</i> – available from voluntary sectors</p> <p>NICE - CG138 – Patient experience in adult NHS services</p> <p>1.4 <i>Continuity of care and relationships</i> particularly at transition points</p> <p>Better Health Better Care Action Plan</p> <p>1.1 <i>Towards a mutual NHS</i> strengthen collaboration and integrated approach to service improvement</p>

	<p>1.2 <i>Delivering together</i> - Collaborative contracts within community health partnerships</p> <p>1.3 <i>Co-Operation and Collaboration</i> – MCNs and partnerships with voluntary and community organisations</p> <p>2.4 <i>Tackling Health Inequalities</i> – multi agency approach involving public private and third sectors</p> <p>3.4 <i>Effectiveness</i> -More efficient management of patient journey through the care pathway</p> <p>4.63- MCNs are fully integrated with local and regional planning</p> <p>Delivery Framework for Adult Rehabilitation Plan</p> <p>1. <i>Access</i> – transitions between care better managed and use mainstream leisure facilities</p> <p>2. <i>Local service provision</i> - better links between rehabilitation services and community services</p> <p>3. <i>Comprehensive evidence based services</i> – cater for distinct phases of care & identify models to seamless transitions</p> <p>4. <i>Sustainable multi professional teams</i> – all informed about roles & services, with joint training</p> <p>5. <i>Capacity</i> – review of staff resource – service redesign and skill mix. Integrated service across health and social care.</p> <p>AHP Delivery Plan</p> <p>3.2. – <i>AHP directors and leads to work in partnership</i> with local third and private sectors to enhance community capacity building and enabling services</p> <p>3.4 – <i>AHPs to improve overall health and wellbeing</i> and include <i>signposting</i> to relevant resources</p>
4)To improve quality of life for people with long-term conditions by reducing unscheduled admissions to acute services and delayed discharge	<p>Heart Disease and Stroke Care Action Plan</p> <p>6.5 <i>Improving Patient Information</i> – make communication issues a priority</p> <p>HEAT target treatment (9) – reduction in hospital admission bed days for those with COPD, Asthma and CHD</p> <p>The NHS Quality Outcomes Framework 2011/12</p> <p>2.3 <i>Reduce time spent in by people with hospital with long term conditions</i></p> <p>Delivery Framework for Adult Rehabilitation Plan</p> <p>1. <i>Access</i> – rehabilitation services should be accessible to service users</p>
5) People with long-term conditions who access the services provided will be assisted to:	<p>Heart Disease and Stroke Care Action Plan</p> <p>3.34 <i>Improving mental health</i> – holistic assessment of physical and mental health needs to improve detection and support</p> <p>5.40 <i>Improving rehabilitation and recovery</i>- NHS Boards should work with leisure industries to improve access to exercise training for stroke</p>

<p>a) enjoy enhanced physical and mental health and wellbeing</p>	<p>NHS QIS-Cardiac Heart Disease Clinical Standards <i>1.1 Provision of information to patient – self mgt</i></p> <p>The NHS Quality Outcomes Framework 2011/12 <i>2.2 Improving functional ability for people with long term conditions</i> <i>3.3 Improving recovery from stroke</i></p> <p>Delivery Framework for Adult Rehabilitation Plan <i>2. Local service provision - strong community focus</i></p>
<p>5) People with long-term conditions who access the services provided will be assisted to:</p> <p>b) remain more active and independent through the greater support offered</p>	<p>Heart Disease and Stroke Care Action Plan</p> <p><i>5.34 Improving early supported discharge – community teams integrated and accessible</i></p> <p><i>5.39 – consider self referral to AHP services by those recovering from stroke</i></p> <p><i>5.40 Improving rehabilitation and recovery Boards should work with leisure industries to improve access to exercise training for stroke</i></p> <p>Better Health Better Care Action Plan</p> <p><i>Equity- breaking down barriers for people accessing services</i></p> <p><i>4.33 – all NHS boards should implement the Heart manual for patient information education and to encourage self management</i></p> <p>Delivery Framework for Adult Rehabilitation Plan <i>3.Enablement and self management -promote independence and self management</i></p> <p>NES - Supporting People to Self Manage</p>
<p>5) People with long-term conditions who access the services provided will be assisted to:</p> <p>c) enjoy greater social engagement and reduced social isolation</p>	<p>Better Health, Better Care Action Plan-</p> <p><i>2.2 An Enabling Health service</i></p> <p>Heart Disease and Stroke Care Action Plan</p> <p><i>4.45 – NHS boards through their cardiac MCNs should work with CHSS to address social isolation through support including meetings, befriending</i></p> <p><i>4.34 – NHS board through their cardiac MCNs should adopt a Braveheart (Mentoring) approach by Dec 2009</i></p>

<p>5) People with long-term conditions who access the services provided will be assisted to:</p> <p>d) Be enabled to continue living at home or in a homely setting</p>	<p>Heart Disease and Stroke Care Action Plan</p> <p>5.34 Improving early supported discharge</p>
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APPENDIX 4 – SUMMARY OF PARCS MCN, HCP, GP AND SERVICE USER SURVEYS

Green – Key Data/Themes

SCOPING PARCS SURVEYS

OVERVIEW OF KEY OBJECTIVES	WORK STRANDS IN RELATION TO OBJECTIVE-SURVEYS	NUMBERS/ REPSONSES	STATUS / PRELIMINARY RESULTS
<u>SCOPING</u> Produce overview profiles in relation to 14 Health Board Regions across Scotland in relation to exercise maintenance/ physical activity opportunities	MCN survey	MCN survey 11/14 returns – some incomplete or one clinical area detailed only	MCN survey <ul style="list-style-type: none"> ➤ DATA COLLECTION - INCONSISTENT - inconsistency in data collection and collation and the role undertaking this ➤ NO SINGLE POINT OF REFERRAL - Majority have no single point of referral across the health board ➤ FUNDING STREAMS FOR SERVICE DELIVERY - LARGE VARIATION – regional variation/inconsistencies of funding streams from statutory bodies for service provision. Leisure the largest source of funding. Sustained funding (if funding is available) variable, some short term funding, some third sector service provision only ➤ FUNDING FOR INSTRUCTOR TRAINING - LARGE VARIATION - regional variation ➤ SPECIALIST INSTRUTOR TRAINING - LARGE VARIATION - regional variation large regional variation in number and levels of specialist trained instructors
	HCP (Health Care Professional) survey	HCP survey 274 'hits'	<ul style="list-style-type: none"> ➤ REFERRAL - GOOD TO LEISURE, POOR TO COMMUNITY SERVICES <p>Majority of HCP DO refer to leisure services 75.6% (n=161)</p> <p>Majority of HCP DO NOT refer to community services 54.5% (n= 111)</p>

			<p>Main reasons for lack of referral – no service provision and lack of knowledge of services</p> <ul style="list-style-type: none"> ➤ SELF REFERRAL OPTION – INCONSISTANT – this was reported as most available for exercise referral for older adults, long term conditions and third sector. However knowledge and responses here were poor and low. ➤ INCONSISTANCY IN PATHWAYS – ranging from no pathway available, to pathways for all conditions – cardiac and exercise referral reported as most established/available, stroke and third sector least ➤ NO SINGLE POINT OF REFERRAL –No single point of referral across the Health Board reported by 79.5% (n=128) ➤ SERVICE DELIVERY -- LARGE VARIATION - in availability and type of service provision e.g. exercise referral scheme, generic/condition specific ➤ FUNDING STREAMS FOR SERVICE DELIVERY – LARGE VARIATION -regional variation/inconsistencies of funding streams from statutory bodies for service provision. Leisure reported as the primary source of funding. Sustained funding (if funding is available) variable, some short term funding, some third sector service provision only ➤ FUNDING FOR INSTRUCTOR TRAINING - LARGE VARIATION ➤ SPECIALIST INSTRUCTOR TRAINING - LARGE VARIATION - large regional variation in number and levels of expertise of specialist trained instructors ➤ DATA COLLECTION – POOR & INCONSISTANT - HCP reported - 62.79% – 96.19%, did not collect data in relation to ex maintenance, referral to ex maintenance, need for services, follow up, cost effectiveness & person centred data (total n=134)
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			<p>➤ KEY THEMES</p> <p>Service Delivery- availability of service, value and importance of exercise options, HCP involvement in referral/service delivery, partnership working, tailored exercise, access – local service/housebound, partnership working, data collection.</p> <p>Pathway – effective referral and signposting, knowledge of services and importance of clinical rehabilitation – e.g. cardiac & pulmonary rehab and community delivery of rehabilitation.</p> <p>Economics- service funding, cost to service user.</p> <p>(From free text comments- in relation to service provision & access, successes and challenges, in order of prevalence)</p>
	GP survey	GP survey 146 'hits'	<p>➤ REFERRAL – limited service provision, inability to refer and knowledge of services</p> <p>Referral to exercise maintenance by GPs across Scotland (n= 121)</p> <ul style="list-style-type: none"> • DO refer to exercise maintenance - 52% (n=63) • DO NOT refer to exercise maintenance - 48 % (n= 58) • in regions with lack of or poor service provision, largely rural, this increases and ranges from 80% -100% DO NOT refer • Not able to refer - 56.91% (n=70) <p>GP primary reasons for not referring (Total responses n= 70)</p> <ul style="list-style-type: none"> • no service in the community -56% (n = 39) • lack of knowledge of services - 56% (n=31) • no service in leisure services - 44% (n=31)

			<ul style="list-style-type: none"> ➤ SERVICE DELIVERY – lack of involvement in collaborative working groups GPs are not members of a collaborative group for exercise maintenance – 89.5% (n=111) ➤ KEY THEMES Service Delivery – positive impact when service available, access issues – local access and access for those housebound, availability of service for all conditions and populations and value of exercise options Pathway – knowledge or lack of knowledge of services and importance of clinical rehabilitation, barriers to referral – systems and processes Economics/Impact – service funding, particularly short term funding and service removal of services due to funding (From free text comments in relation to service provision and access/impact in order of prevalence)
	Leisure services/ Service provider survey	Leisure services 40 ‘hits’	<ul style="list-style-type: none"> ➤ SERVICE DELIVERY- exercise referral and LTC are the most available types of classes, followed by cardiac specific, stroke and respiratory specific least available ➤ NO SINGLE POINT OF REFERRAL –No single point of referral across the Health Board reported by 79.% (n=23) ➤ PATHWAY – established pathways for exercise referral, exercise referral for older adults, exercise referral for LTC, cardiac, respiratory and stroke (in order of prevalence) ➤ SERVICE CO-ORDINATOR - low responses, was most reported for exercise referral,

			<p>exercise referral for older adults, exercise referral for LTC</p> <ul style="list-style-type: none"> ➤ FUNDING STREAMS – leisure key funders of exercise maintenance delivery and instructor training ➤ DATA COLLECTION – inconsistent with most responses to collection of usage and attendance ➤ KEY THEMES <p>Pathway – effective referral and signposting, importance of clinical rehabilitation, lack of knowledge of services</p> <p>Economics/Impact - service funding</p> <p>(From free text comments- in relation to service provision & access, successes and challenges, in order of prevalence)</p>
	<p>Service user survey (PARCS - British Lung Foundation to complement with non-engagers and hard to reach)</p>	<p>Service user survey 221 returns</p> <p>(CHSS affiliated groups)</p> <p>Cardiac: n = 143,</p> <p>Respiratory: n = 53,</p> <p>Stroke: n = 25</p> <p>Or which co – morbidities n = 21</p>	<ul style="list-style-type: none"> ➤ ATTENDANCE /ADHERENCE HIGH - majority members of exercise group for more than 3 year (56% n=100) ➤ PHYSICAL ACTIVITY TARGETS ACHIEVED – 69% (n=124) meet physical activity targets compared to national averages of 15% ➤ EXERCISE GROUP IMPORTANT CONTRIBUTOR TO PHYSICAL ACTIVITY & IMPROVEMENT OF CONDITION - exercise group 2nd largest reported type of physical activity after walking & 76% (n=136) report feeling their condition has improved since joining exercise group ➤ PHYSICAL, SOCIAL, PSYCHOLOGICAL, SELF MANAGEMENT & SOCIETAL BENEFITS OF EXERCISE GROUP – main reported benefits of exercise group: (in order of prevalence) social support, remain more active, motivation to exercise, improved well being, maintain activity levels, understand my condition, encouraged me to do more activity, improved function, improved mental health,

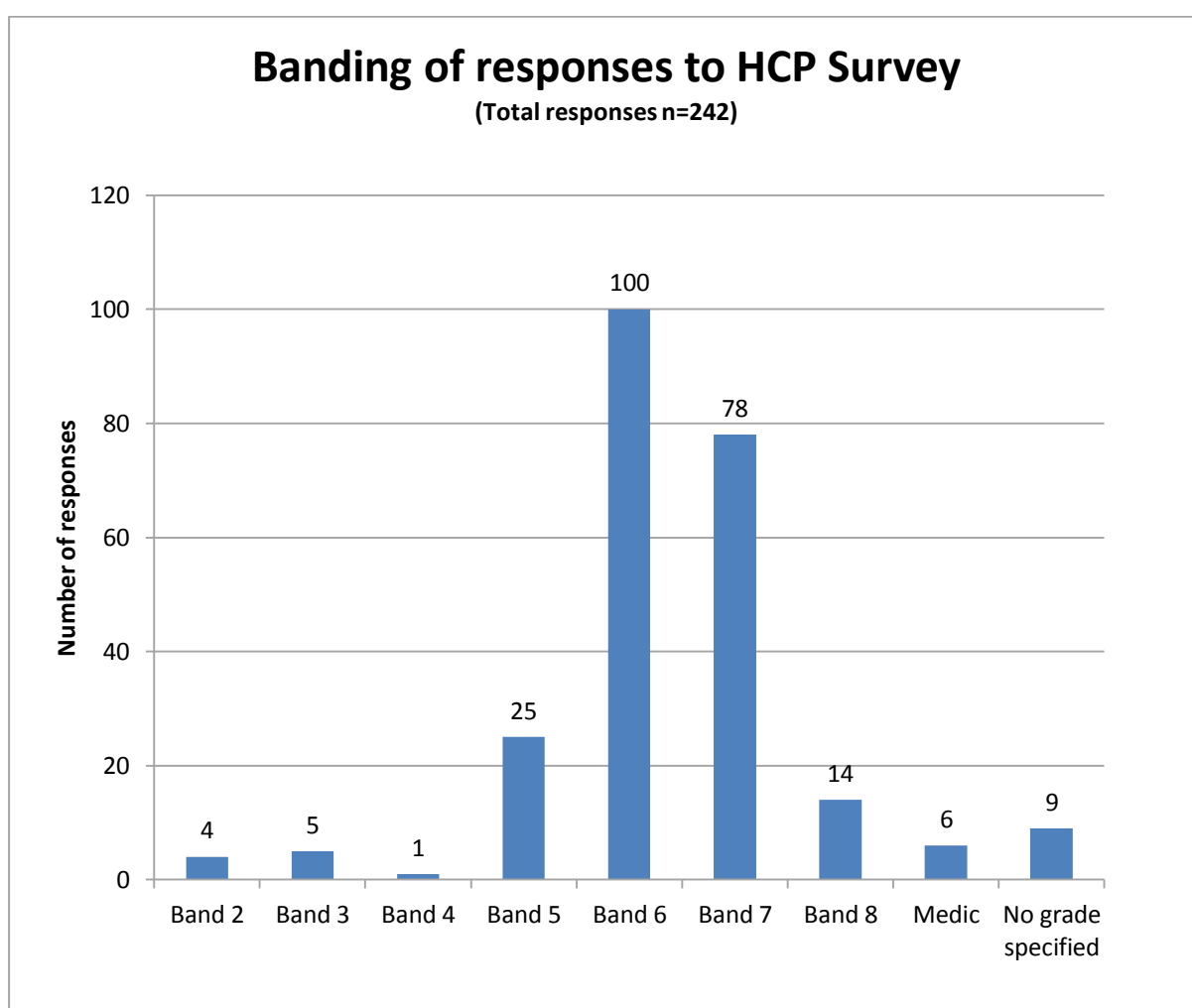
			<p>feel part of a community</p> <ul style="list-style-type: none"> ➤ PHYSICAL, SOCIAL, PSYCHOLOGICAL, SELF MANAGEMENT & SOCIETAL BENEFITS OF SUPPORT GROUP ➤ BRIEF INTERVENTION/ PHYSICAL ACTIVITY MESSAGE ACHIEVED – 86% (n=180) told about the importance of physical activity ➤ HCP PROFESSIONALS KEY IN DELIVERING PHYSICAL ACTIVITY MESSAGE – Physical activity message delivered by Physiotherapist (n=117), nurse (n=107) , GP (n=93) and hospital doctor (n=76), support group (n=53) self-management myself (n= 59) ➤ POTENTIAL IMPACT ON HOSPITAL ADMISSIONS – 74% (n=163) reported no hospital admissions in the last year <p>Comparison with national averages planned – awaiting ISD data set</p> <ul style="list-style-type: none"> ➤ CLINICAL REHABILITATION, SELF REFERRAL AND ROUTINE APPOINTMENTS KEY FOR INFORMATION ABOUT EXERCISE MAINTENANCE/CLASSES - Information about exercise class delivered at cardiac rehabilitation (n=110) ,pulmonary rehab (n= 25), self-initiated (n=26), routine appointment (n=18)
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APPENDIX 5 – COLLATED SURVEY RESULTS REPSONSES BY QUESTION
FROM HCPs, GPs, SERVICE PROVIDERS (mainly leisure) AND SERVICE USERS

RESULTS OF RESPONSES FROM PARCS HCP SURVEY

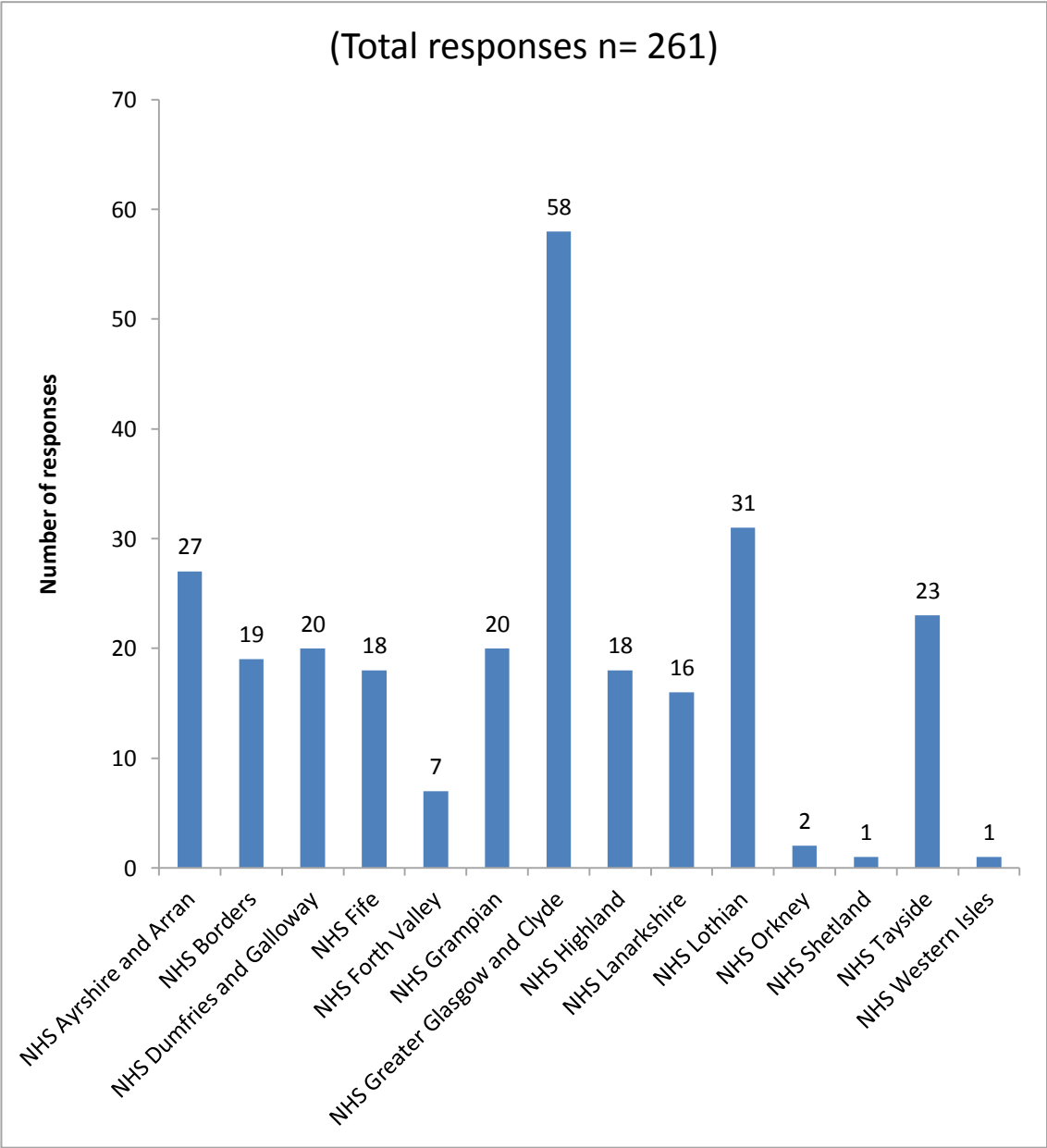
Health Care Professional (HCP) – Total hits n= 274

Q1. Personal details - a wide range of Agenda for Change bandings responded ranging from 2 to 8.

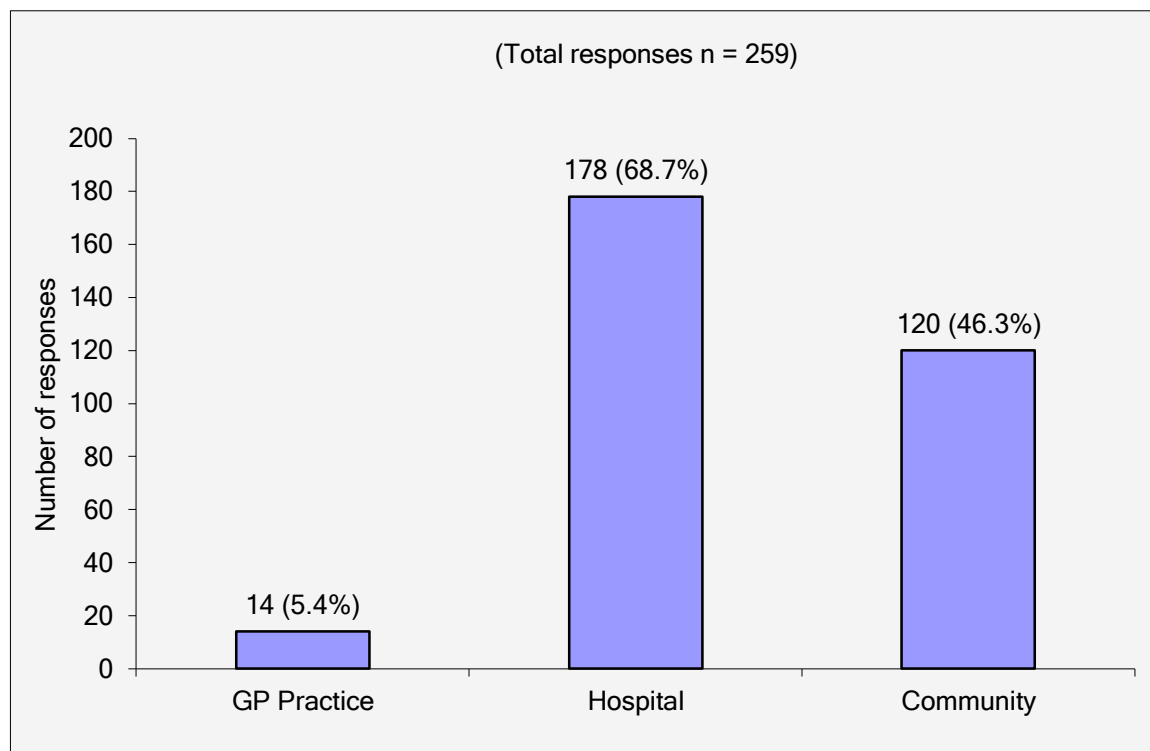


The following graphs and charts indicate the overall responses (i.e. response from all geographical areas) from HCP to the questions detailed in the title of each graph/chart.

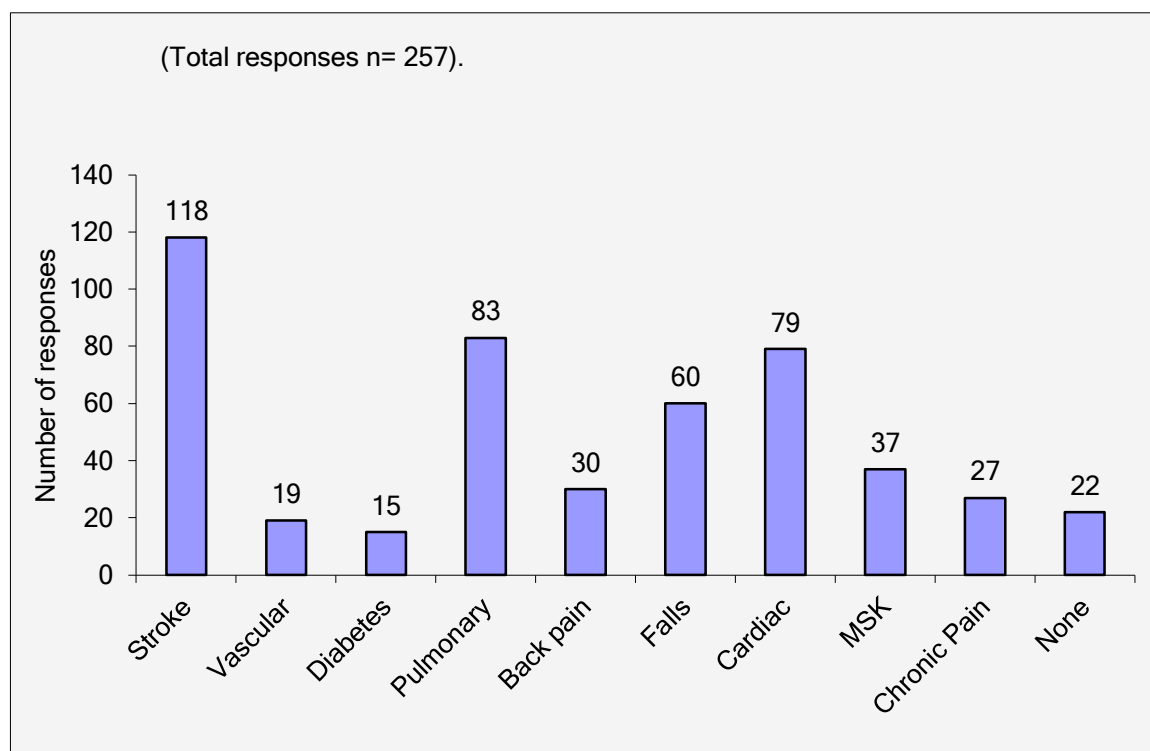
Q2. Health Board:



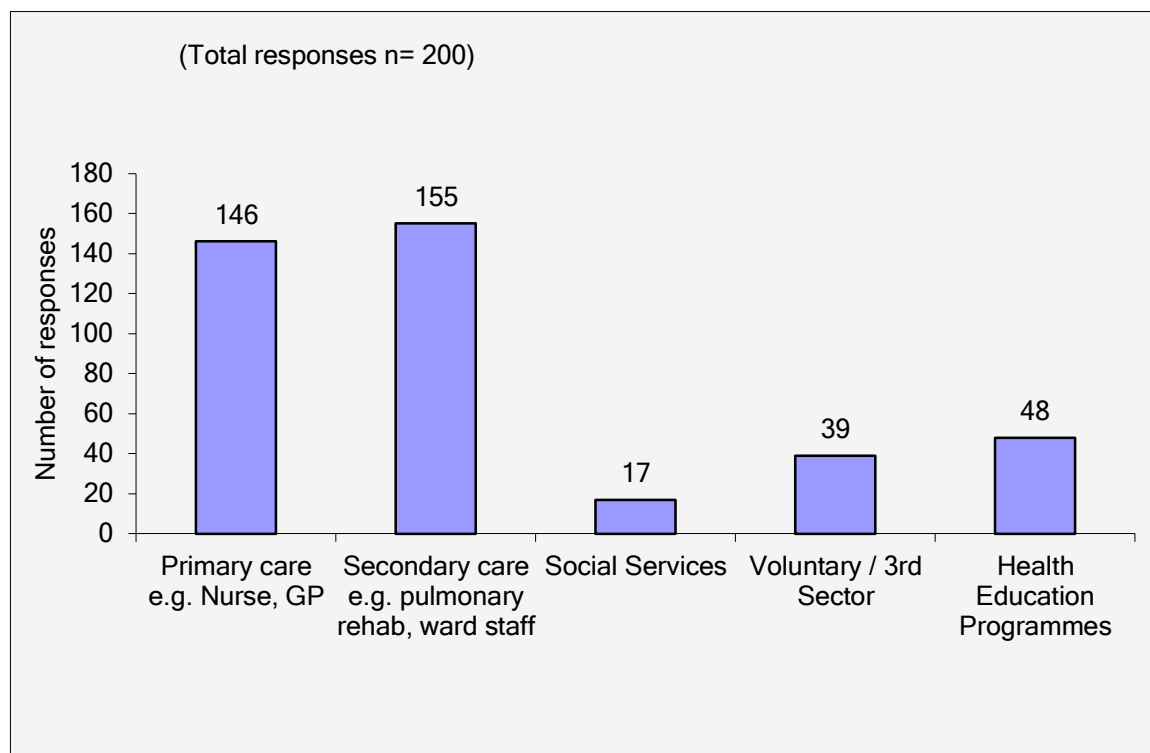
Q3. Place of work



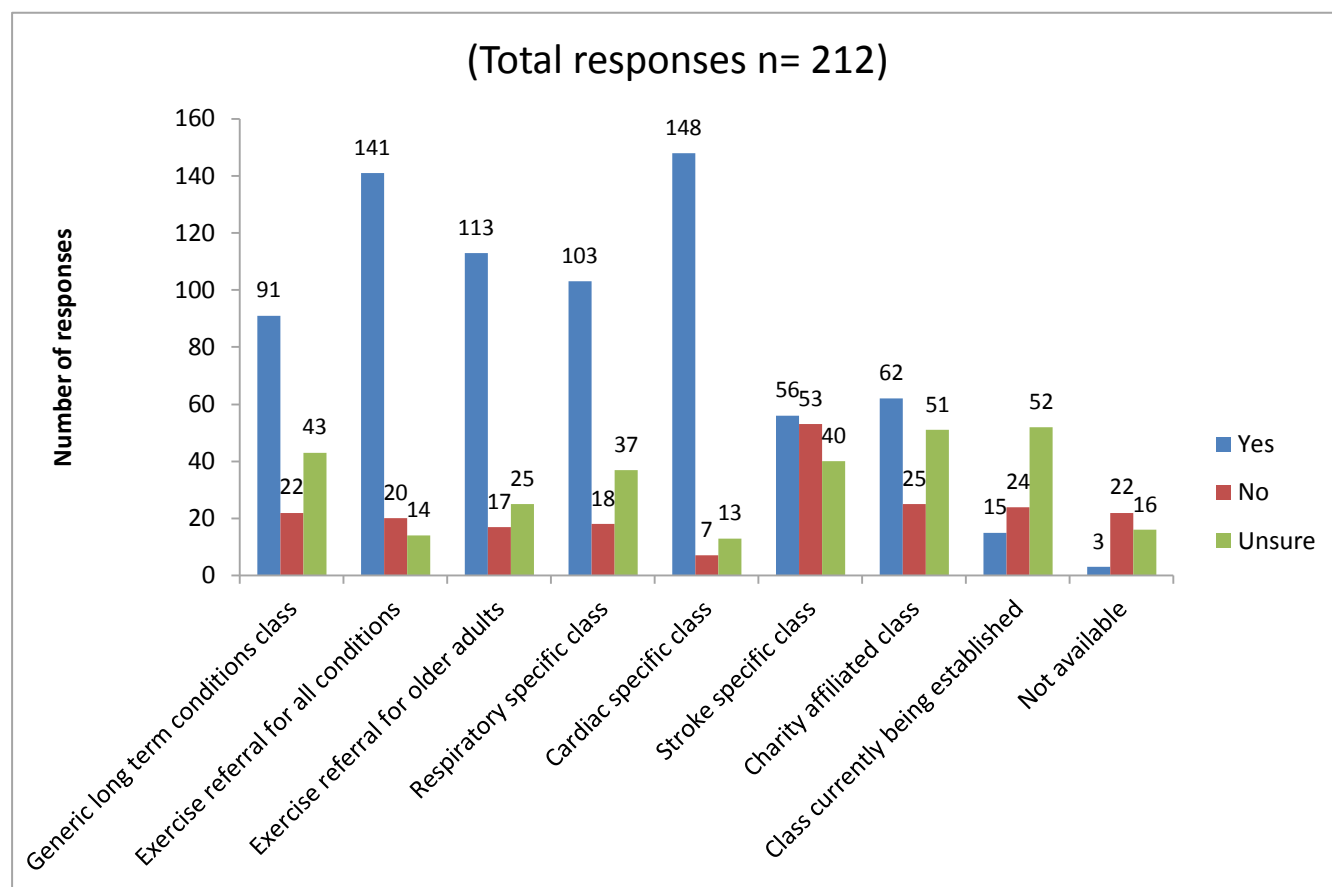
Q.4 What type of rehabilitation do you deliver? Please tick any/all that apply



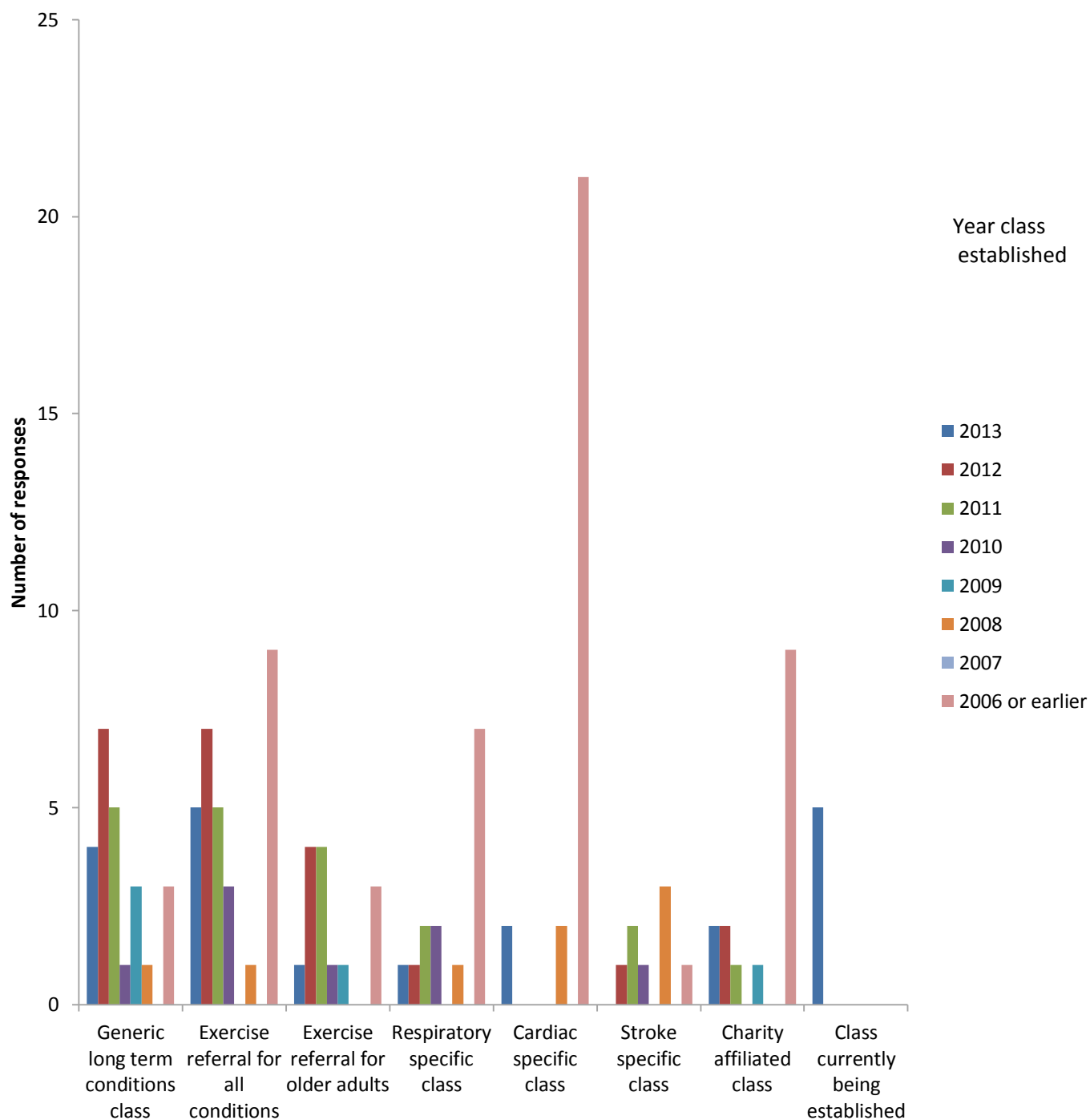
Q5. Which sectors refer to exercise maintenance classes in your region? Please tick any/all that apply.



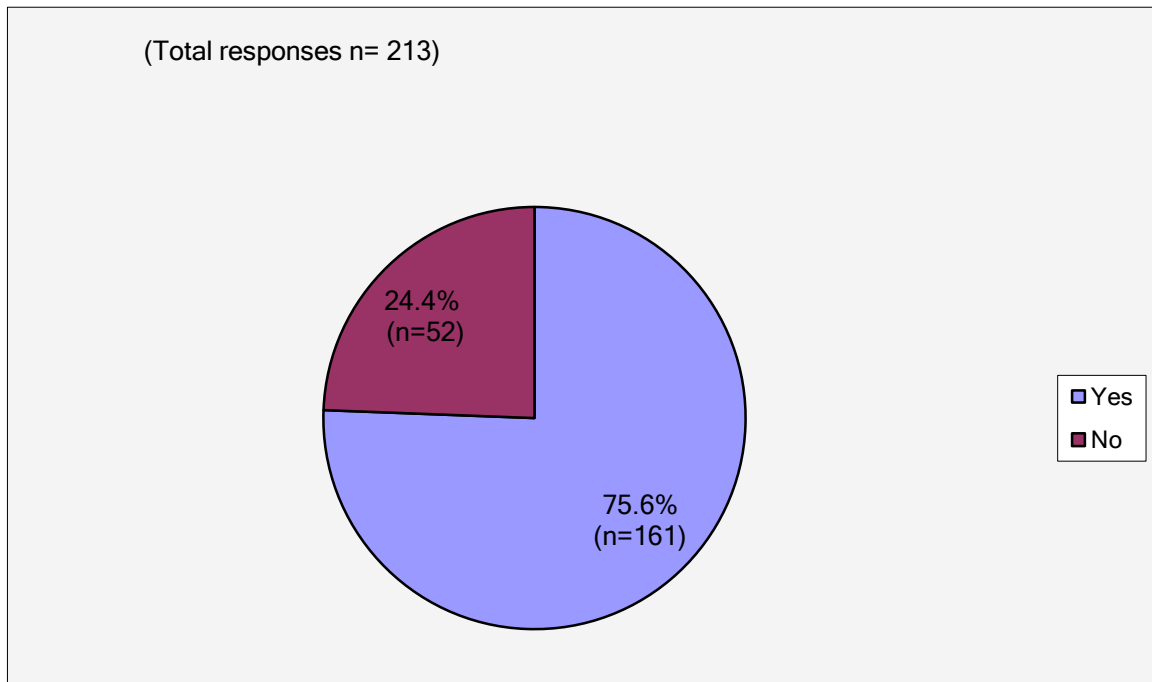
Q6. What types of exercise maintenance classes are available in your region?



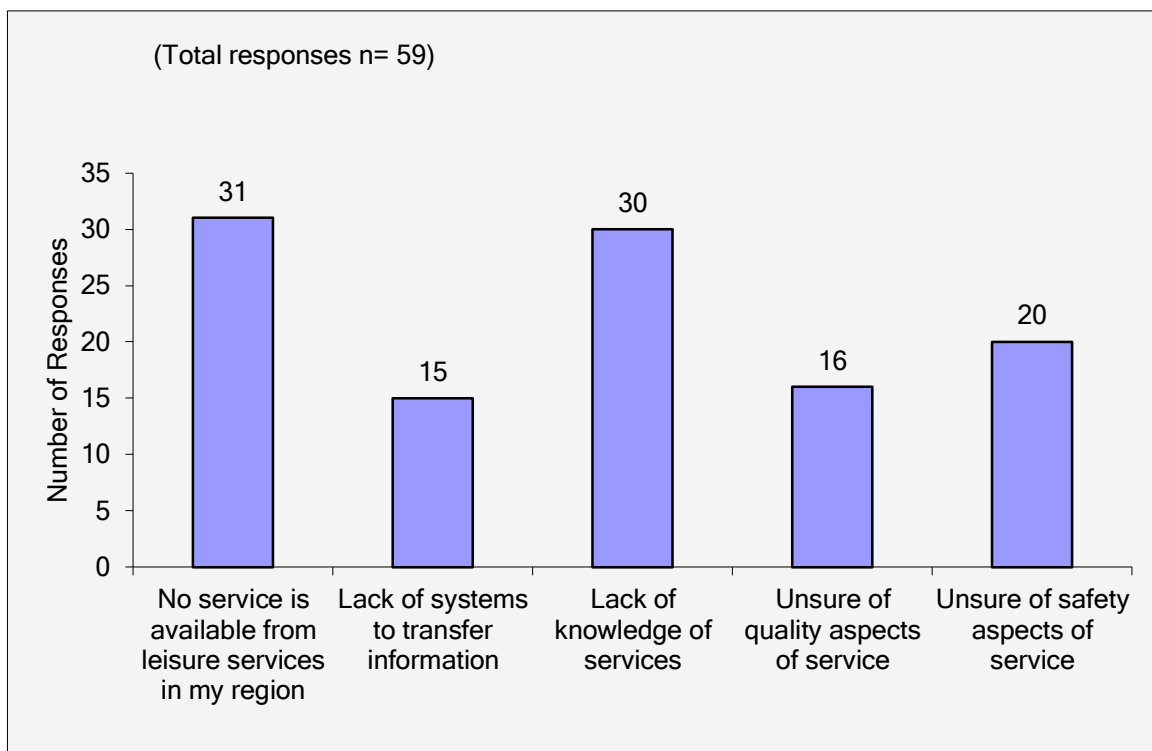
What types of exercise maintenance classes are available in your region? Please indicate the year established if known.



Q7. After clinical rehabilitation is complete do you REFER to maintenance exercise groups in the community led by LEISURE SERVICES?

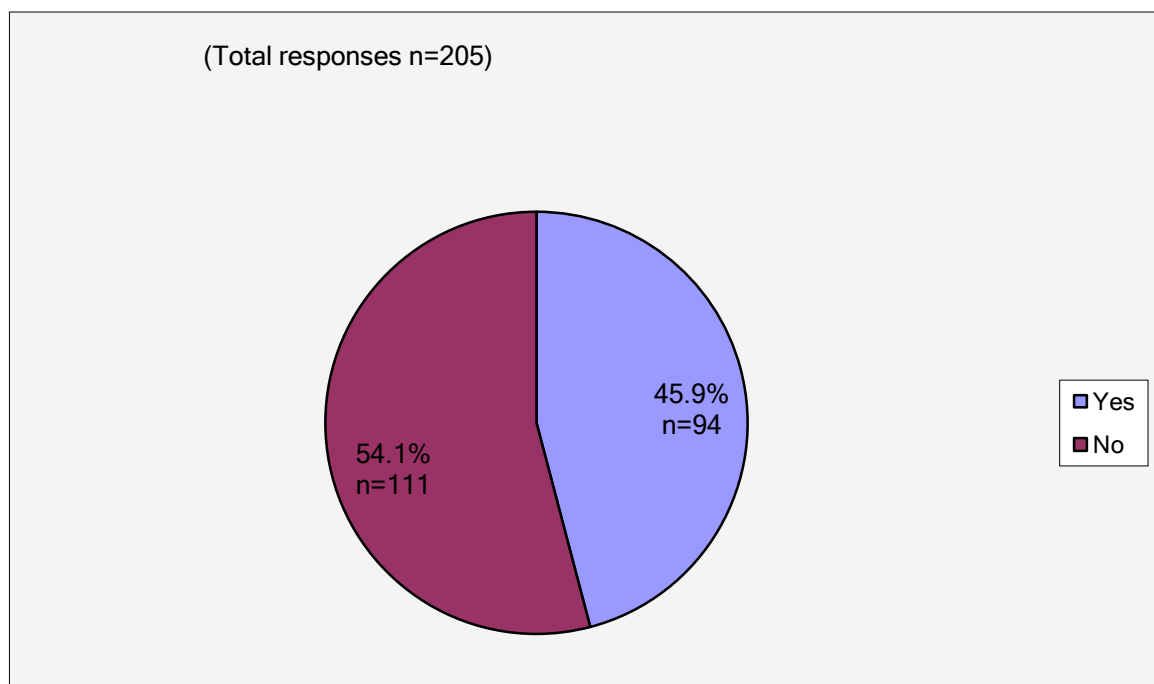


Q8. What issues prevent you from referring? Please tick any/all that apply.

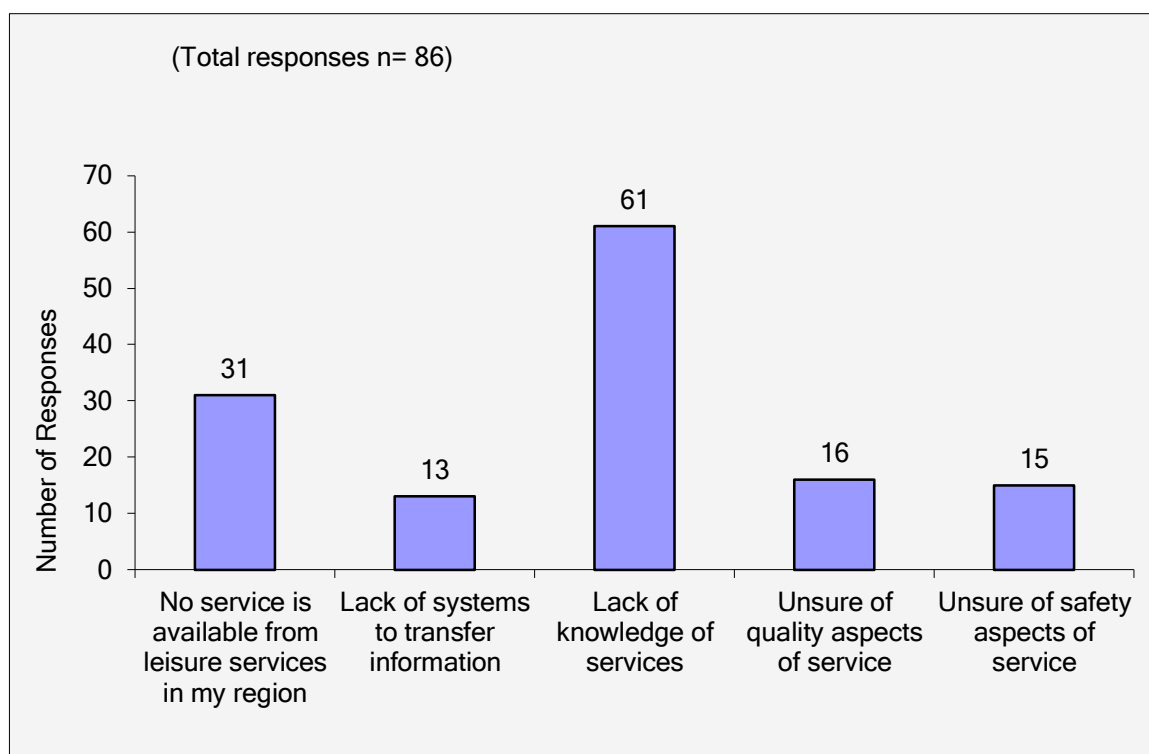


Answer Choices –	Responses –
No service is available from leisure services in my region	52.54% 31
Lack of systems to transfer information	25.42% 15
Lack of knowledge of services	50.85% 30
Unsure of quality aspects of service	27.12% 16
Unsure of safety aspects of service	33.90% 20
Total Respondents: 59	

Q9. After clinical rehabilitation is complete do you REFER to maintenance exercise groups in the community lead by COMMUNITY GROUPS?



Q10. What issues prevent you from referring to community groups? Please tick any/all that apply.



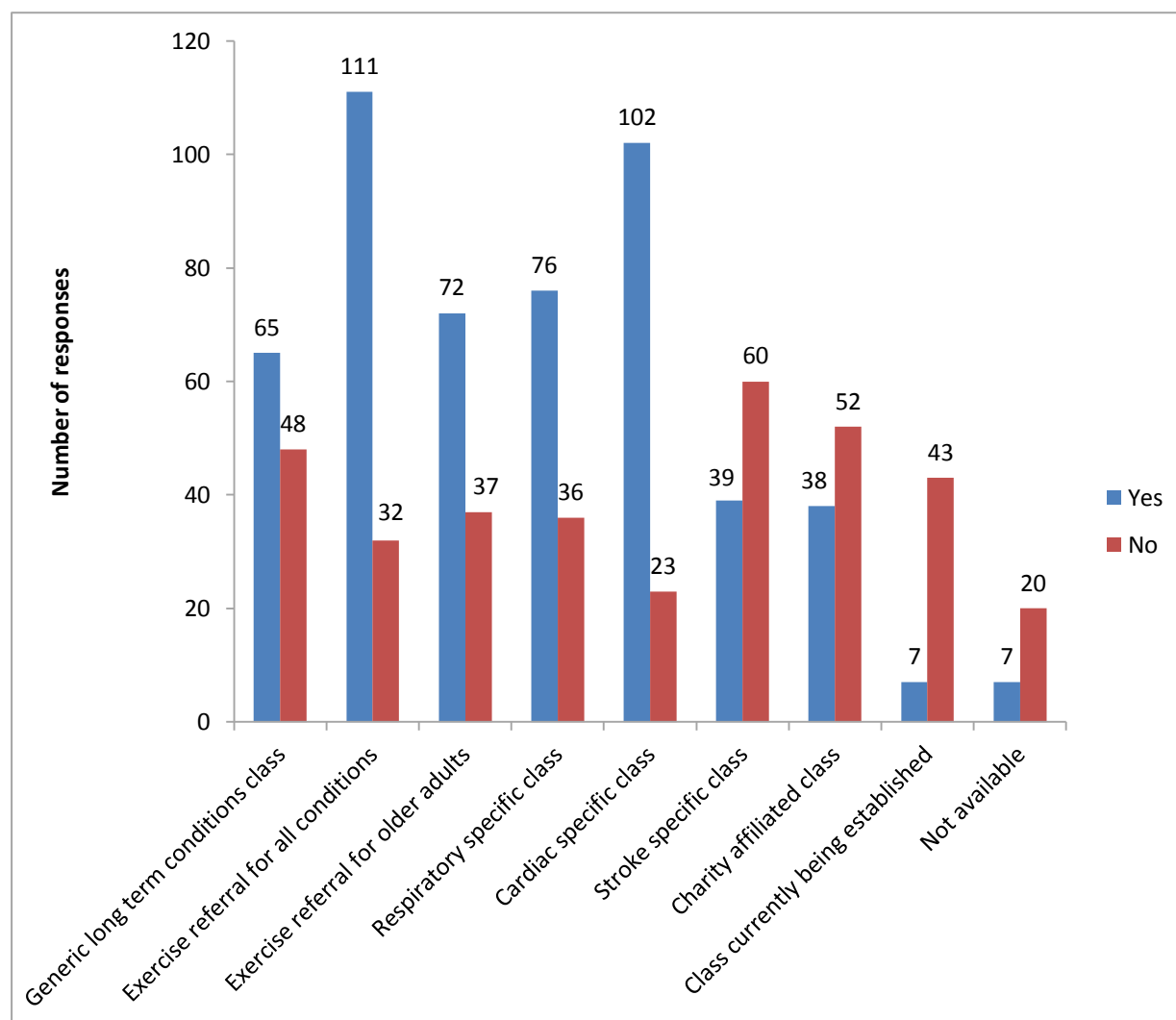
What issues prevent you from referring to community groups? Please tick any/all that apply.

Answer Options	Response Percent	Response Count
No service is available from leisure services in my region	36.0%	31
Lack of systems to transfer information	15.1%	13
Lack of knowledge of services	70.9%	61
Unsure of quality aspects of service	18.6%	16
Unsure of safety aspects of service	17.4%	15
Other (please specify)		20
Total		86

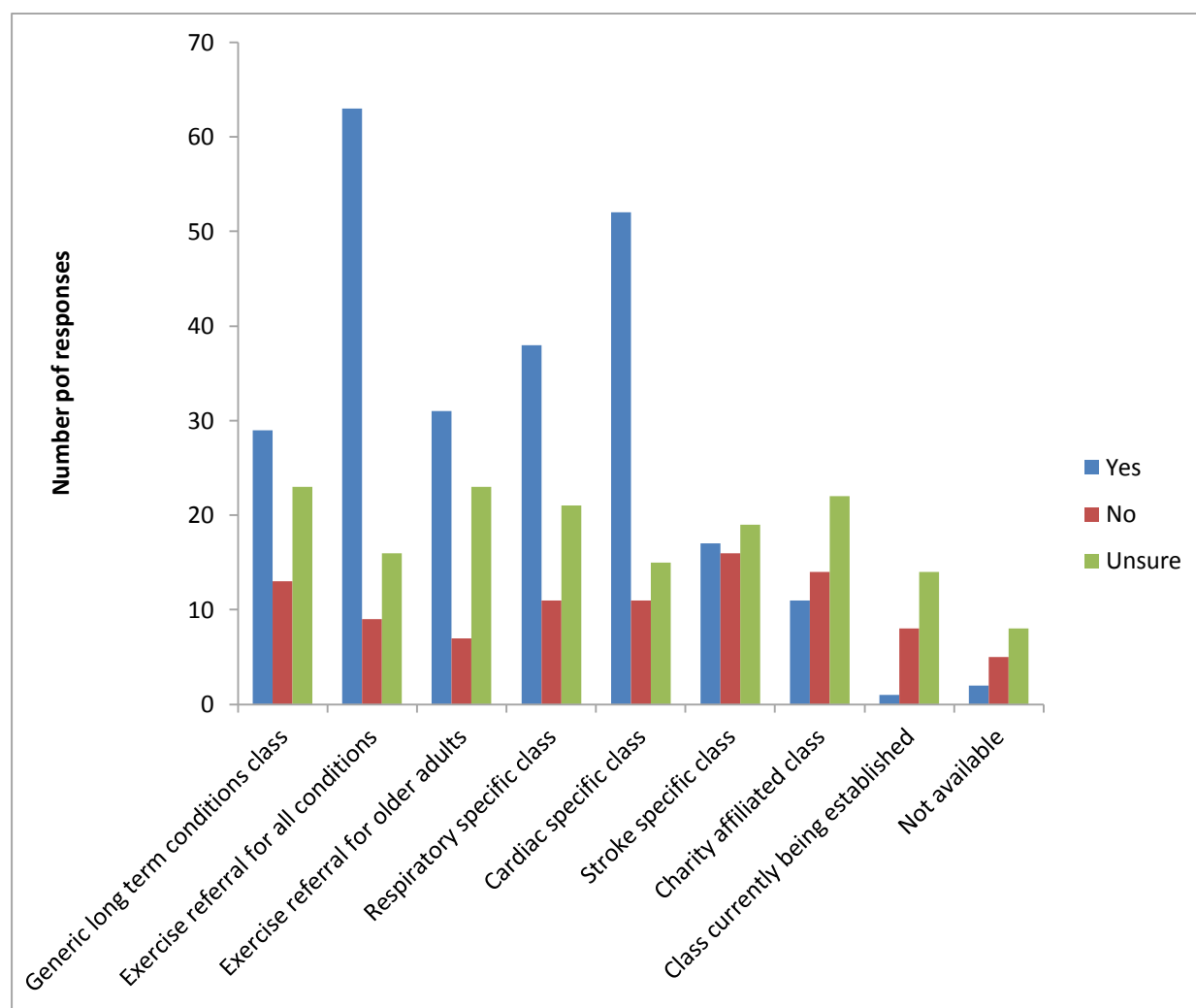
Q11. Exercise Maintenance Pathway

From your clinical specialism please indicate if there is an established pathway to the following exercise maintenance classes? Total number of responses n= 189

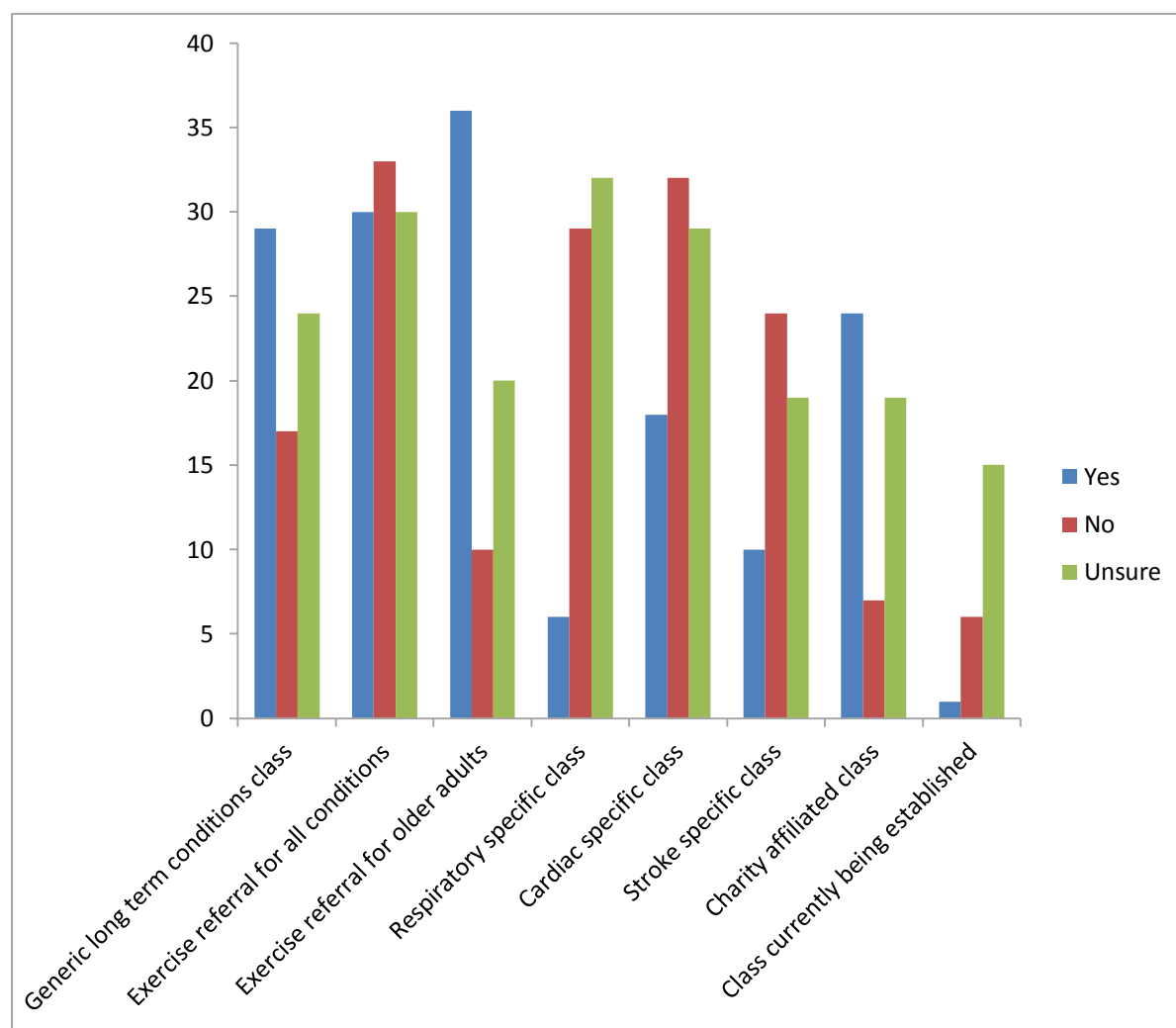
Answer options – Yes/ No, Available Board wide? Self-referral available?

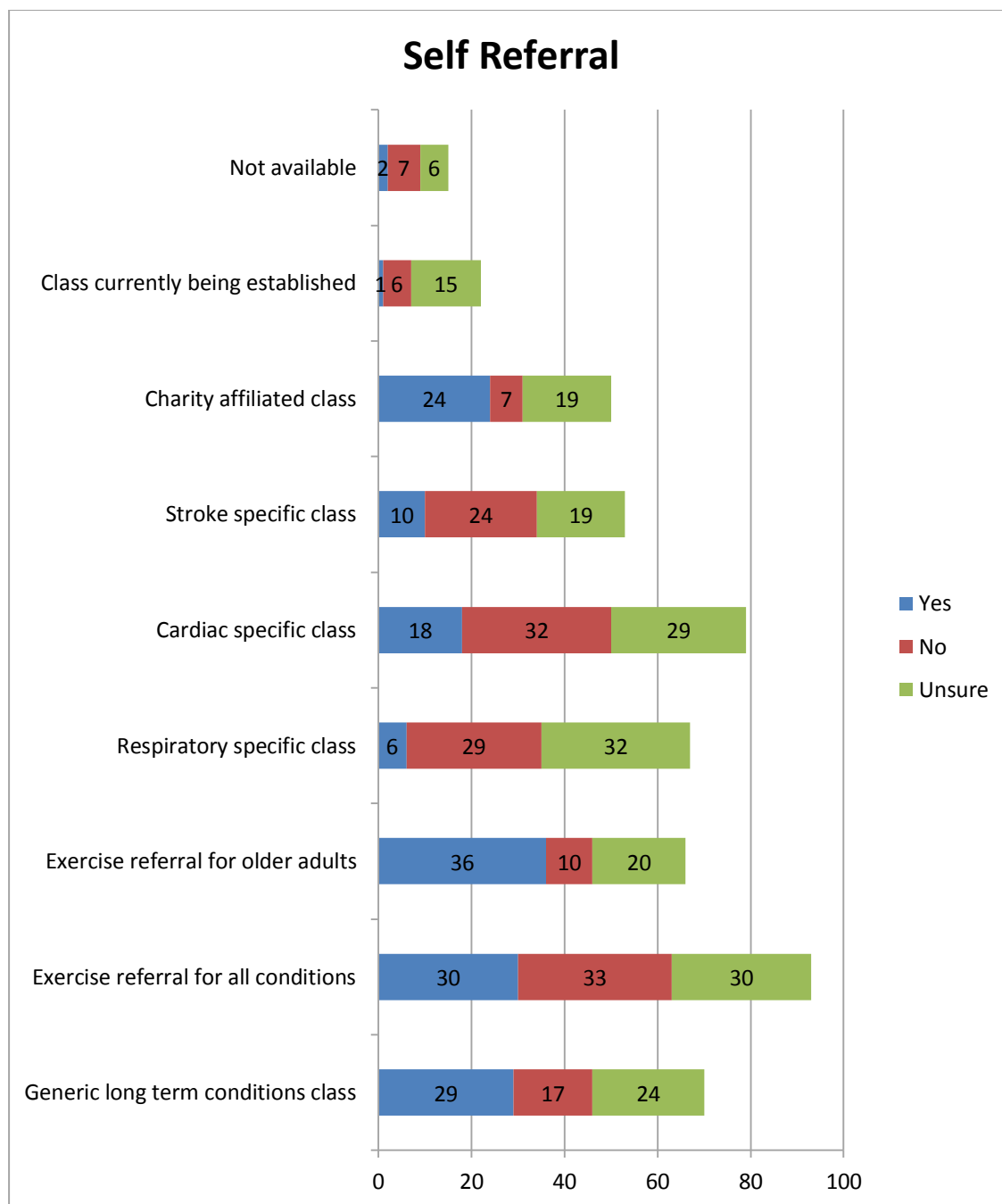


Available board-wide?



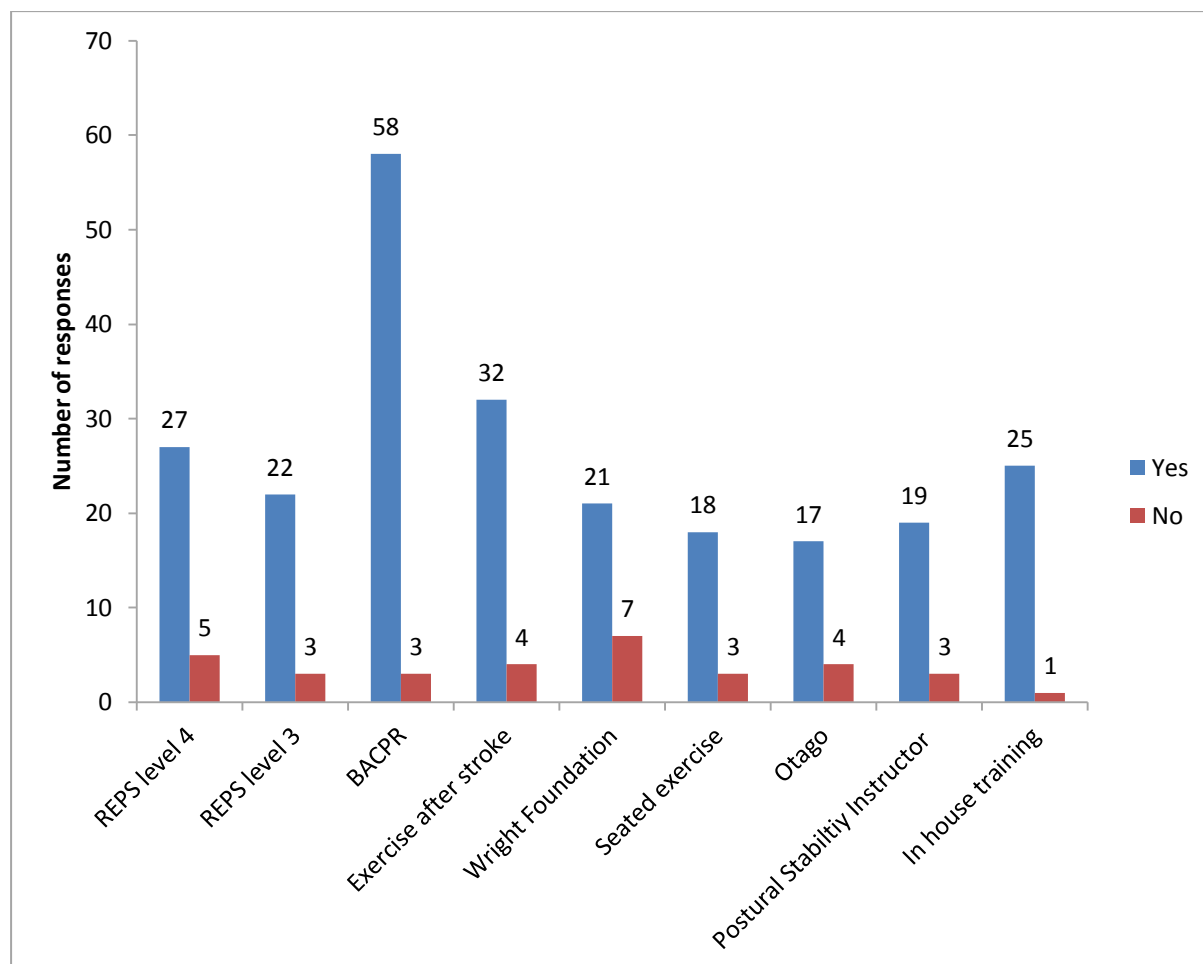
Self - referral?



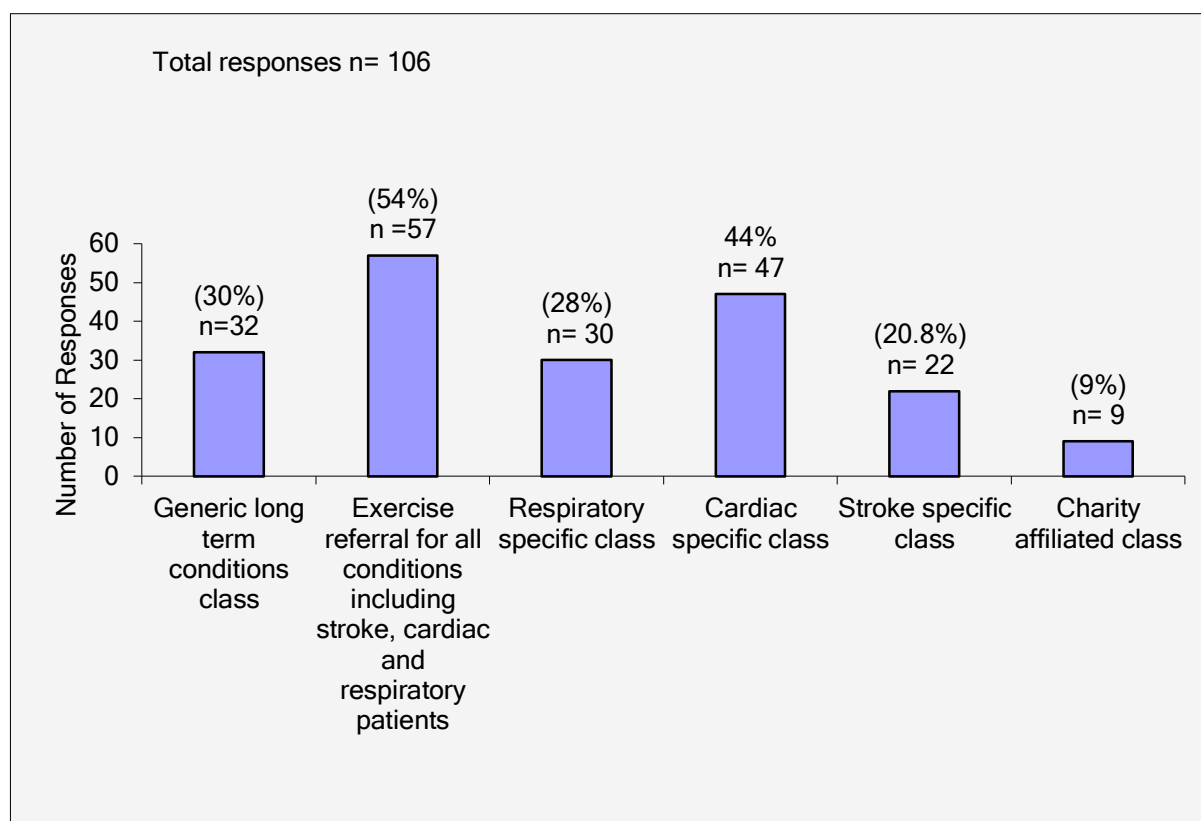


Q12 - Which qualifications do specialist instructors have that deliver exercise community maintenance classes? If known please indicate the number of instructors who hold this qualification.

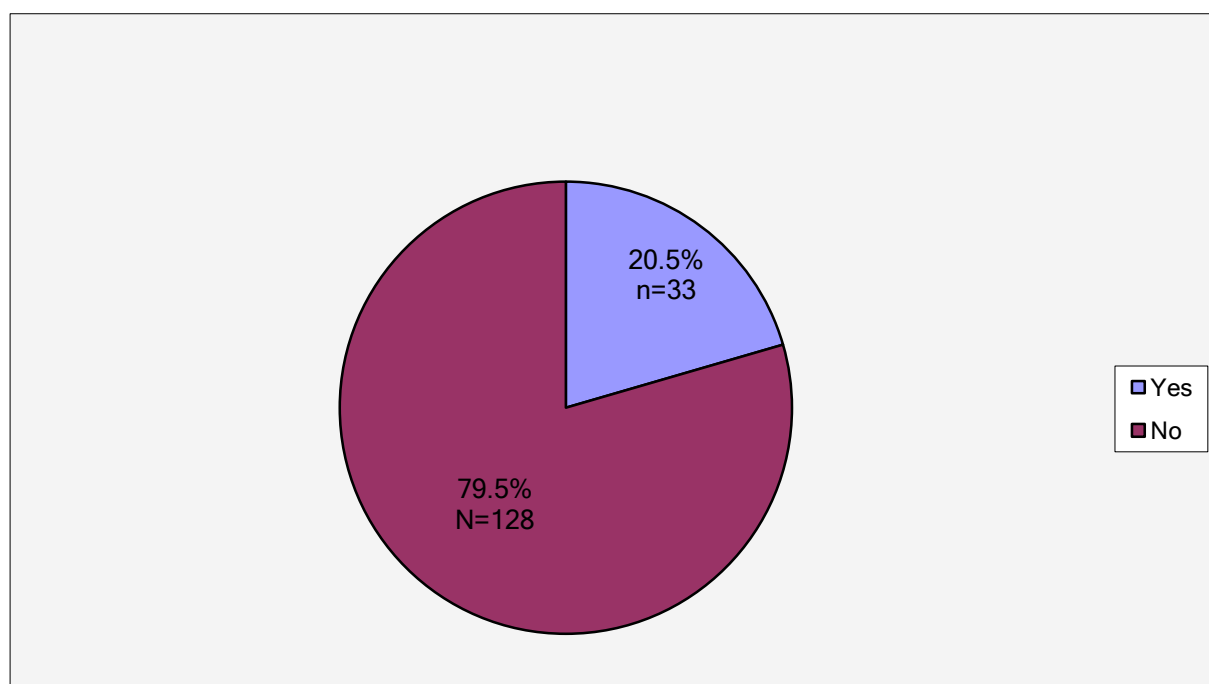
Answer option – Yes/No



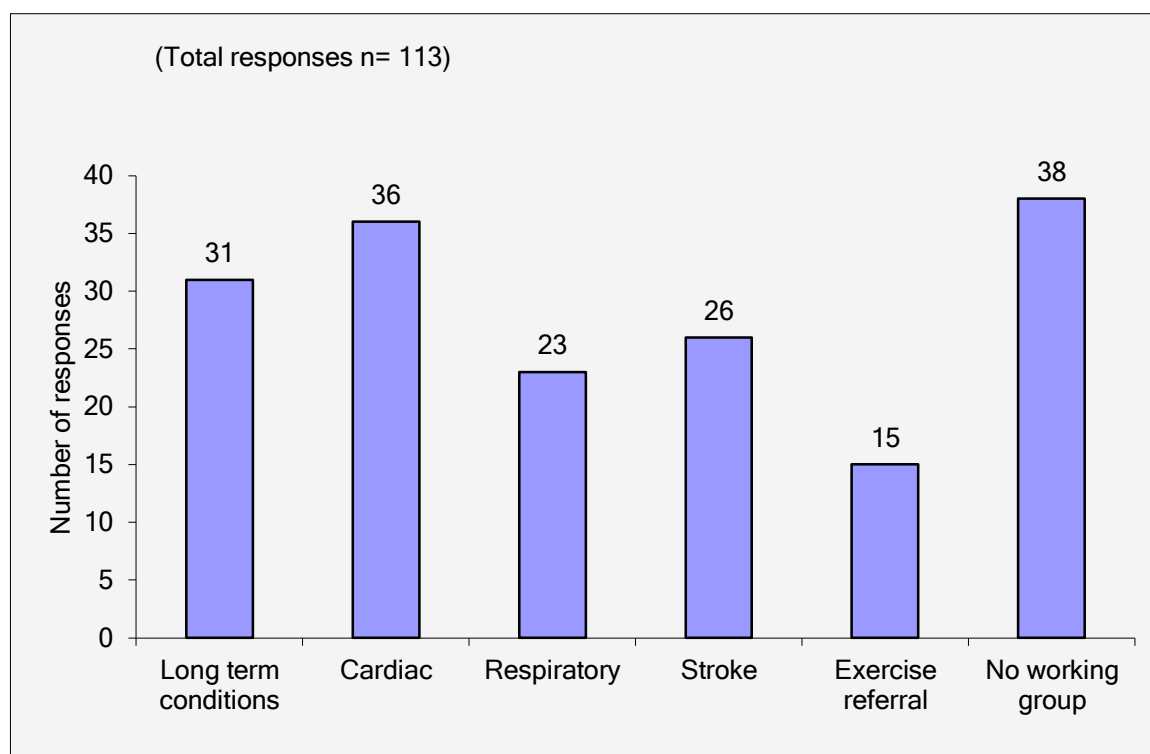
Q13. Is there a service co-ordinator in your region for the management and delivery of exercise maintenance? Please tick any/all that apply.



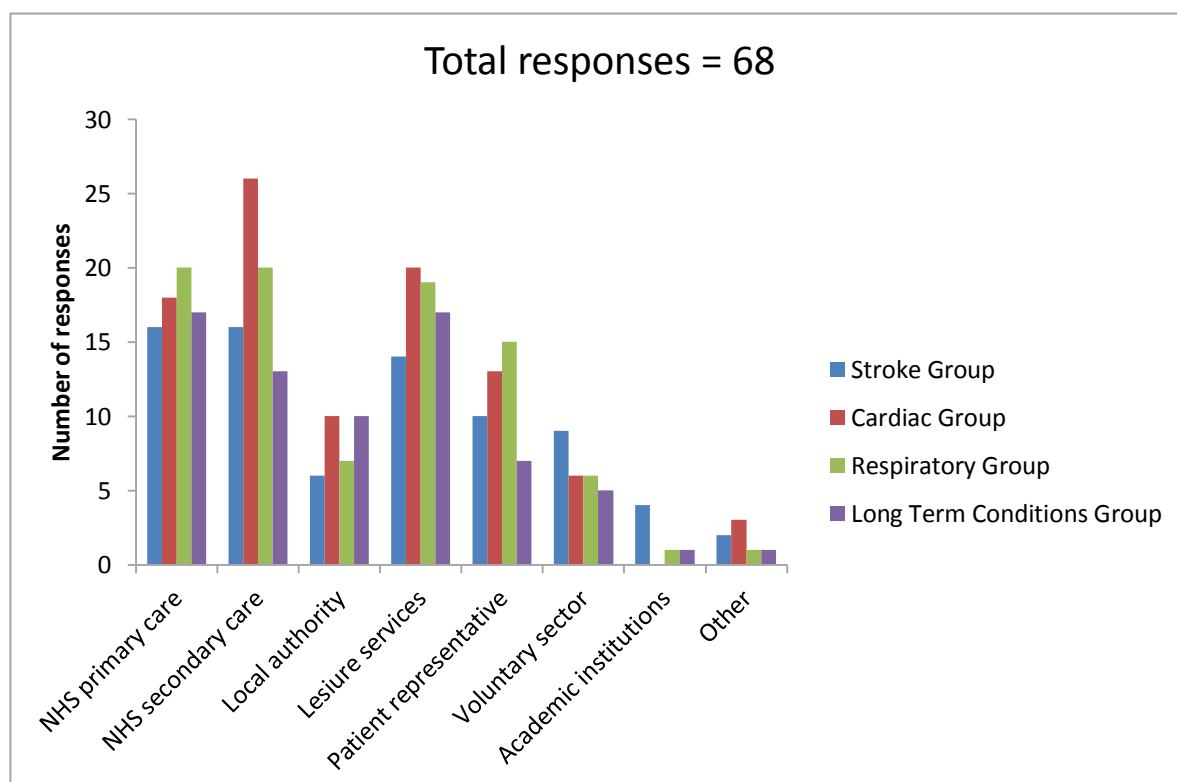
Q14. Is there a single point for referral for all long term conditions from clinical rehabilitation across the Board?



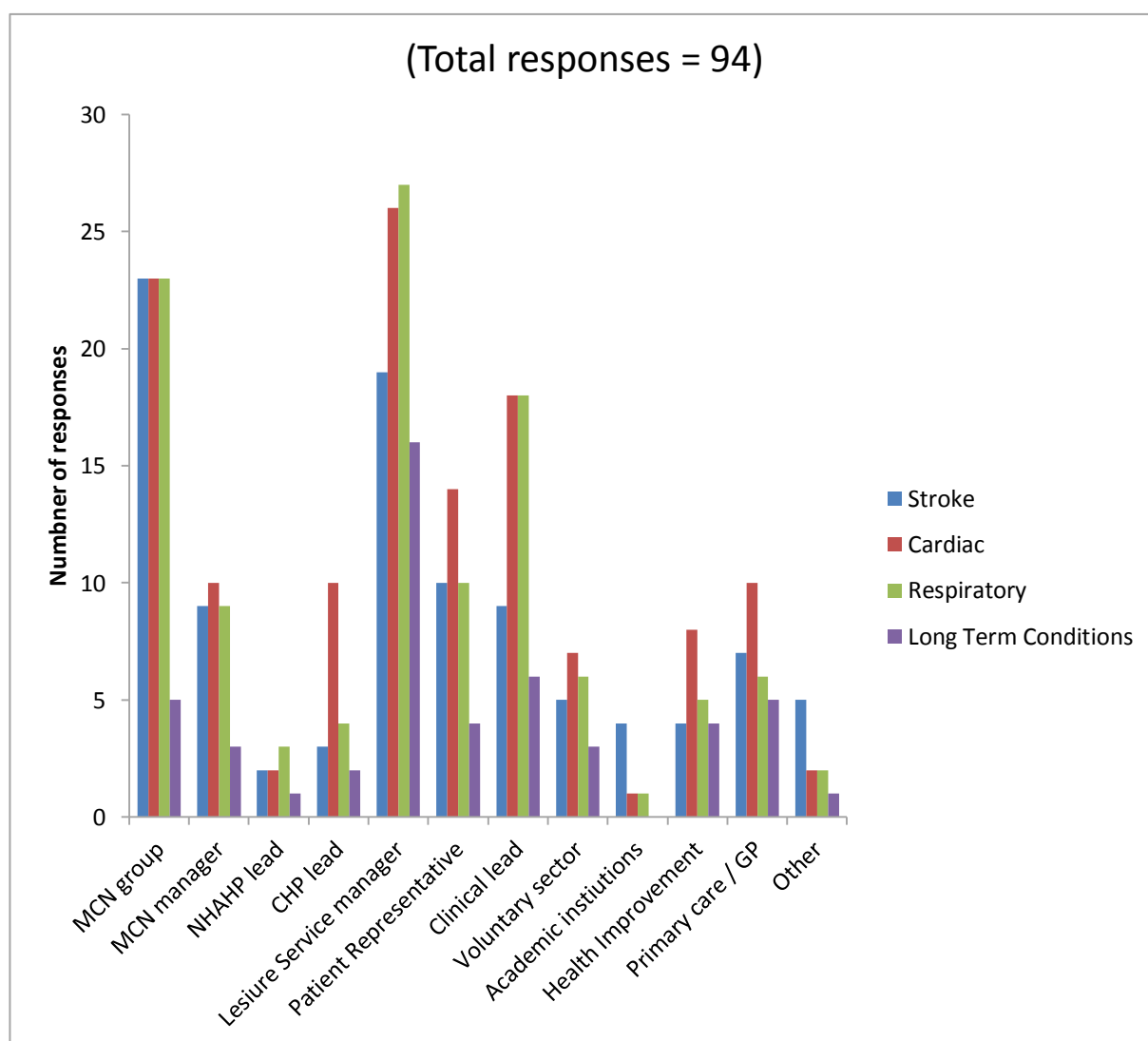
Q15. Is there a collaborative working group for exercise maintenance in your region?
Please tick any/all that apply.



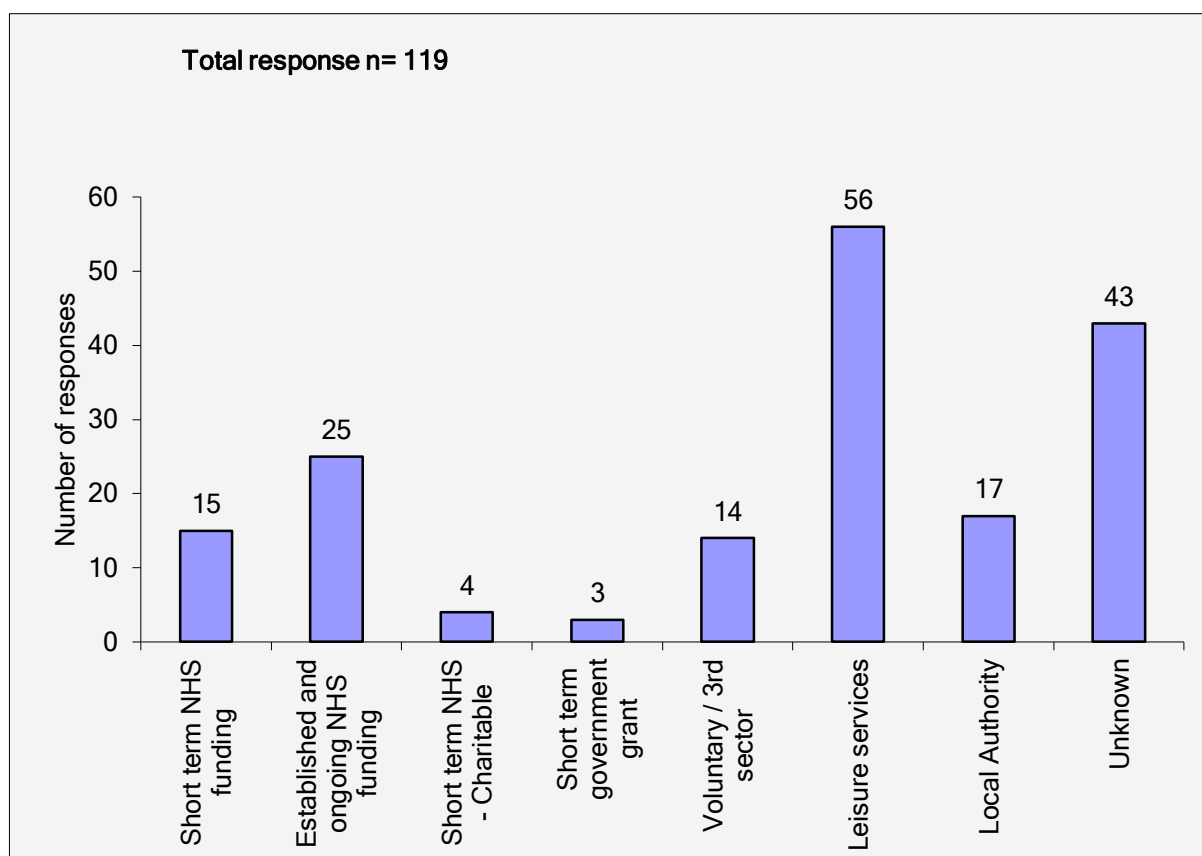
Q16. Which organisations are members of a collaborative working group for exercise maintenance in your region? Please tick any or all that apply.



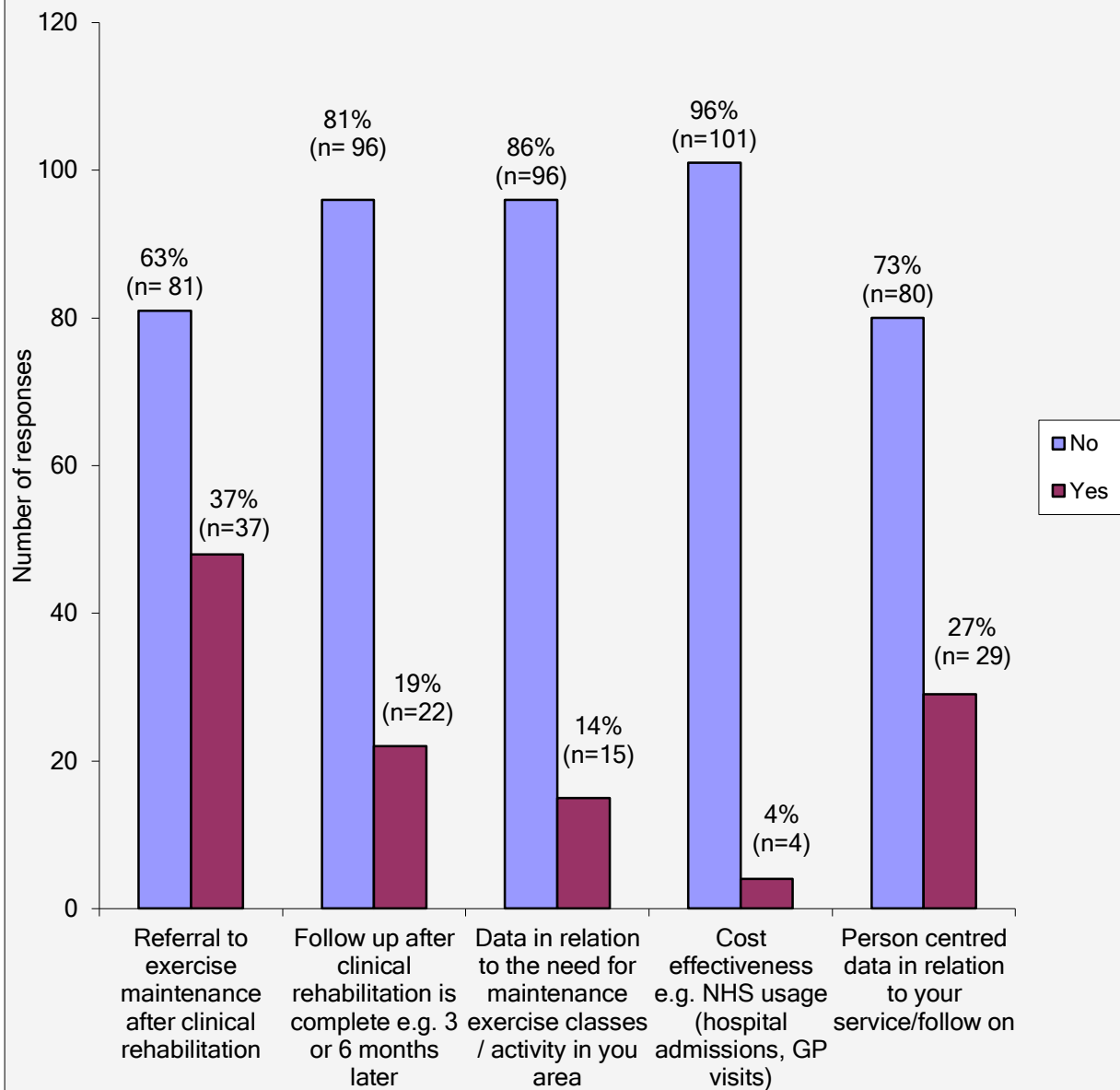
Q17. Which roles are involved in service delivery of exercise maintenance?



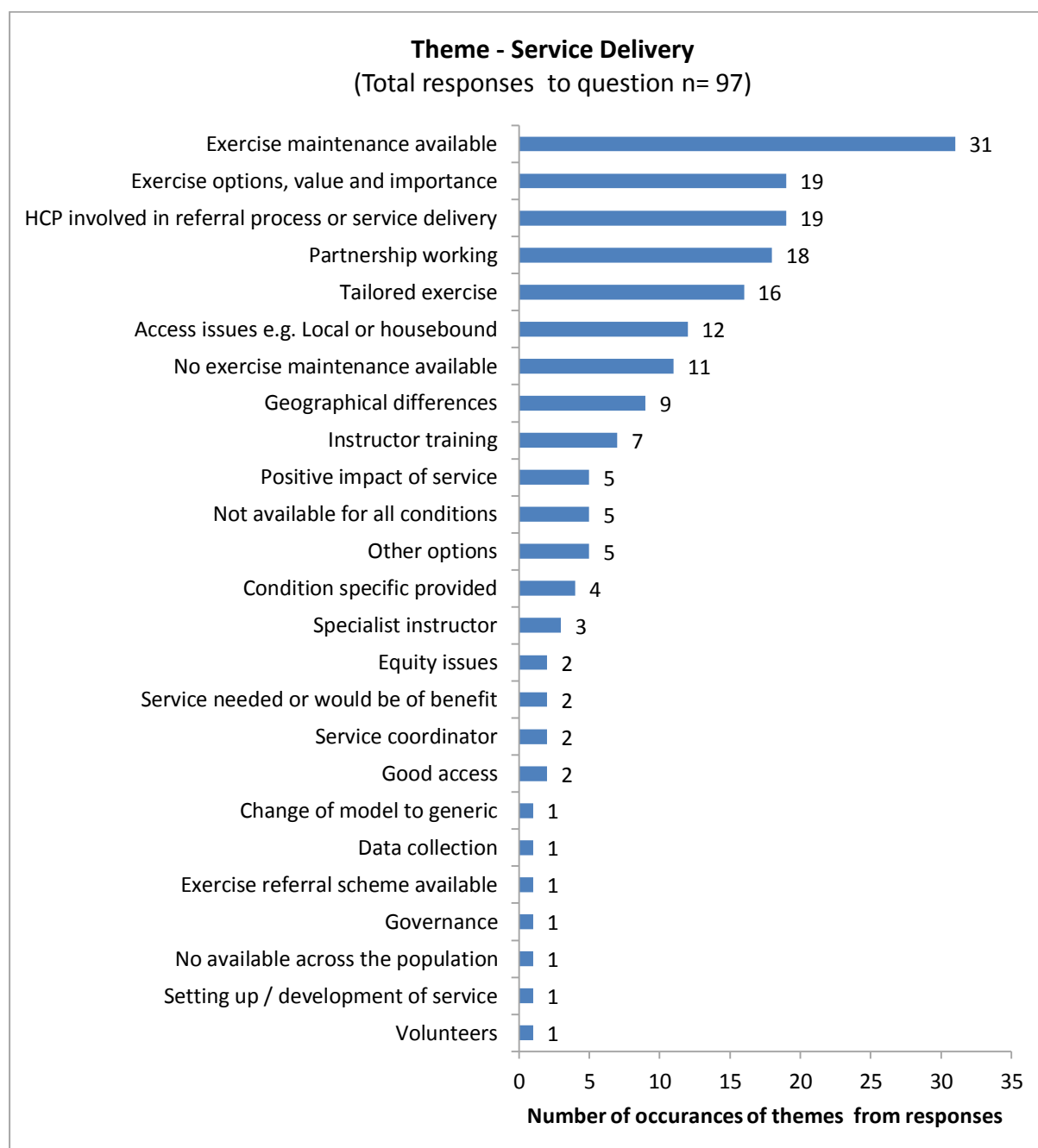
Q18. Who are the funding partners for service delivery of exercise maintenance in your region? Please tick any/all that apply.



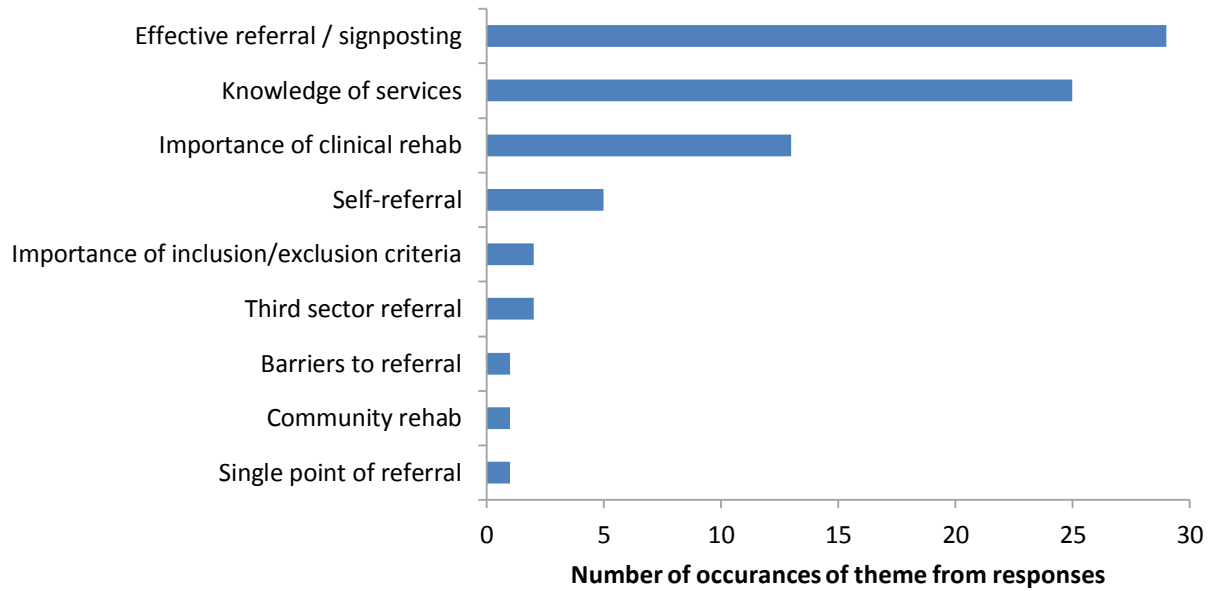
Do you collect any evaluation data for the following (Total responses n= 134)



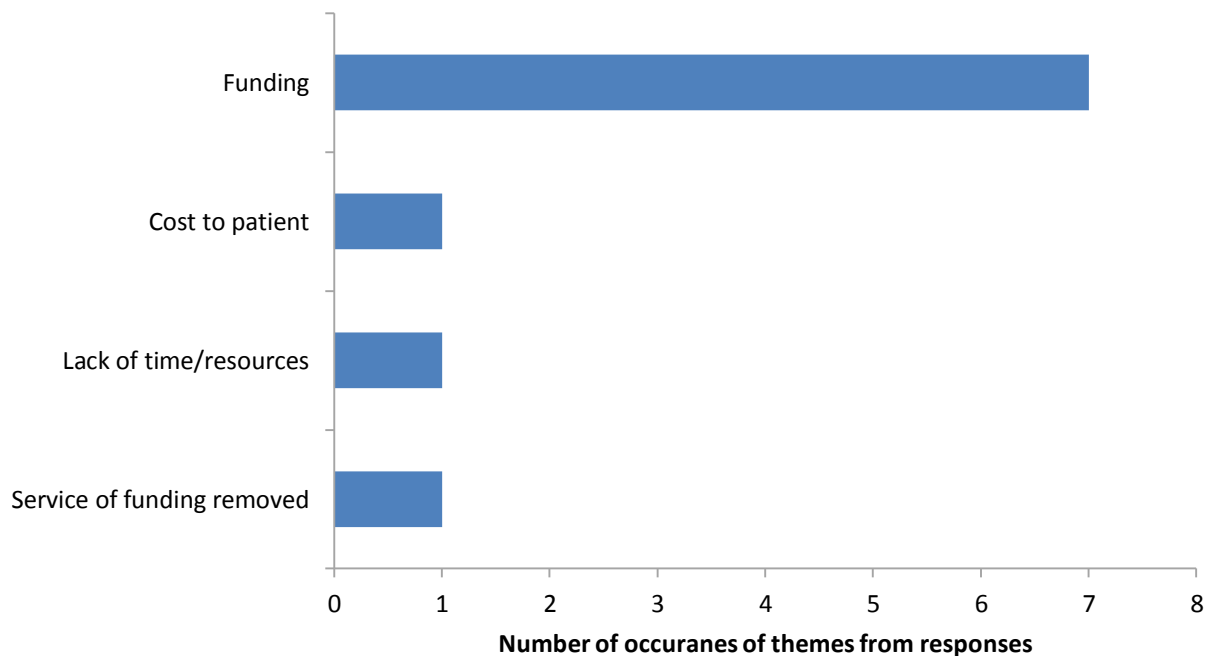
Q20. Please give a comment to SUMMARISE your understanding of access to and service provision of EXERCISE MAINTENANCE that follow on from clinical rehabilitation in your area.



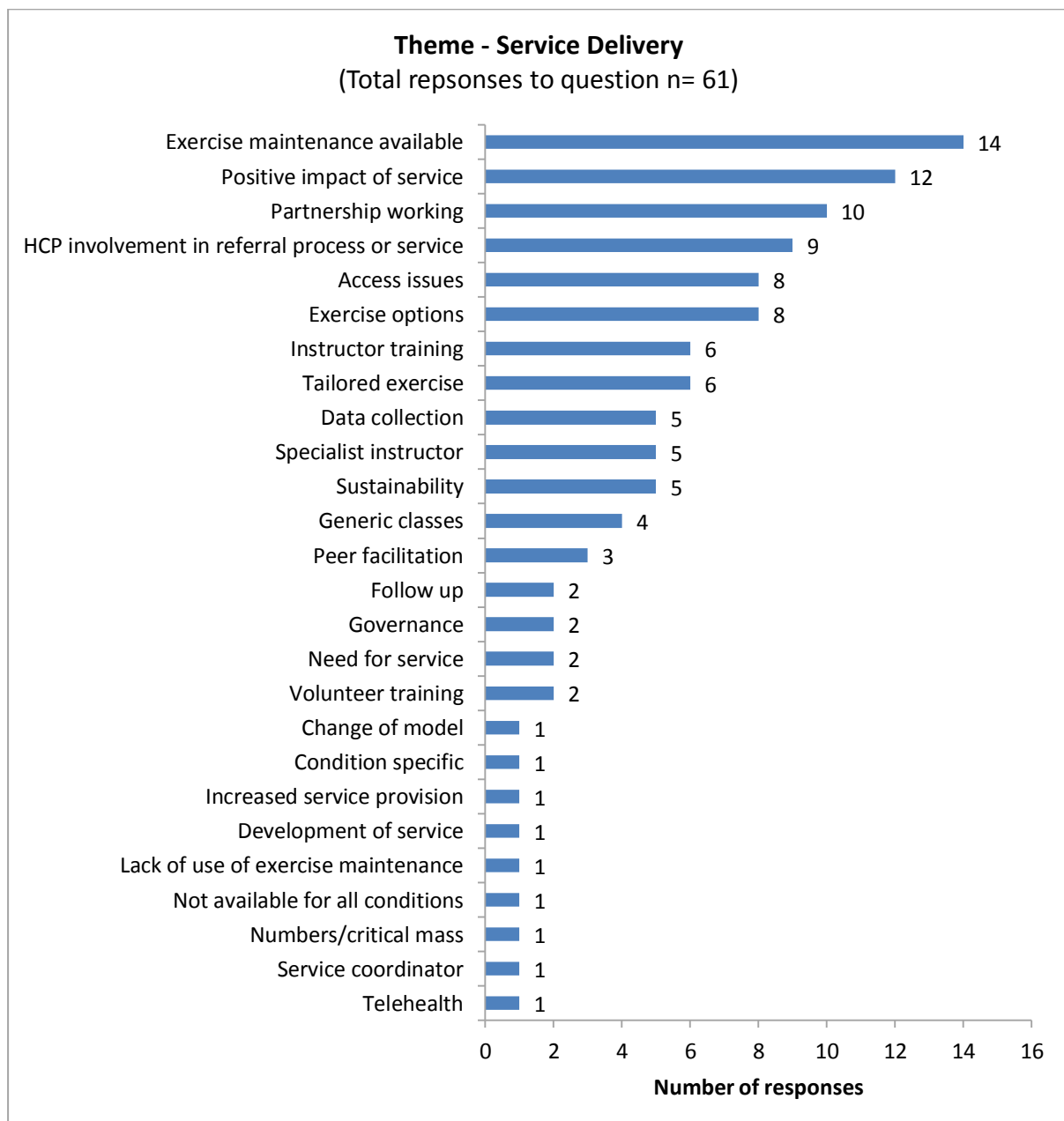
Theme - Pathway / Journey
(Total responses to question n= 97)

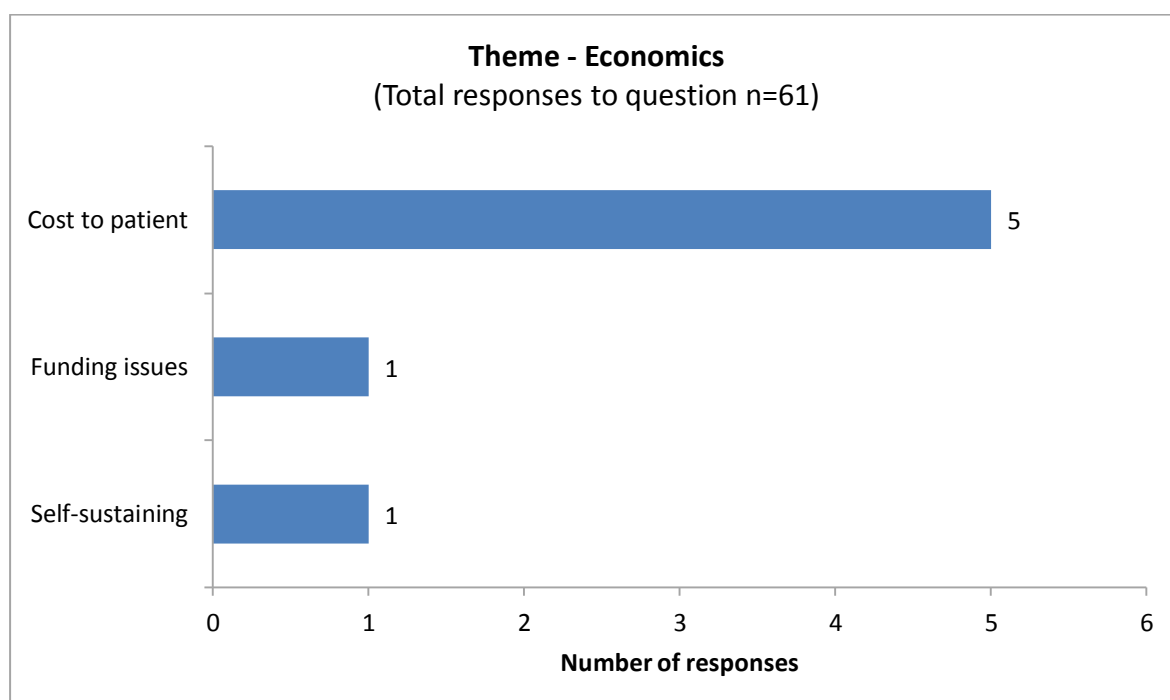
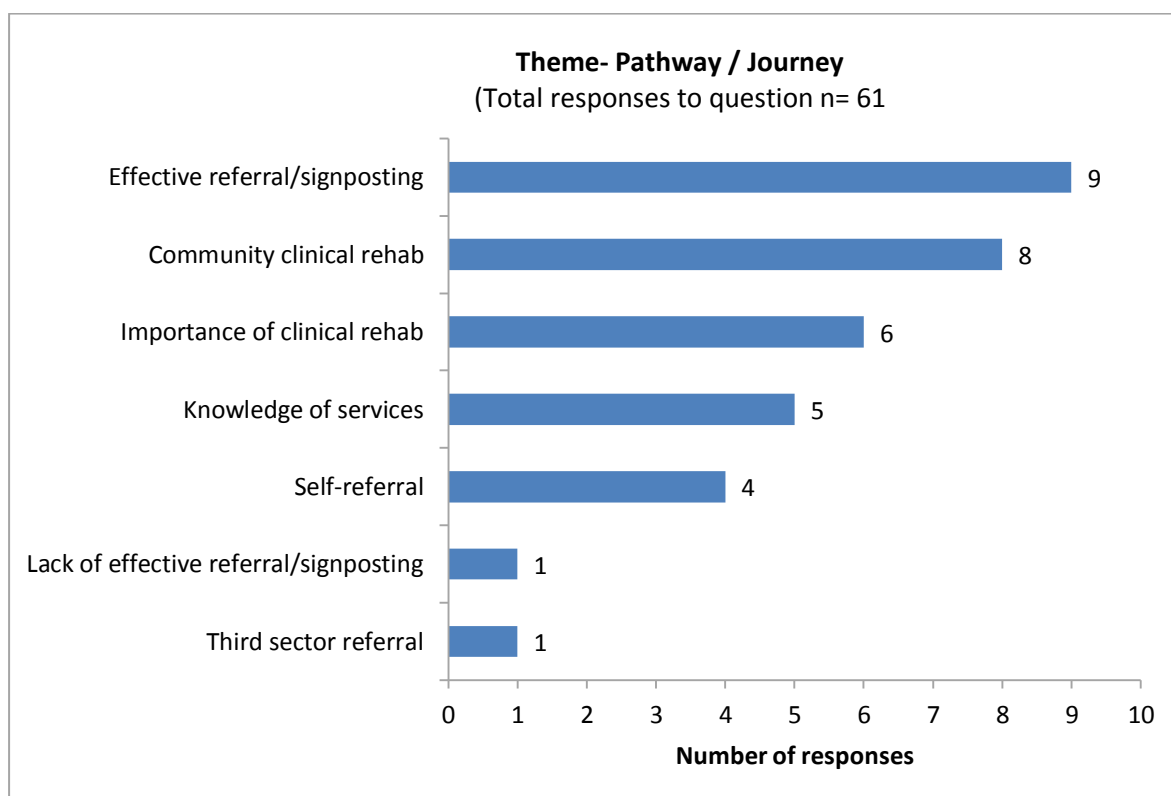


Theme - Economics
(Total responses to question n= 7)

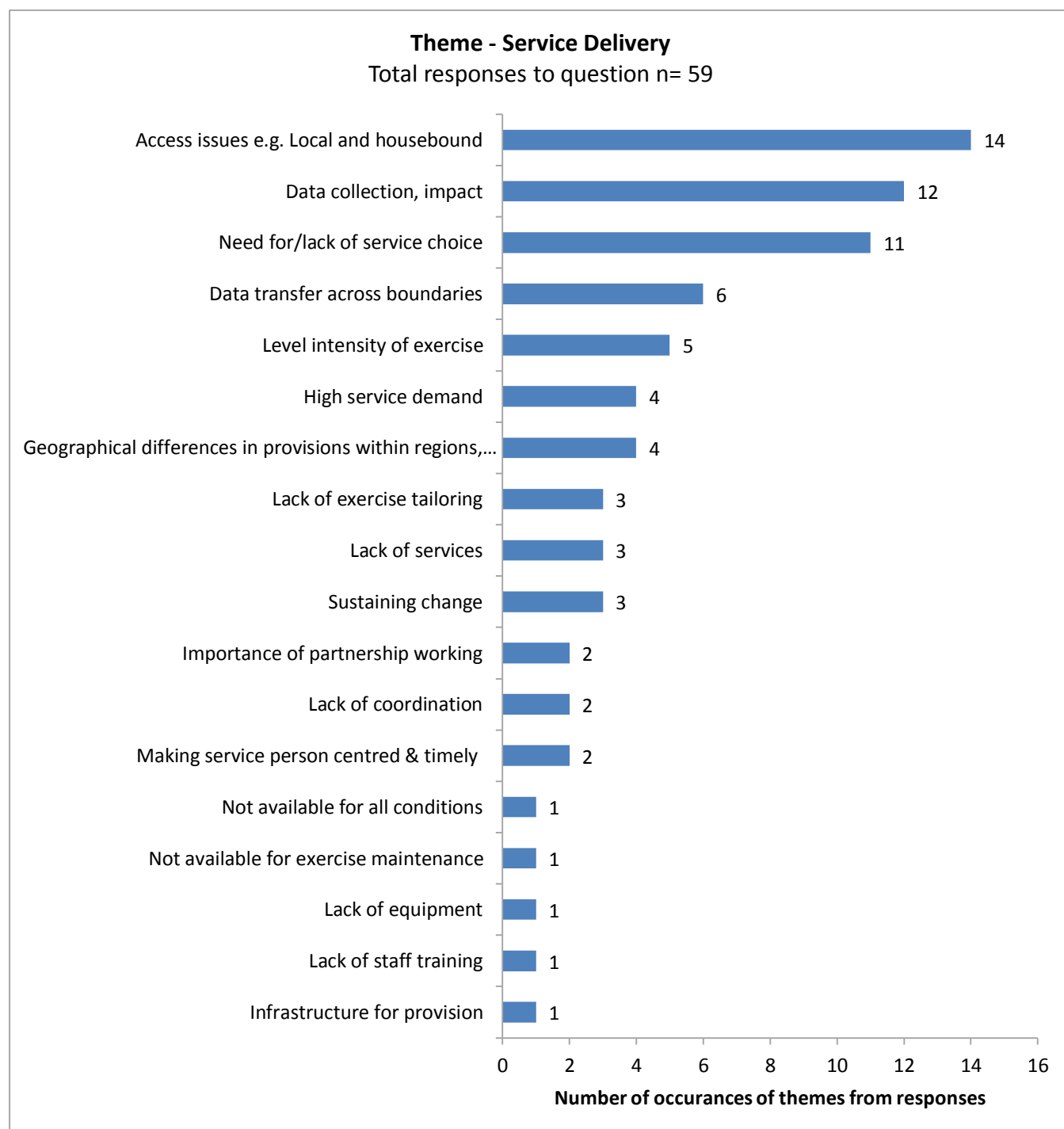


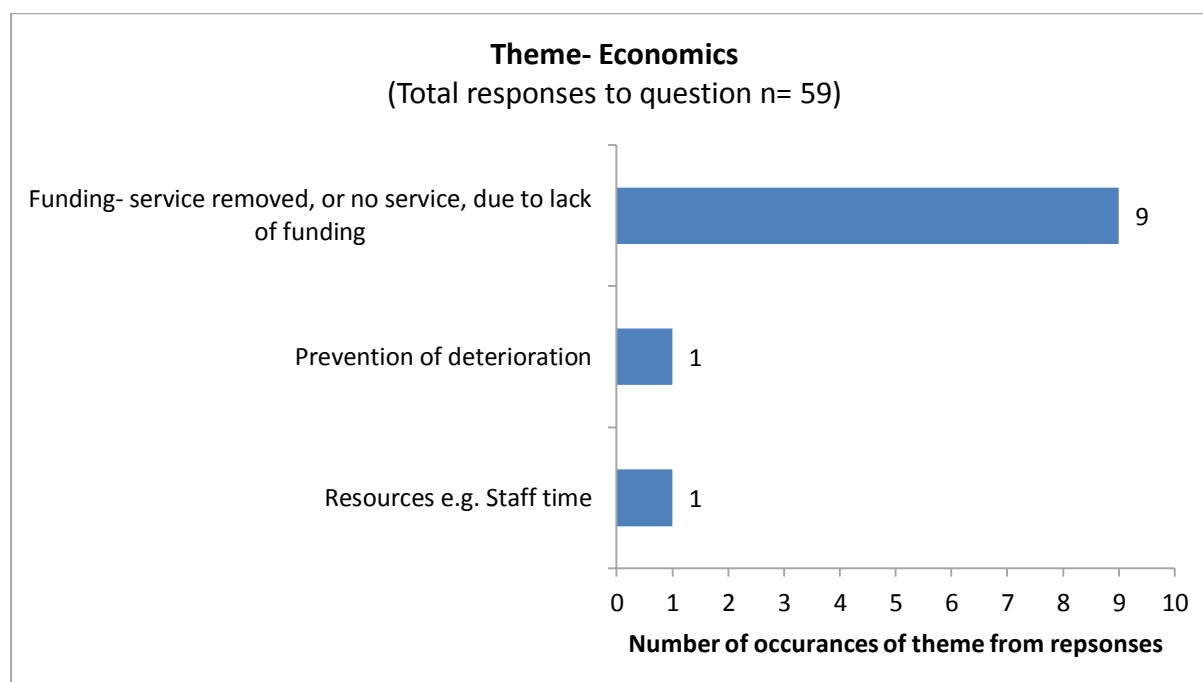
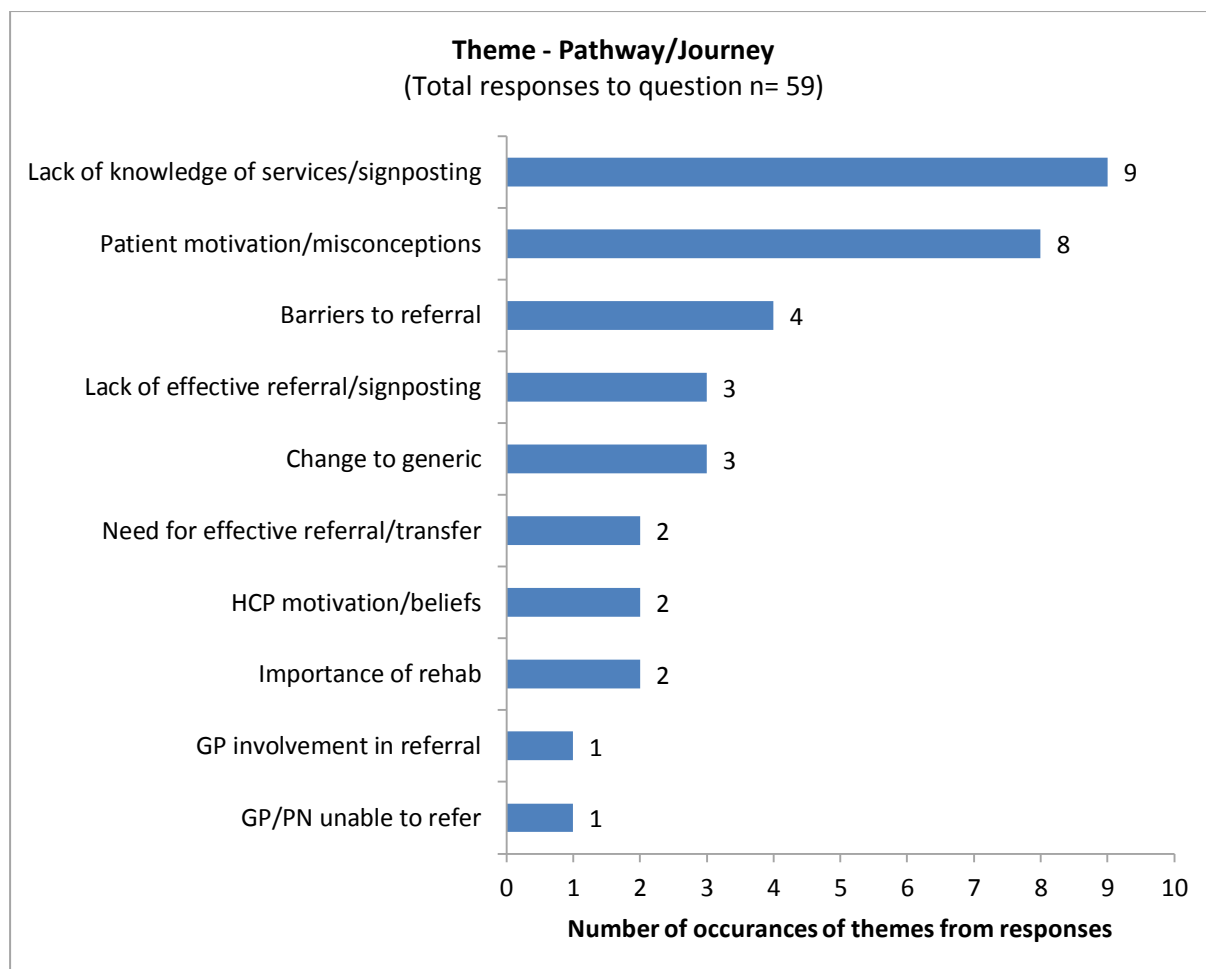
Q21. Please comment on KEY SUCCESSES e.g. delivery, usage, adherence, innovators, in relation to exercise maintenance:





Q22 - Please comment on CHALLENGES e.g. data collection, lessons learnt, in relation to Exercise Maintenance:





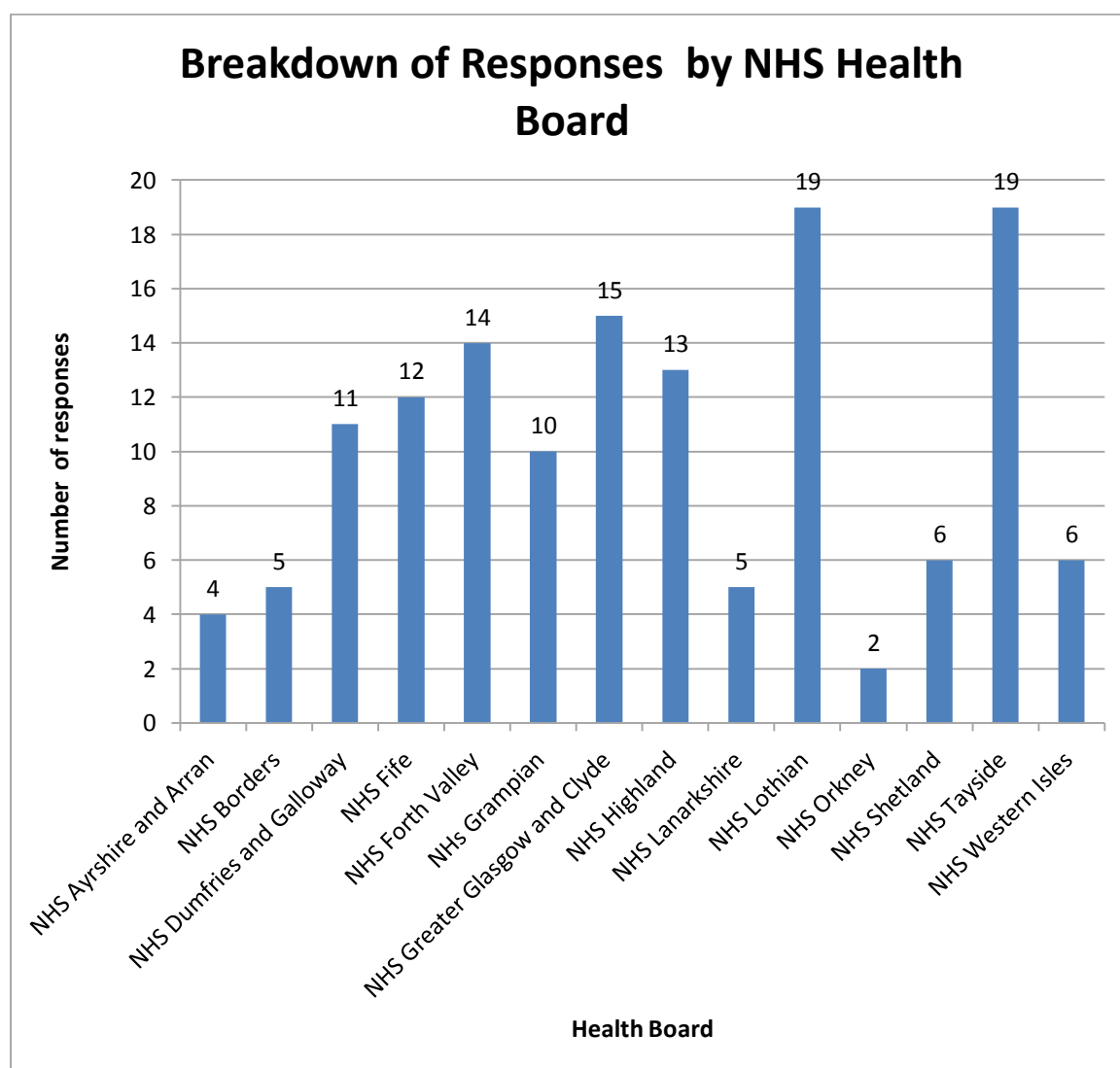
RESULTS OF PARCS GP SURVEY

GPs total number of hits n= 146

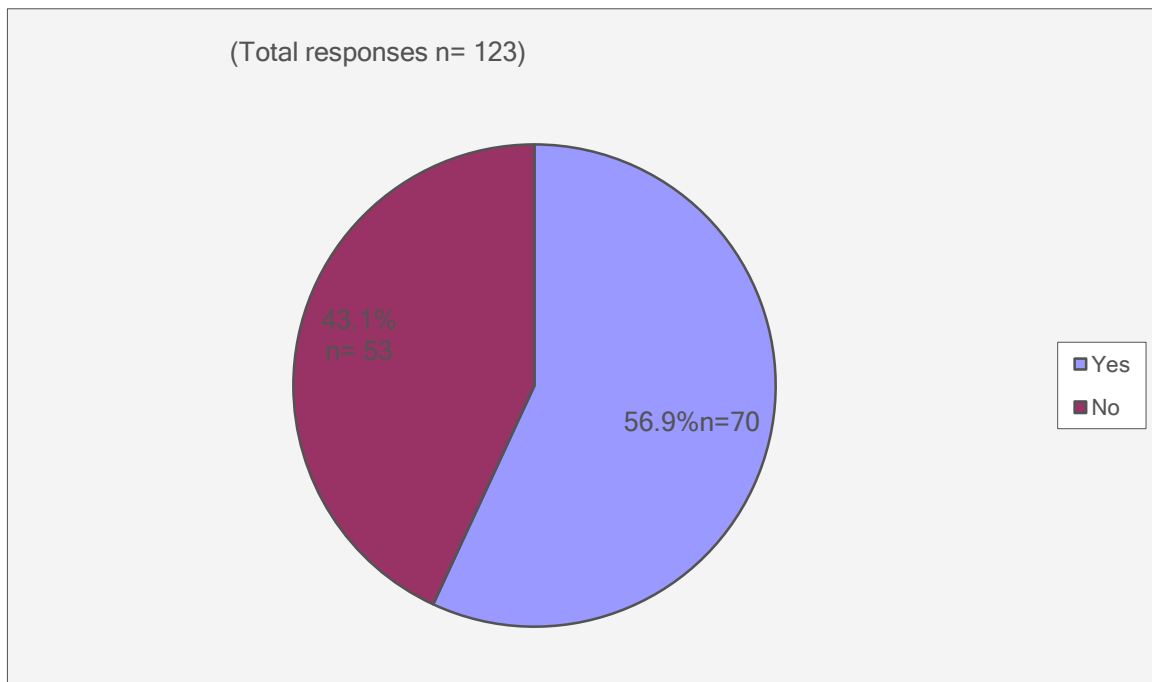
The following graphs and charts indicate the overall responses (i.e. response from all geographical areas) from GPs to the questions detailed in the title of each graph/chart.

Q1. Contact details (optional)

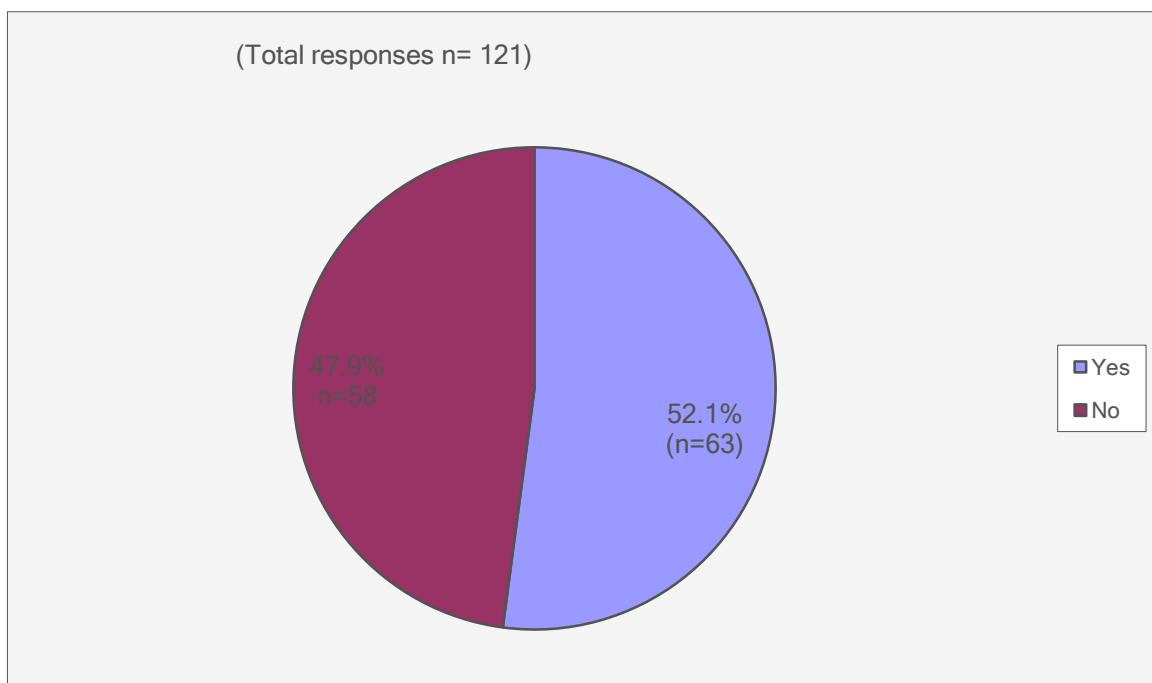
Q2. Health Board:



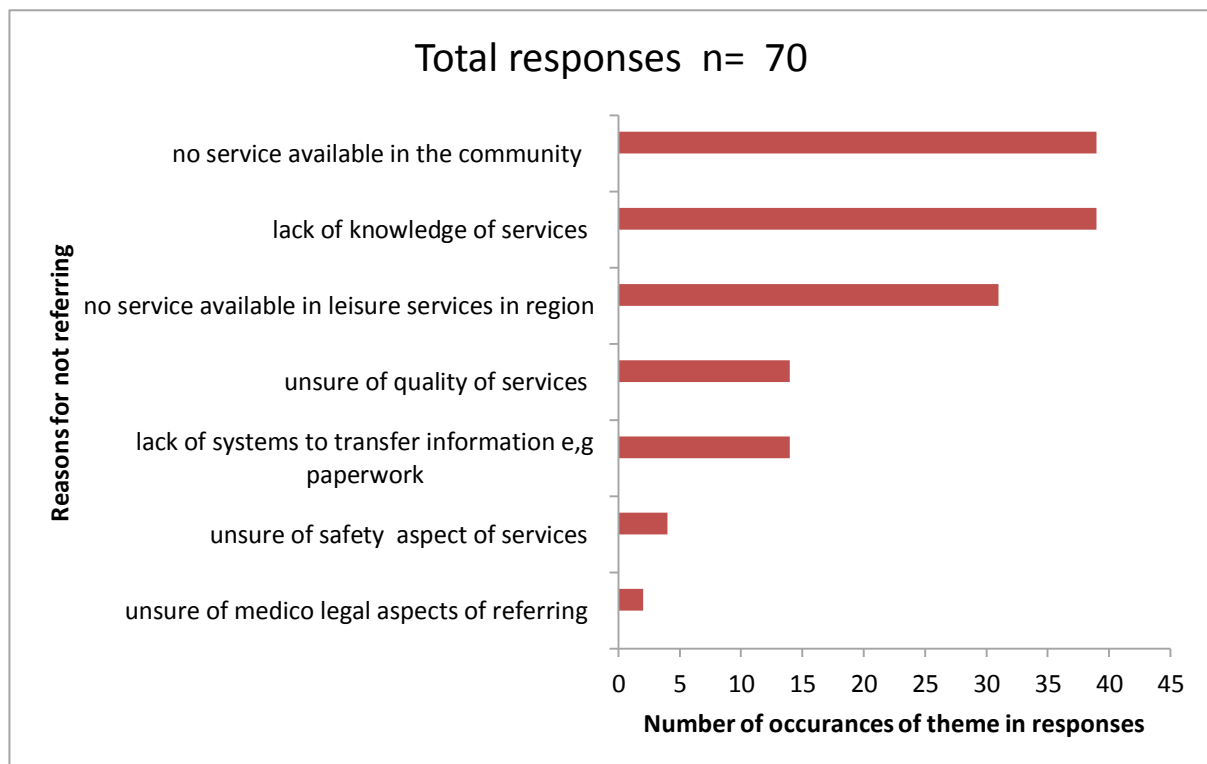
Q3. Can you refer to exercise maintenance in your area?



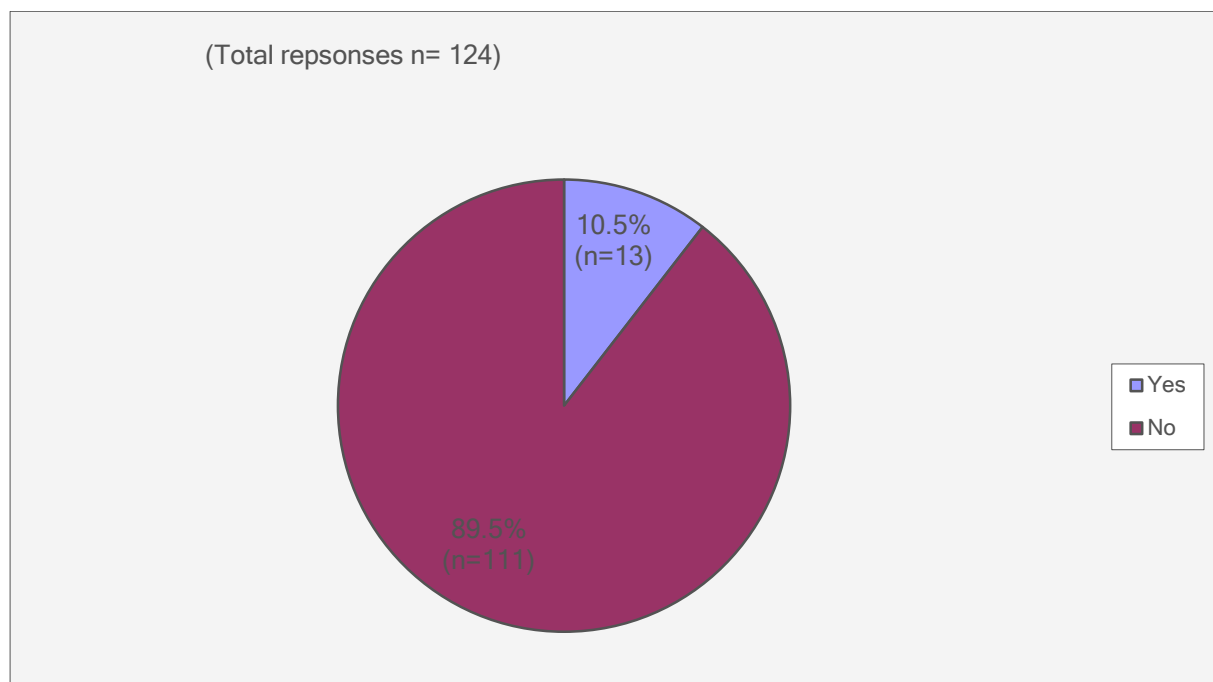
Q4. Do you refer to exercise maintenance in your area?



Q5. What are your reasons for not referring? Please tick any or all that apply.

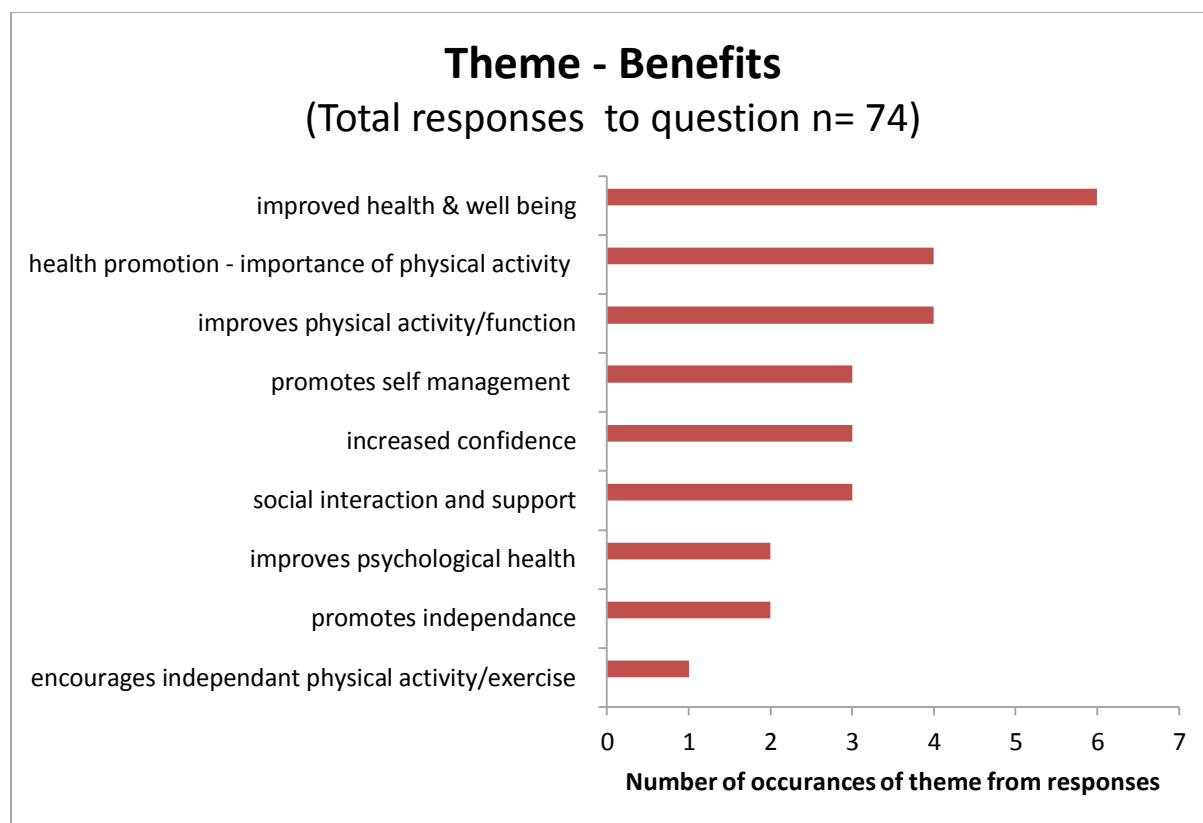


Q6. Are you part of a collaborative working group for exercise maintenance in your region?

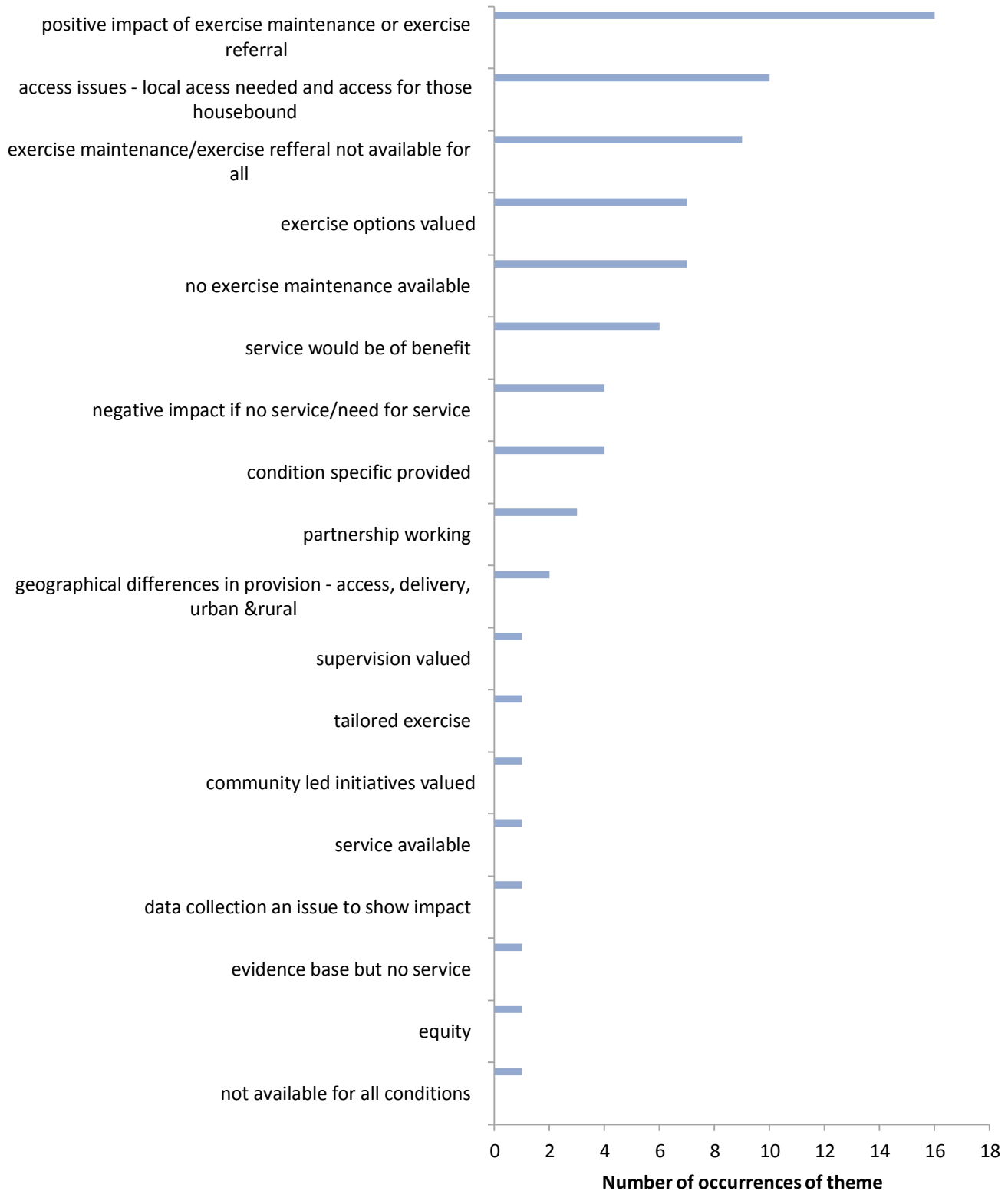


Q7. Please comment on the impact service provision for exercise maintenance (or lack of service provision for exercise maintenance) has on your patients.

Total responses to question n = 74

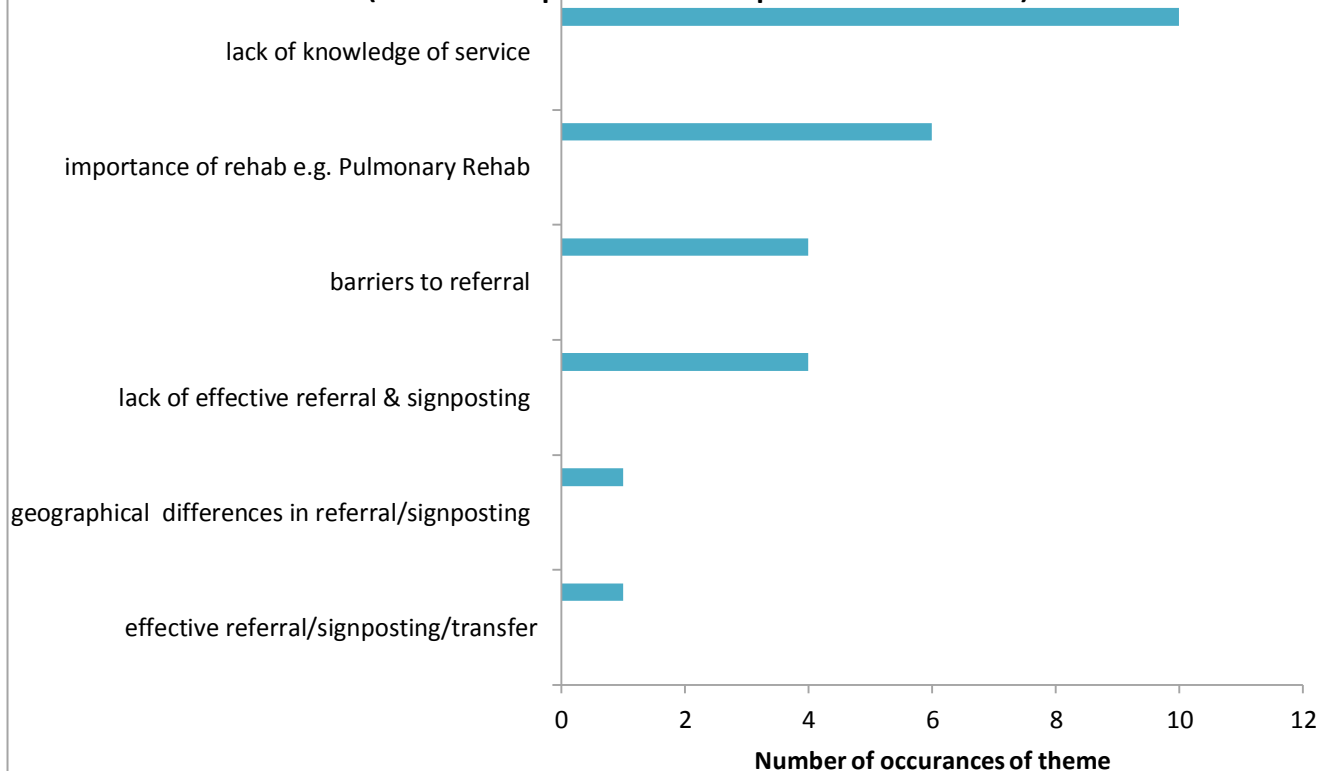


Theme - Service Delivery (Total responses to question n=74)



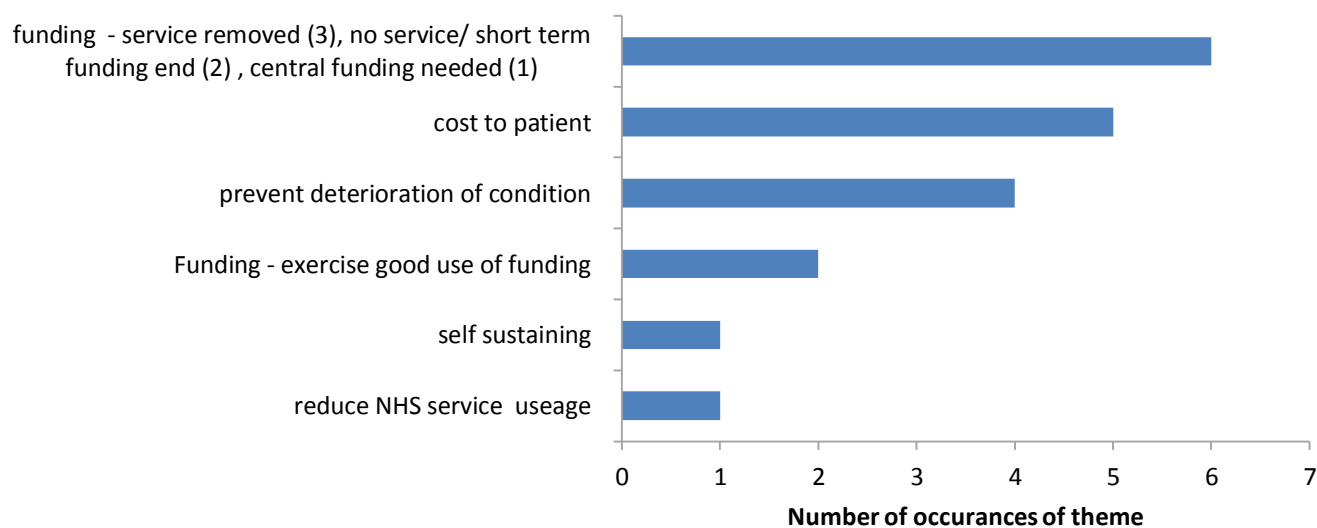
Theme - Pathway

(Total responses to question n=74)



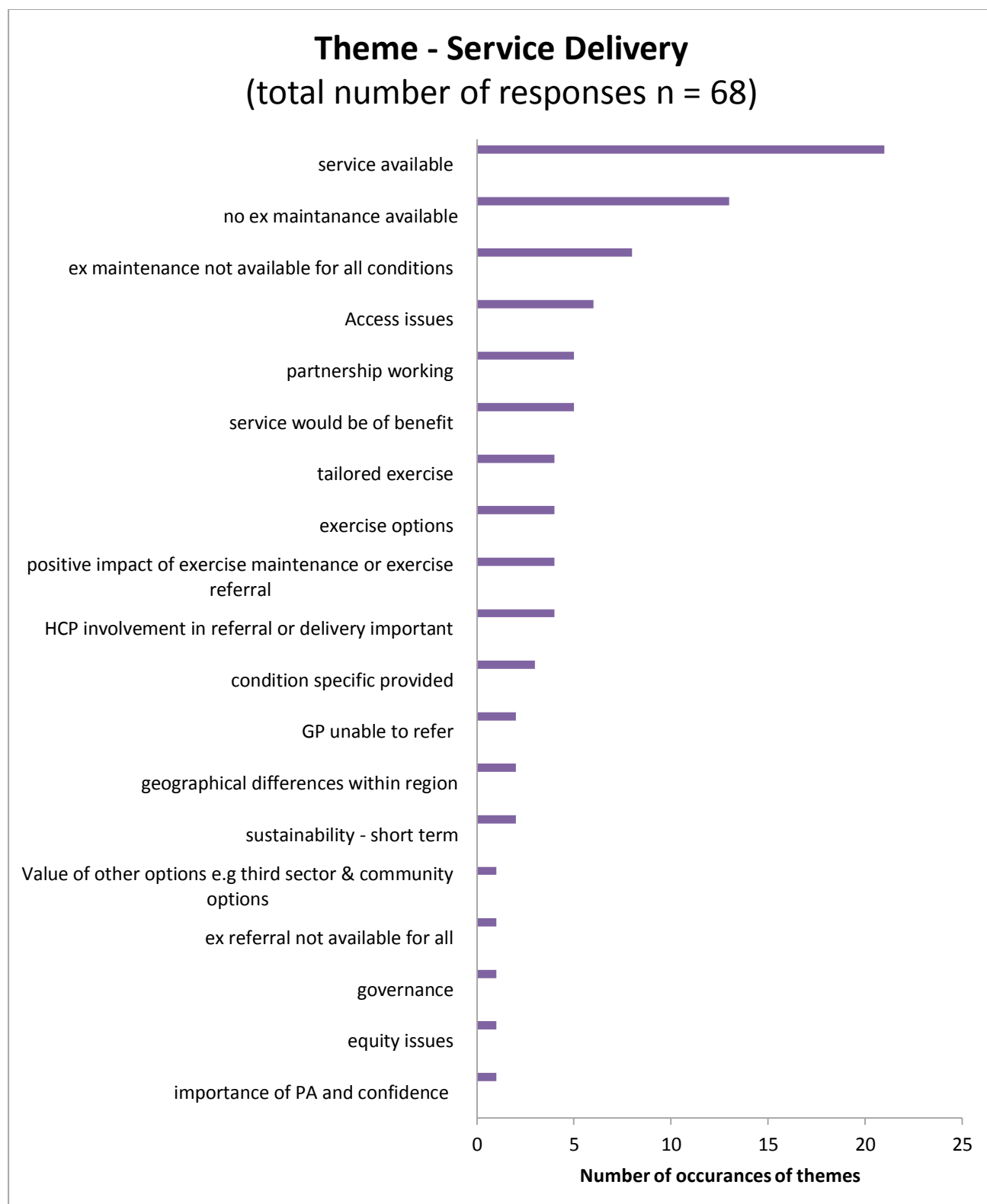
Economics

(Total number of responses n= 74)

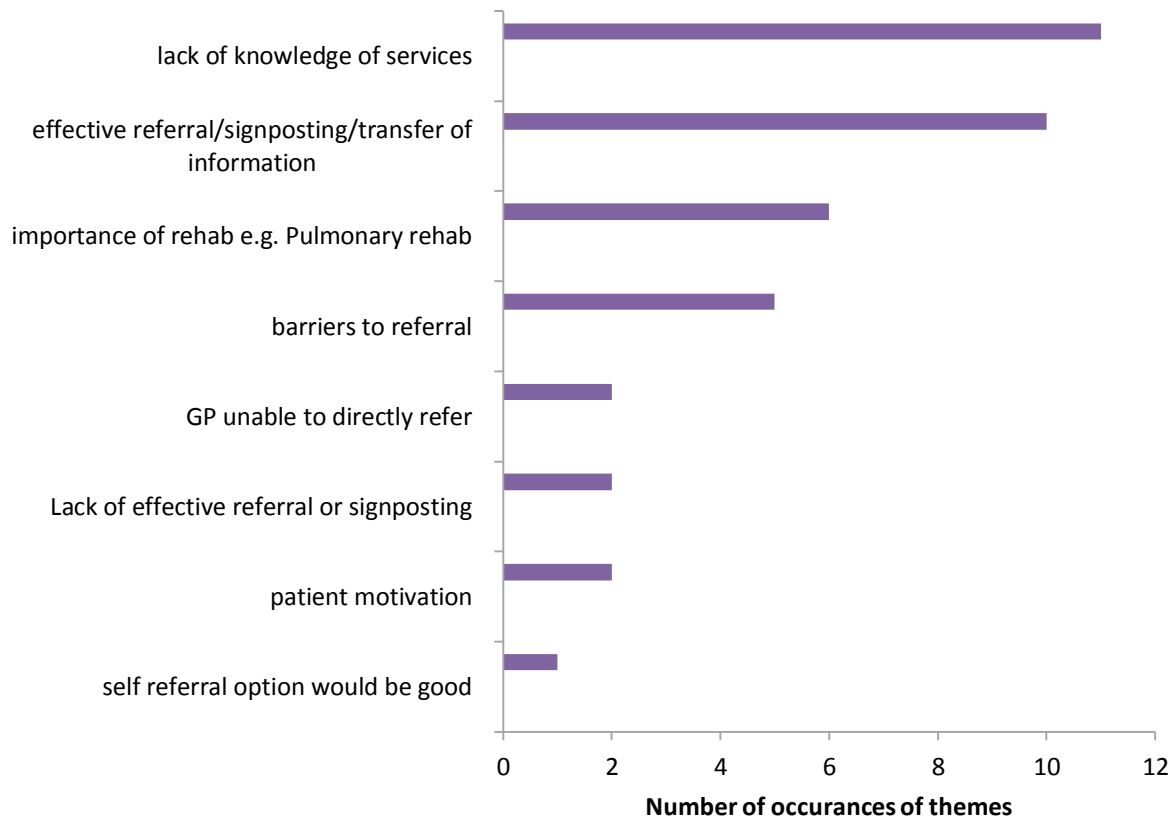


Q8. Please give a comment to summarise your understanding of access to and service provision of exercise maintenance after clinical rehabilitation in your area.

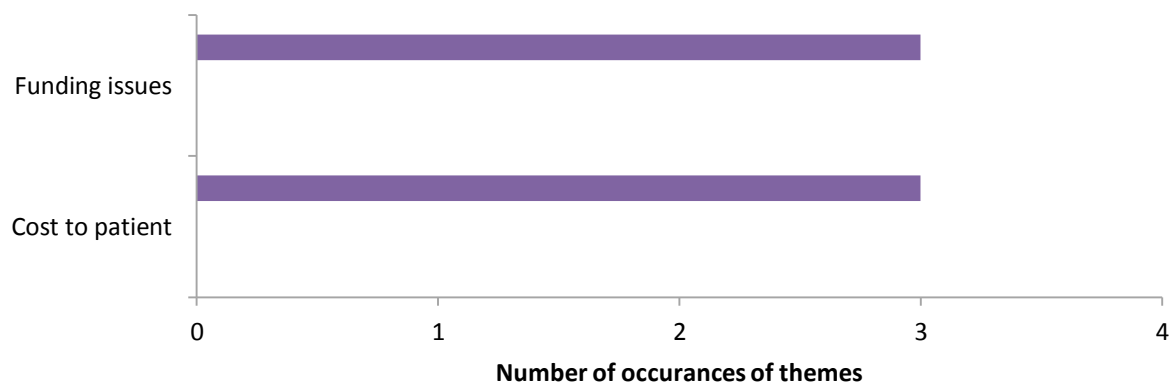
Total responses n= 68



Theme - Pathway (total number of responses n= 68)



Theme - Economics (total number of responses n = 68)

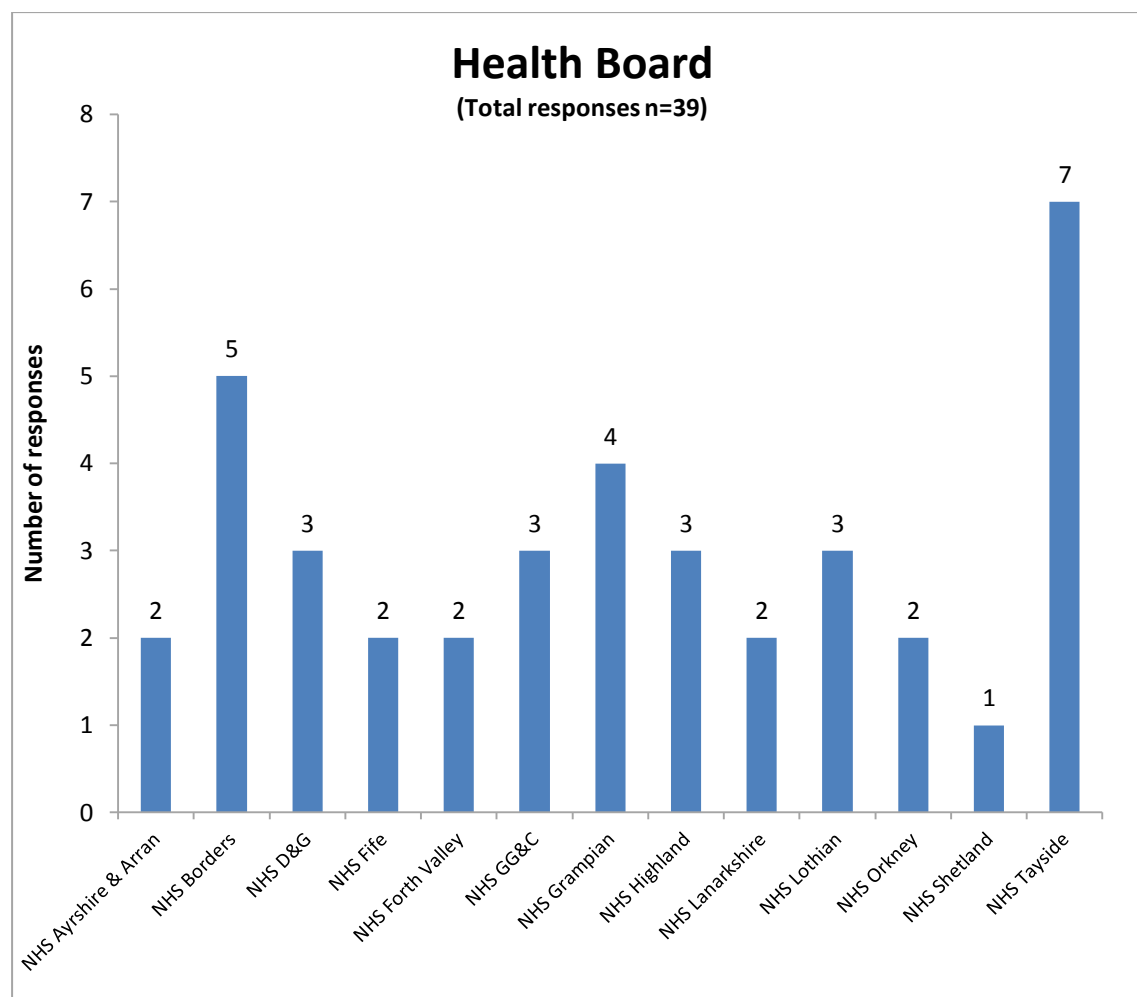


RESULTS OF RESPONSES FROM PARCS LEISURE SERVICES SURVEY

Leisure Services – Total hits n=40

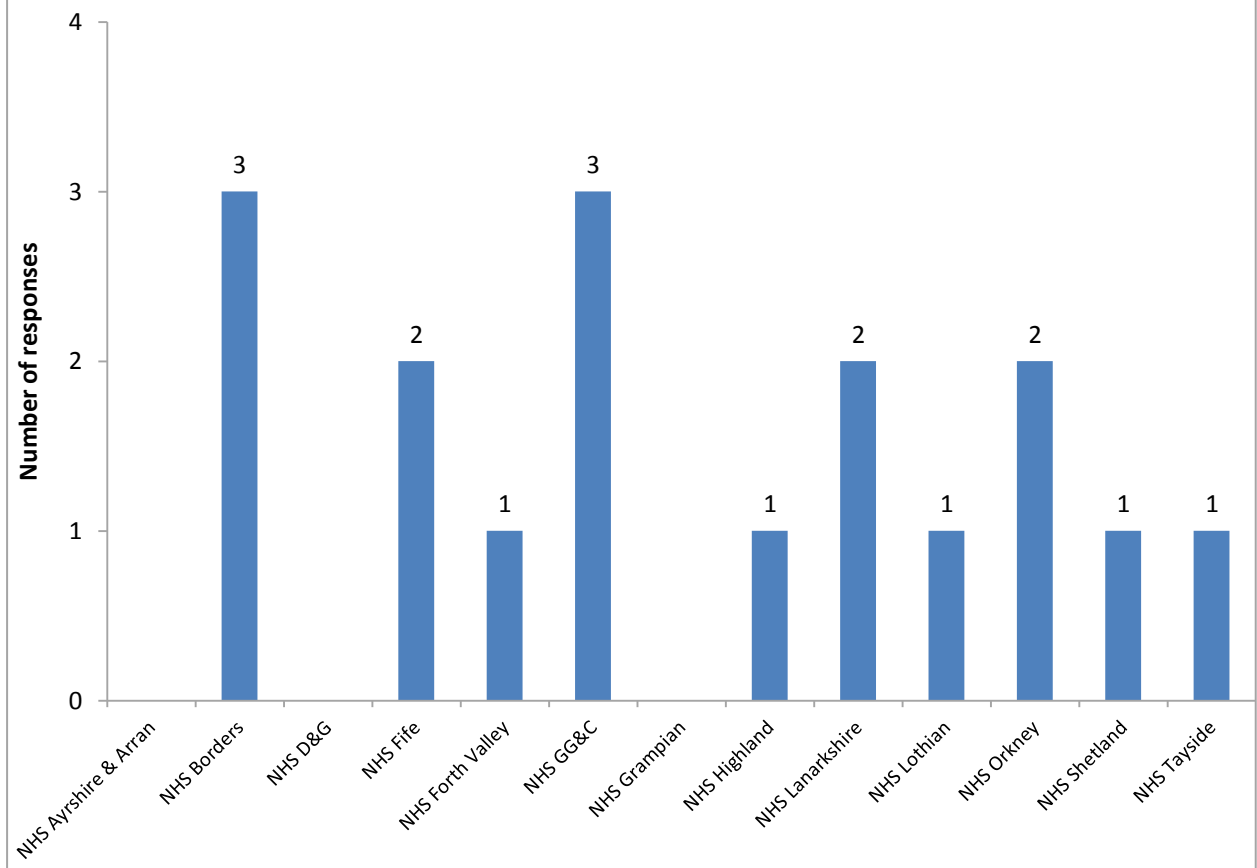
The following graphs and charts indicate the overall responses (i.e. response from all geographical areas) from Leisure Services to the questions detailed in the title of each graph/chart.

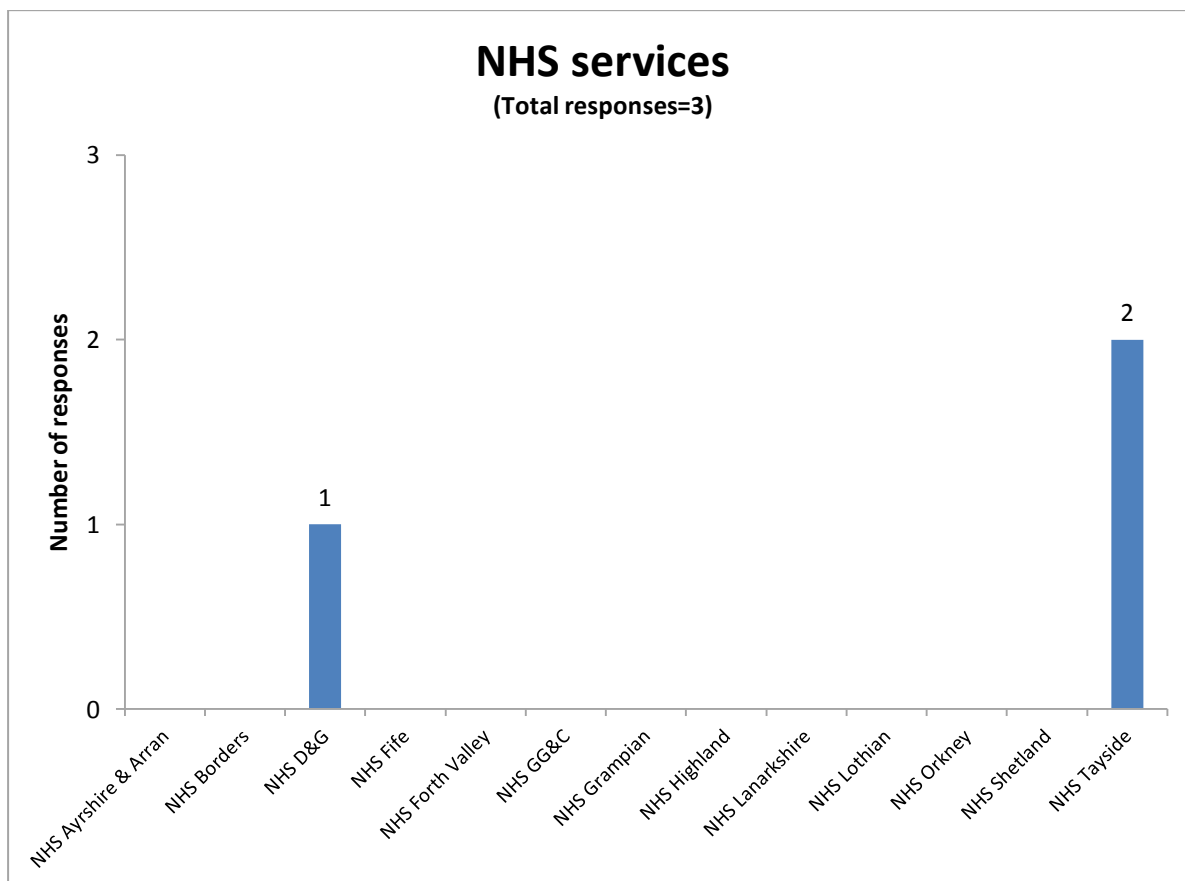
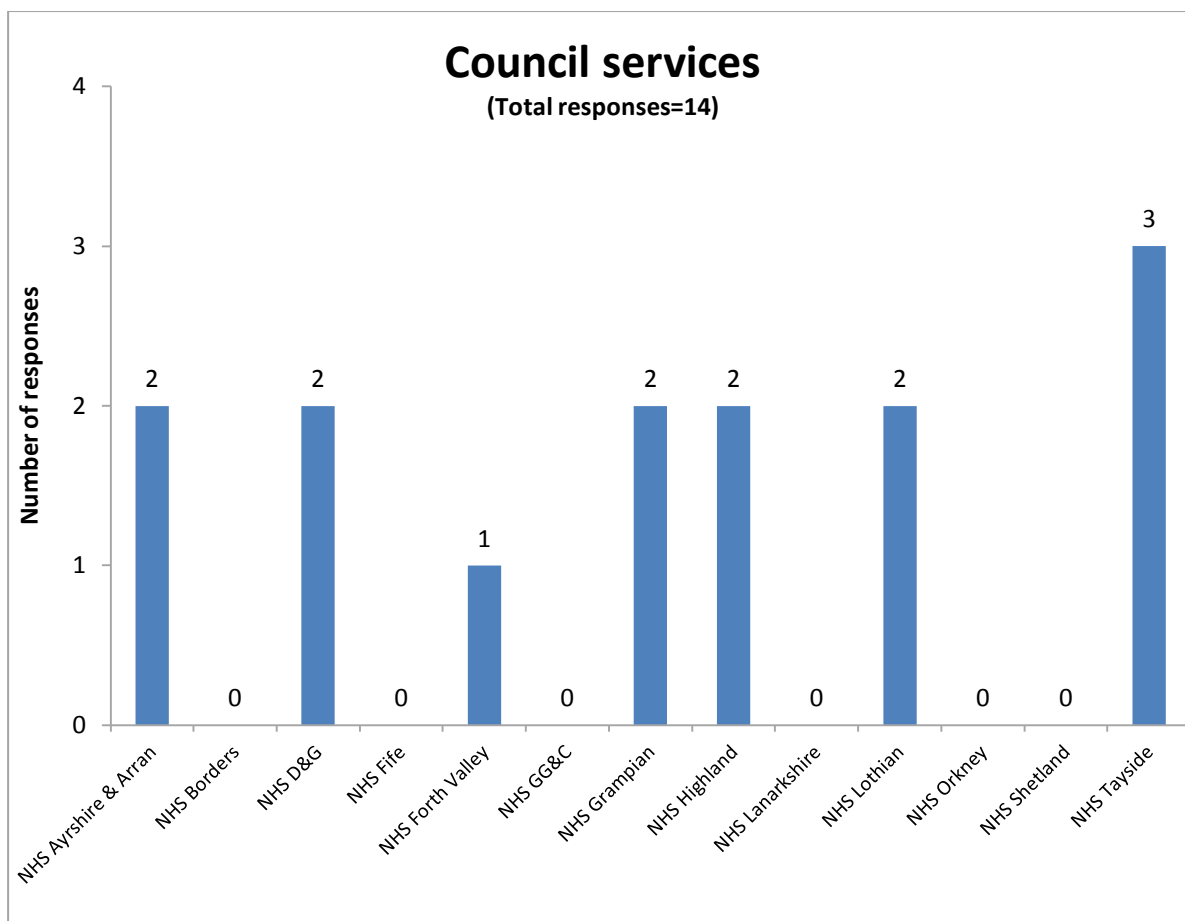
Q1. Personal Details (optional including Health Board)

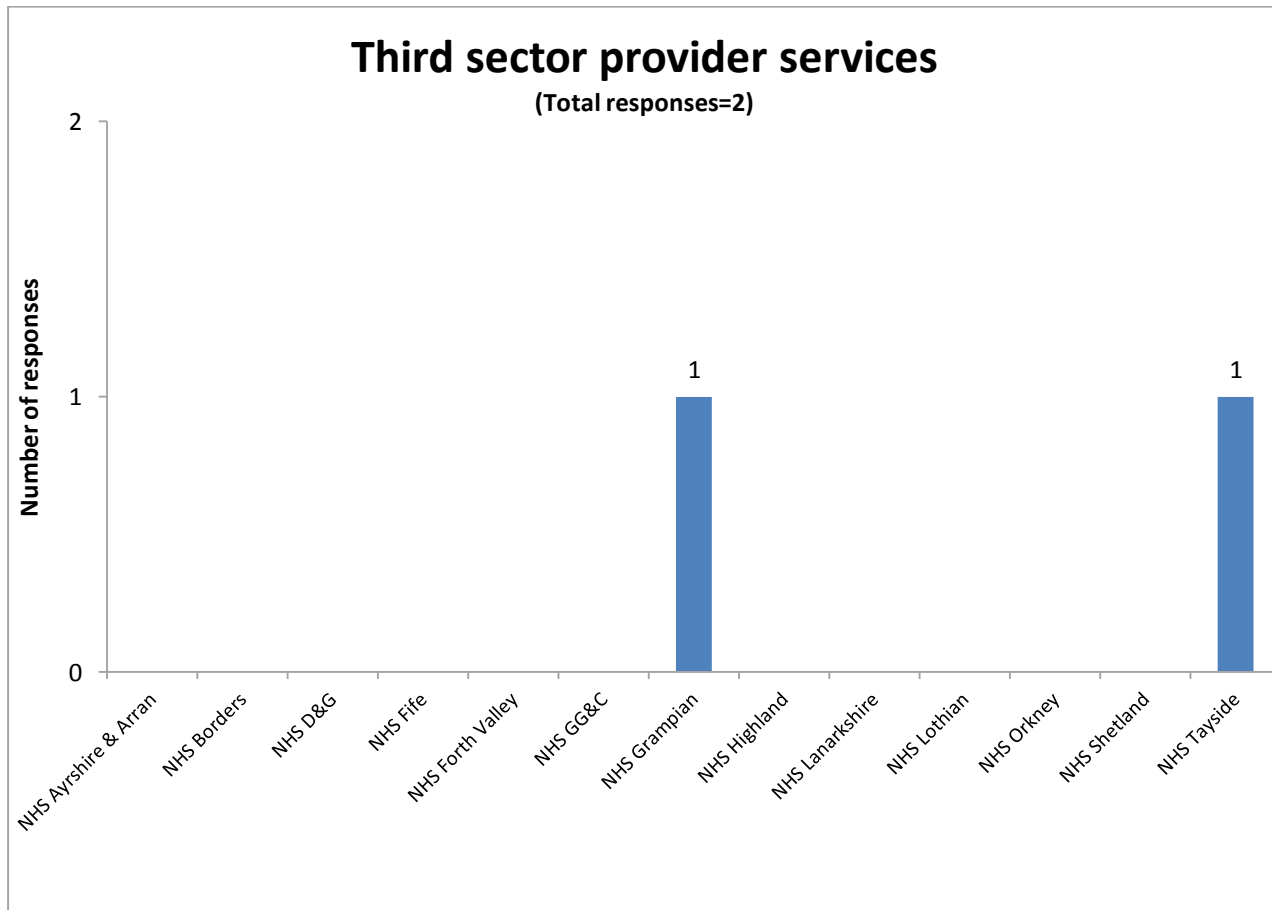
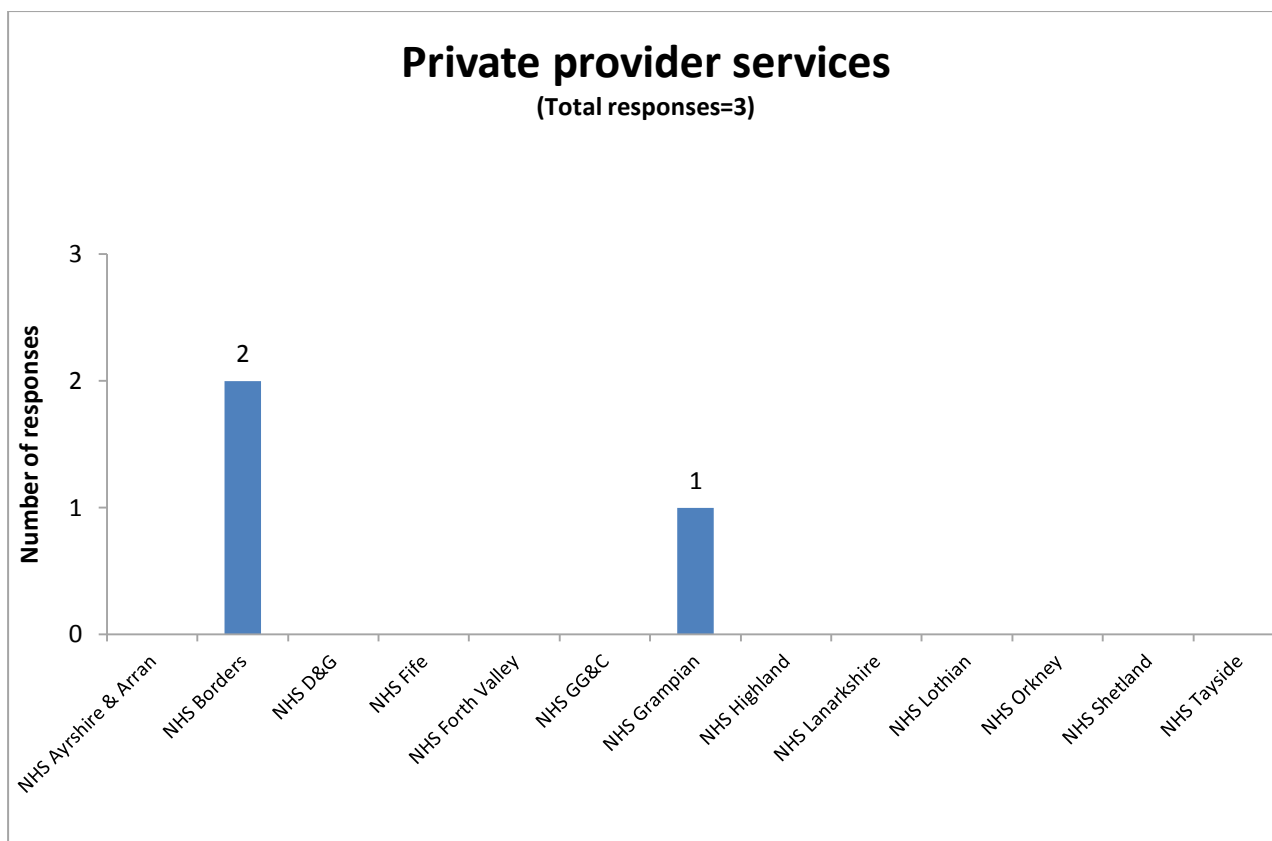


Leisure services

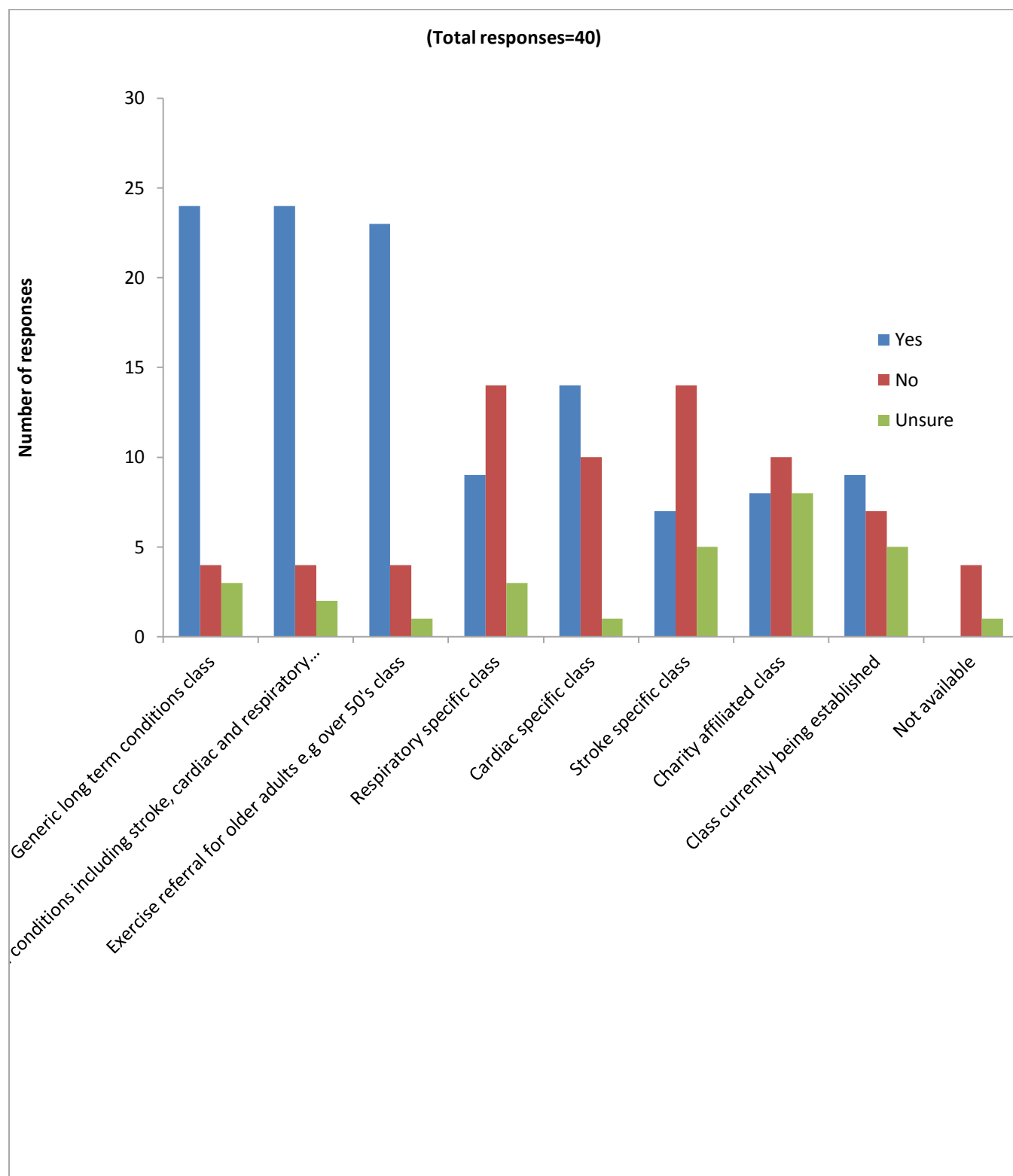
(Total responses n=17)





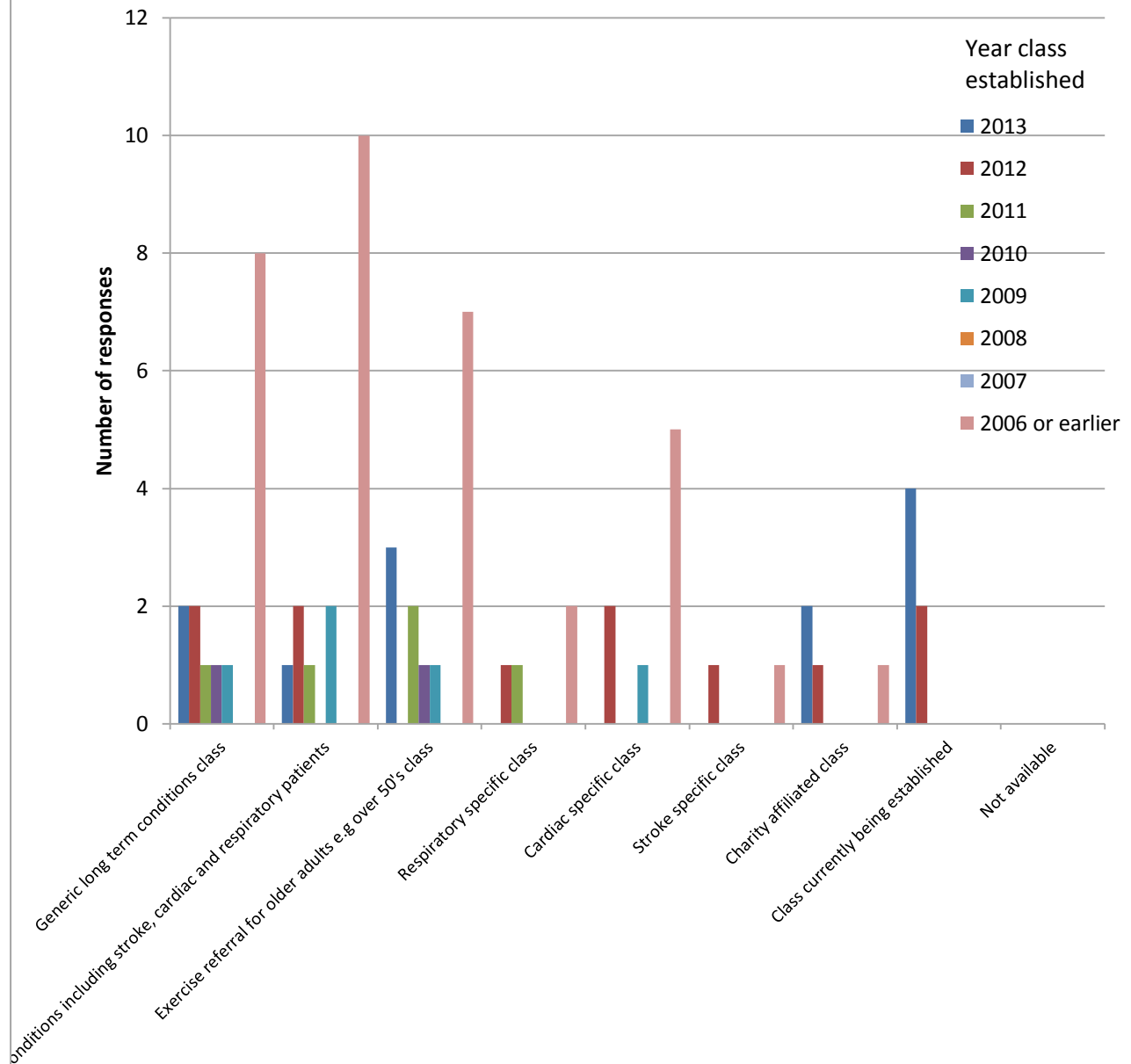


Q2. What types of follow on exercise maintenance classes are available in your region? Please indicate the year established if known.

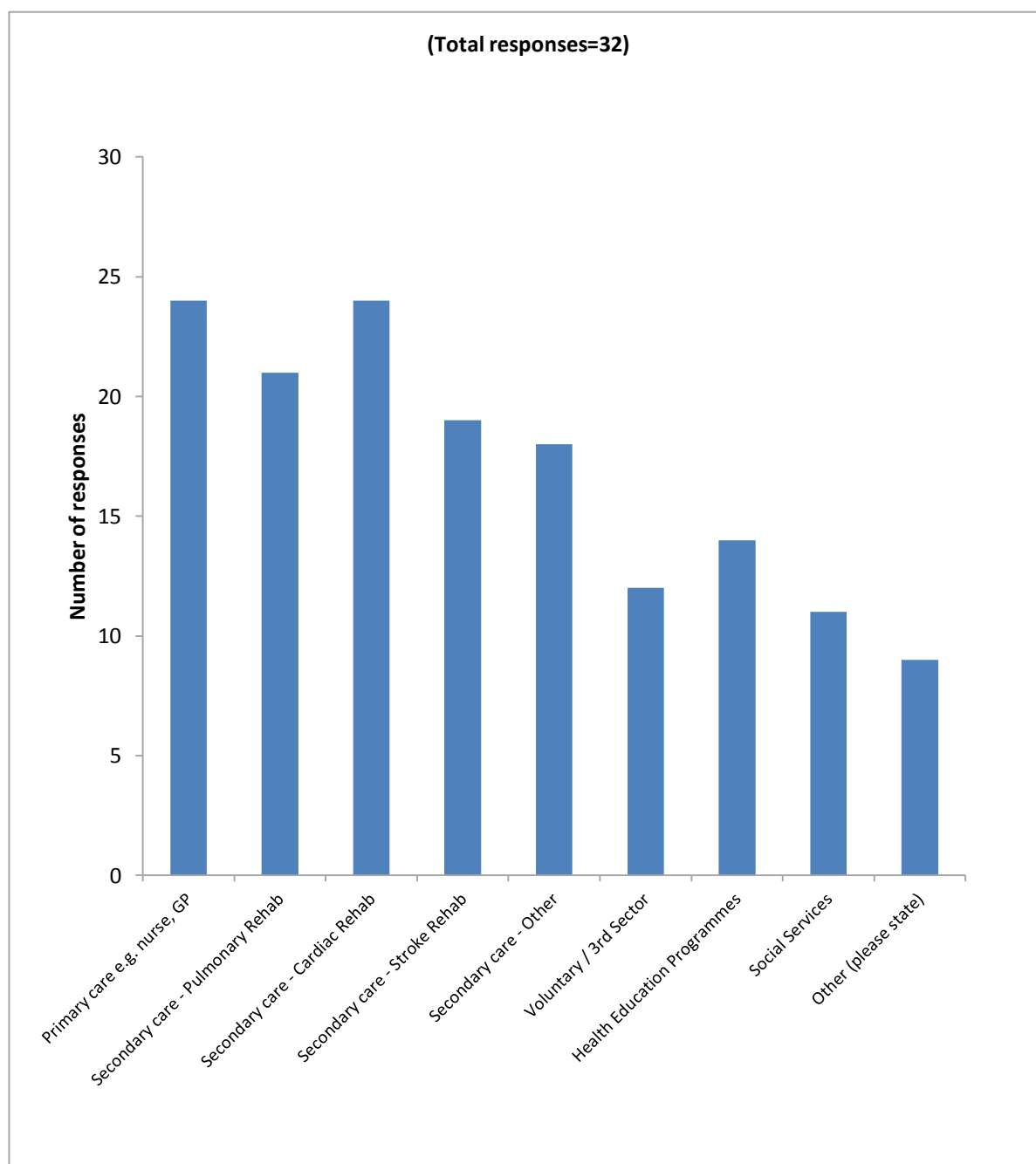


Which year were the exercise maintenance services established?

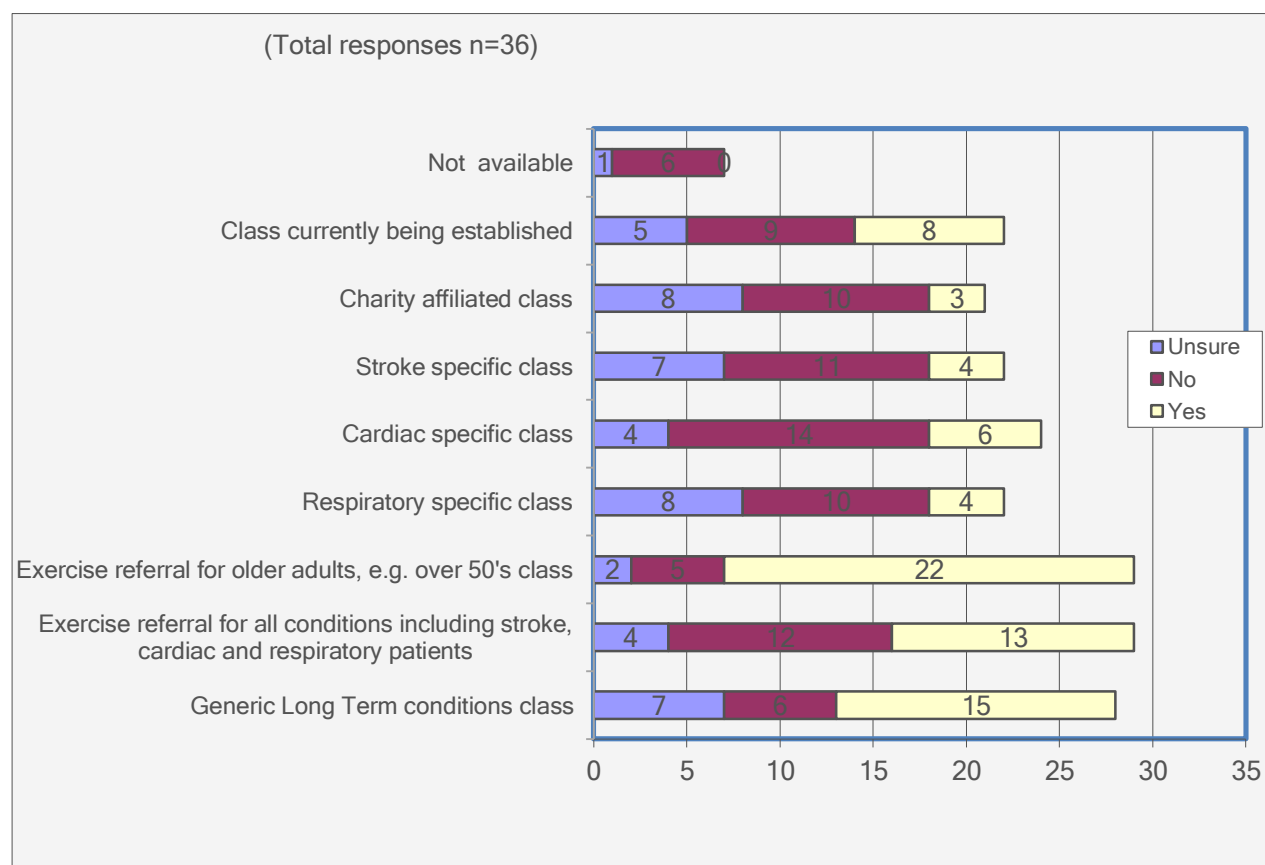
(Total responses=40)



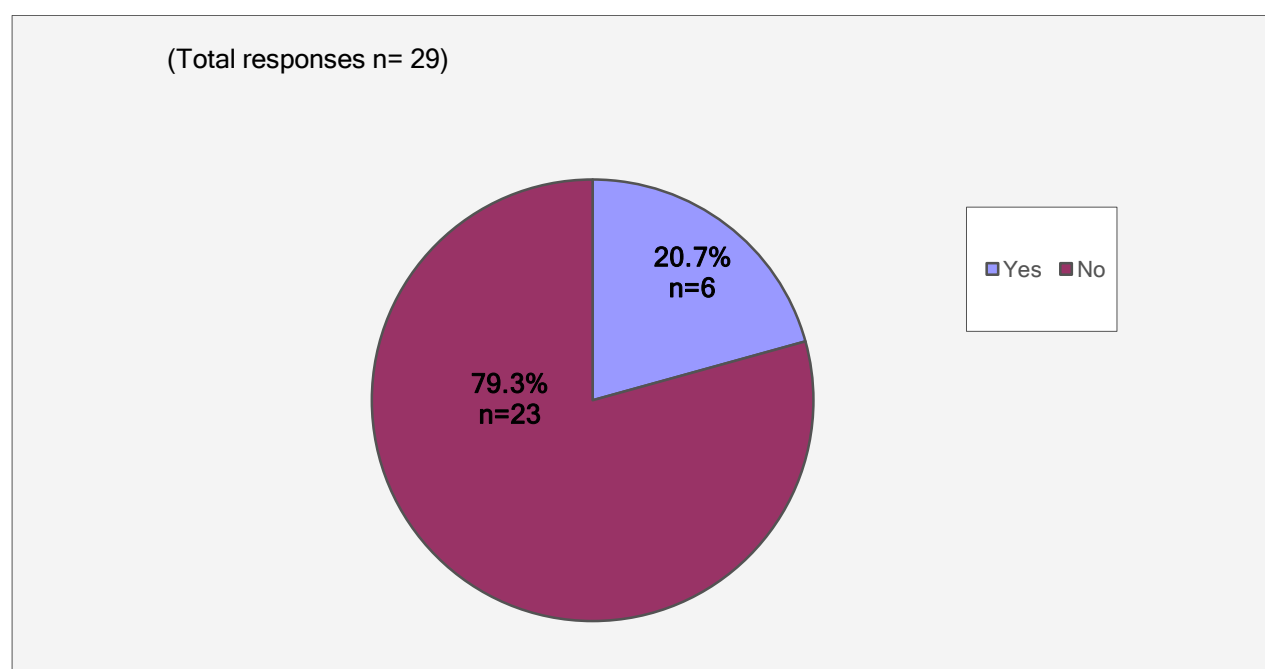
Q3. Which sectors refer to exercise maintenance classes in your region? Please tick any/all that apply.



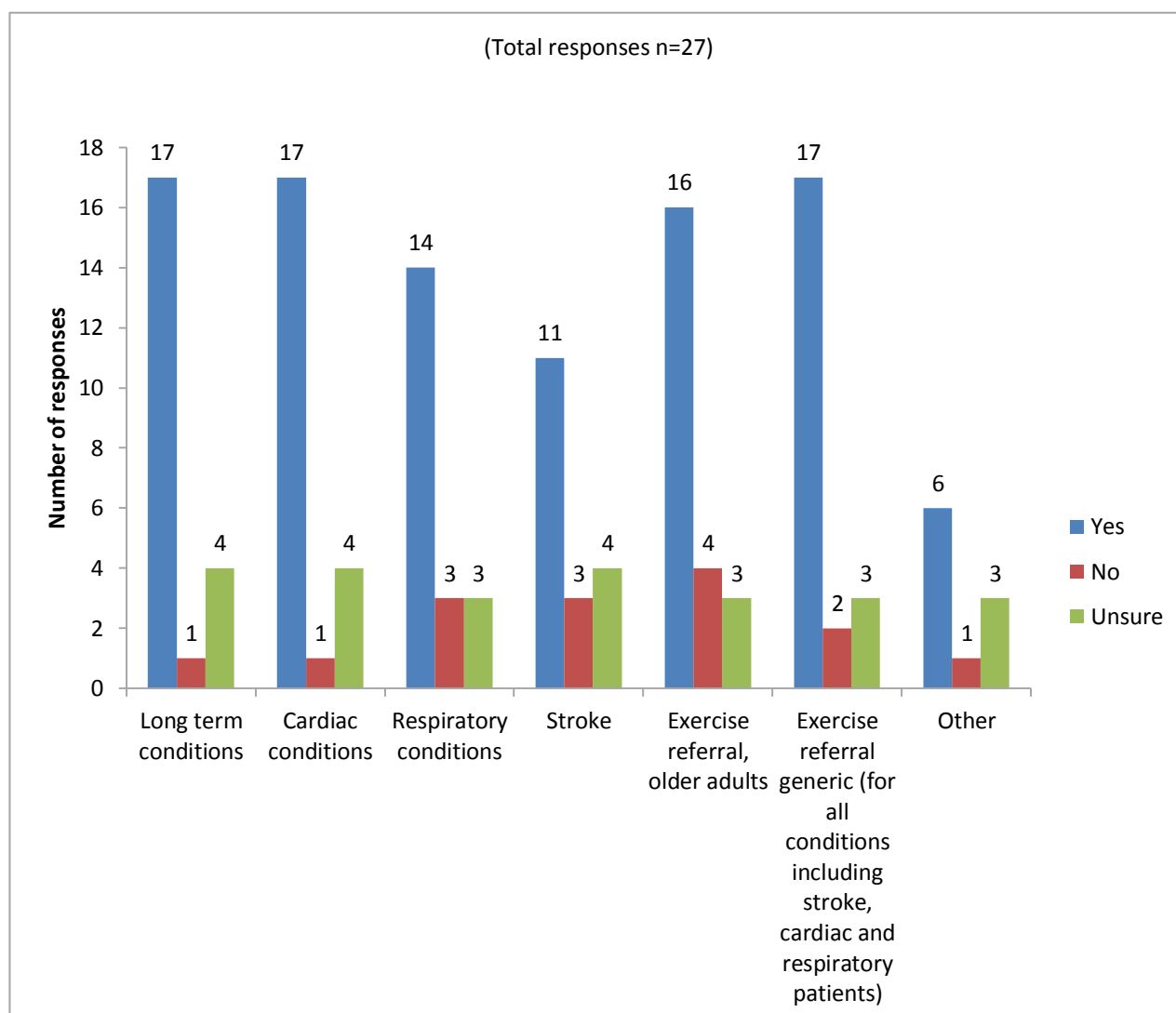
Q4. Is self-referral available to the following exercise maintenance classes?



Q5. Is there a single point of contact for all long term conditions from clinical rehabilitation across the Heath Board?

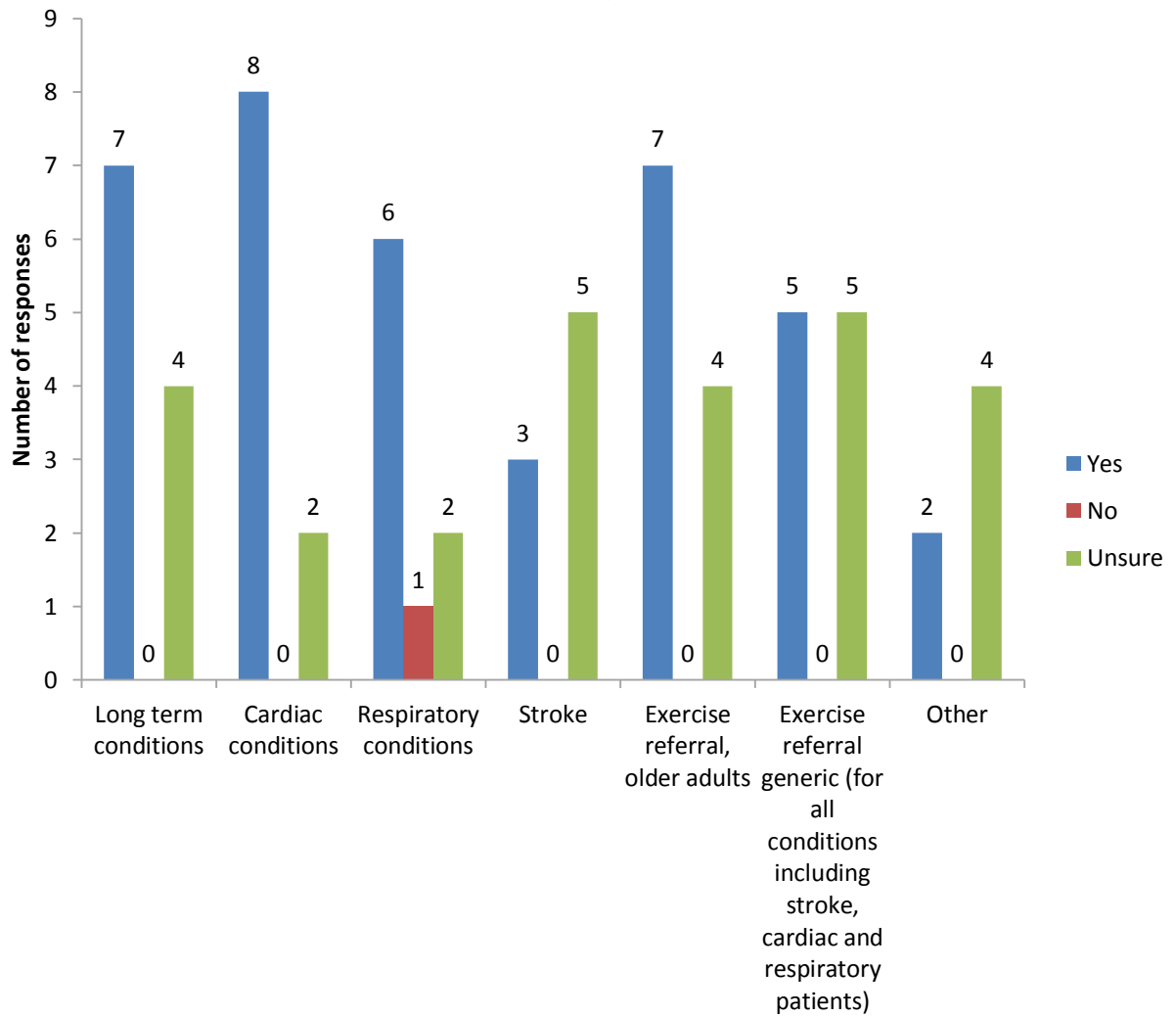


Q6. Is there an established pathway to exercise maintenance classes in your region for the following?

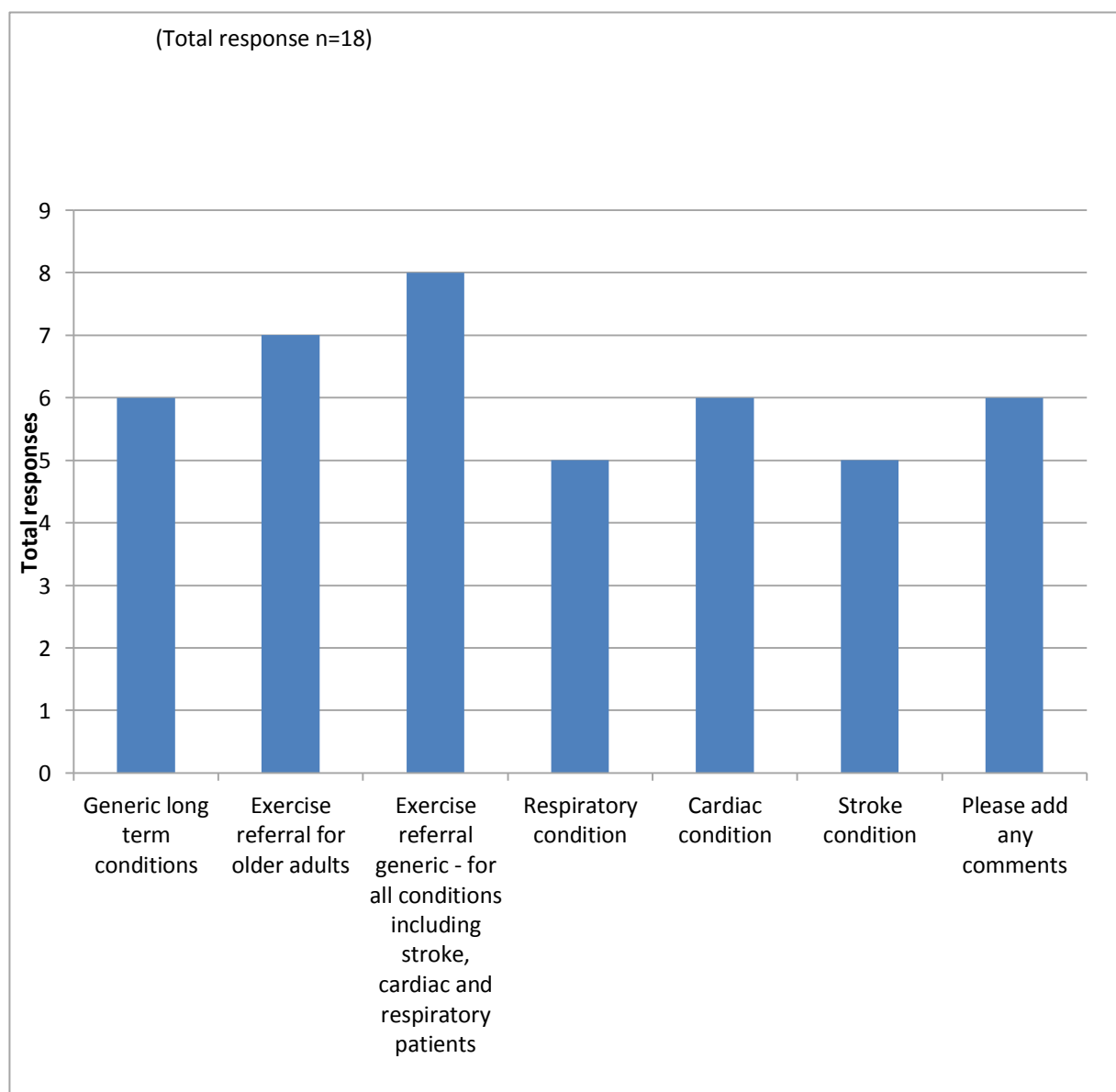


Across Health Board

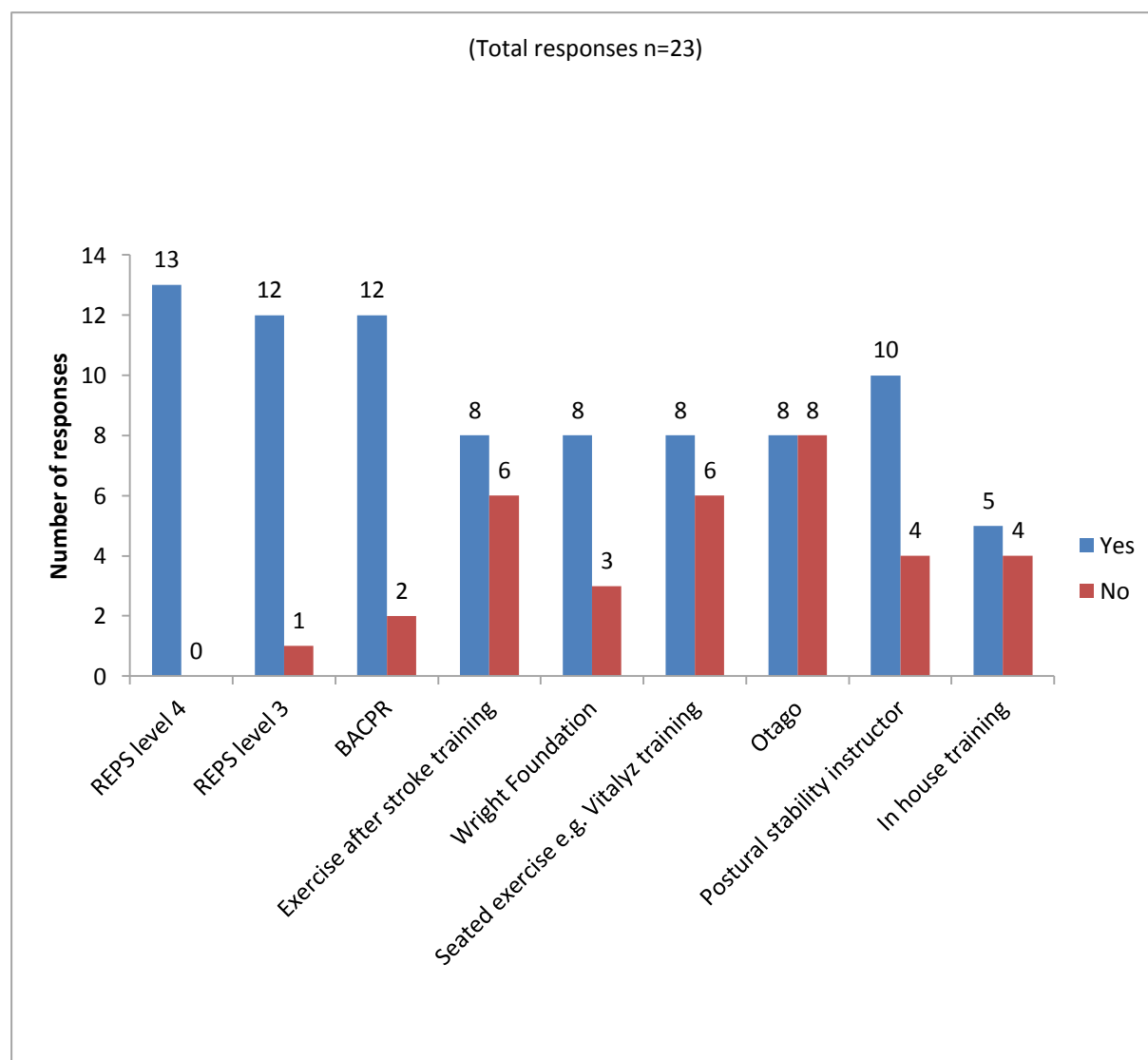
(Total responses n=27)



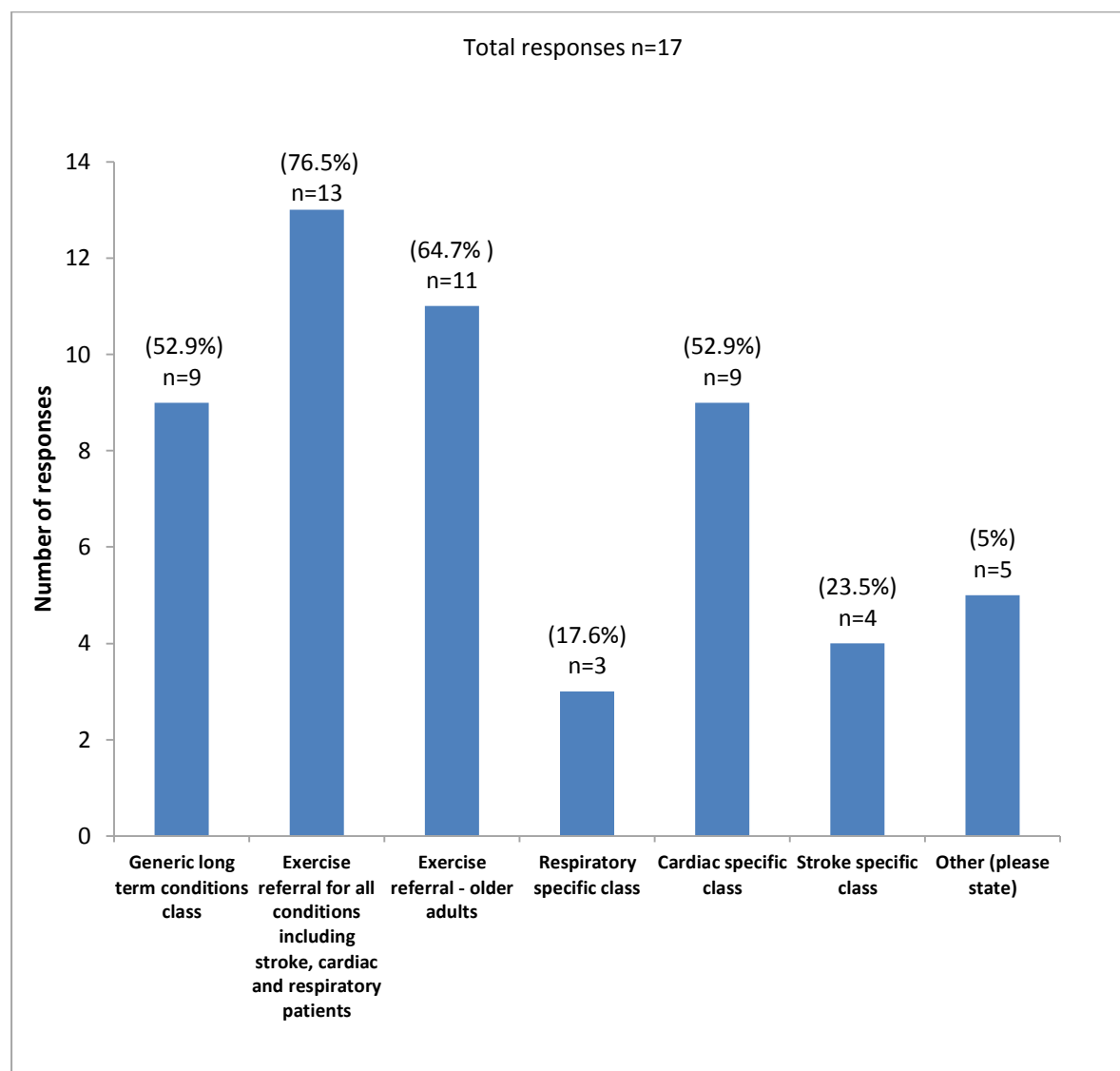
Q7. Please state NUMBERS PER ANNUM by condition going through your service indicating the year and whether the calendar or financial year, e.g. 80 respiratory, 2010-11, Jan-Dec



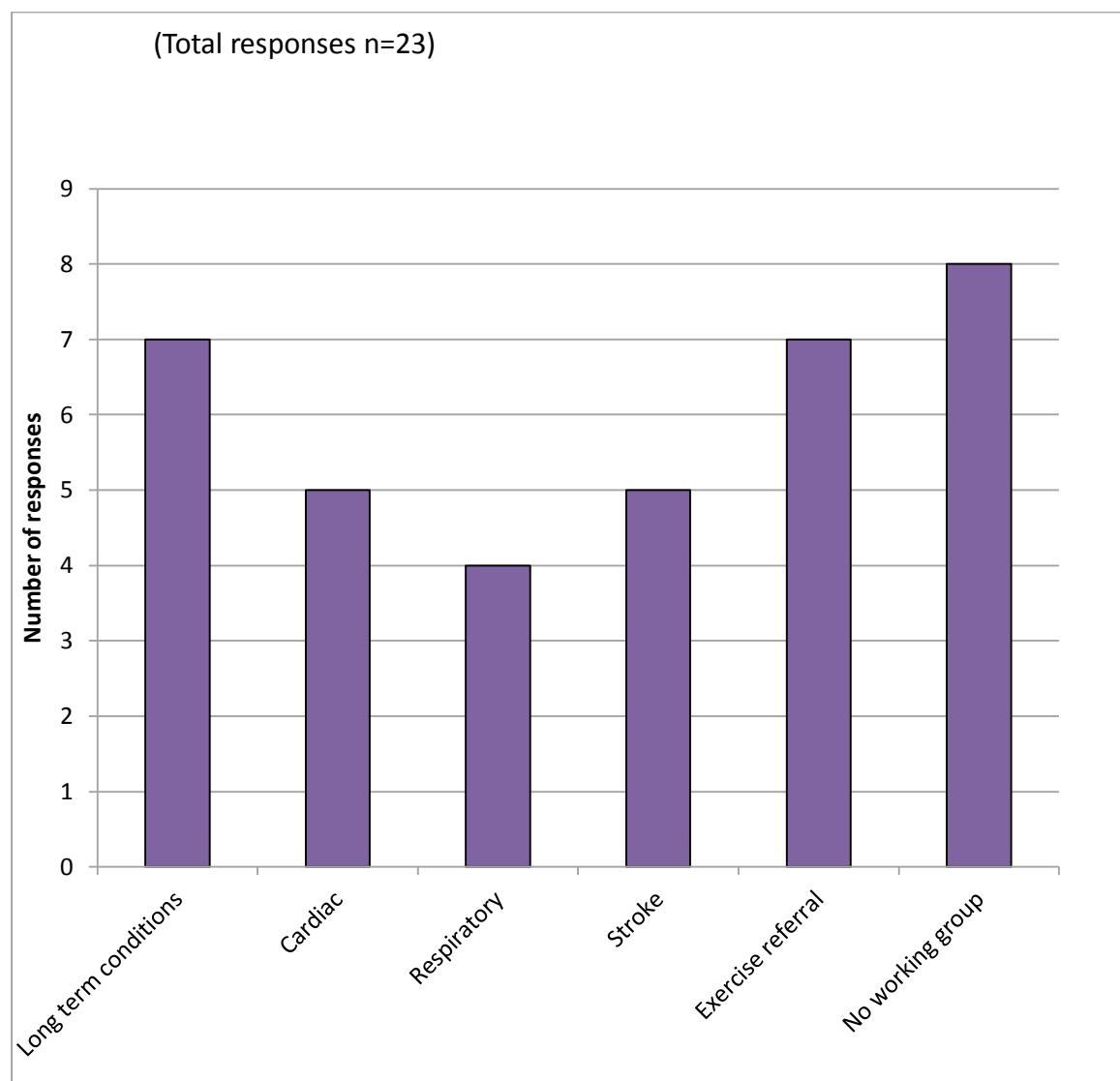
Q8. Do you know what qualifications specialist instructors have that deliver exercise community maintenance classes? If known please indicate the number of instructors who hold this qualification.



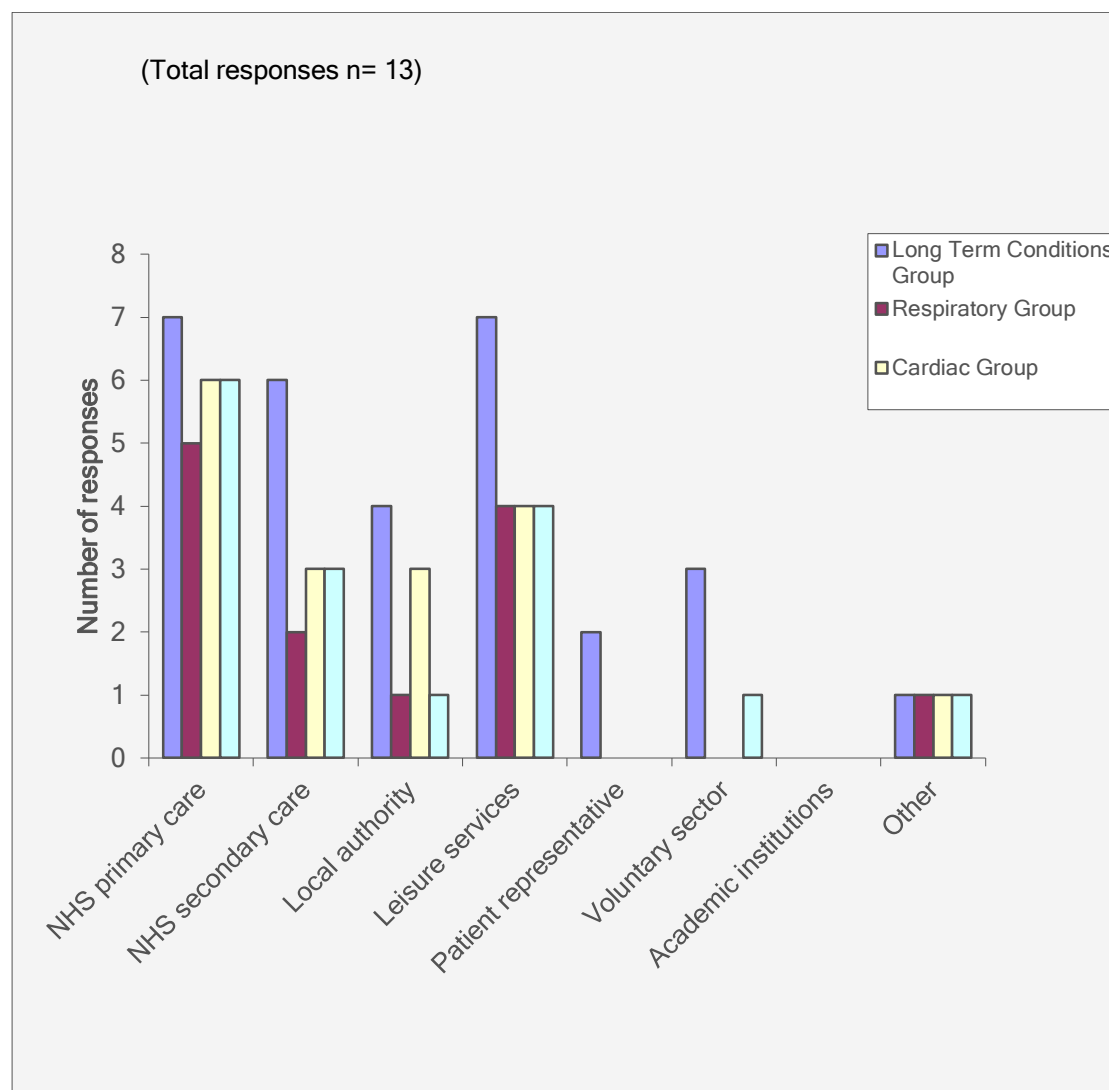
Q9. Is there a service co-ordinator in your region for the management and delivery of exercise maintenance? Please tick any/all that apply.



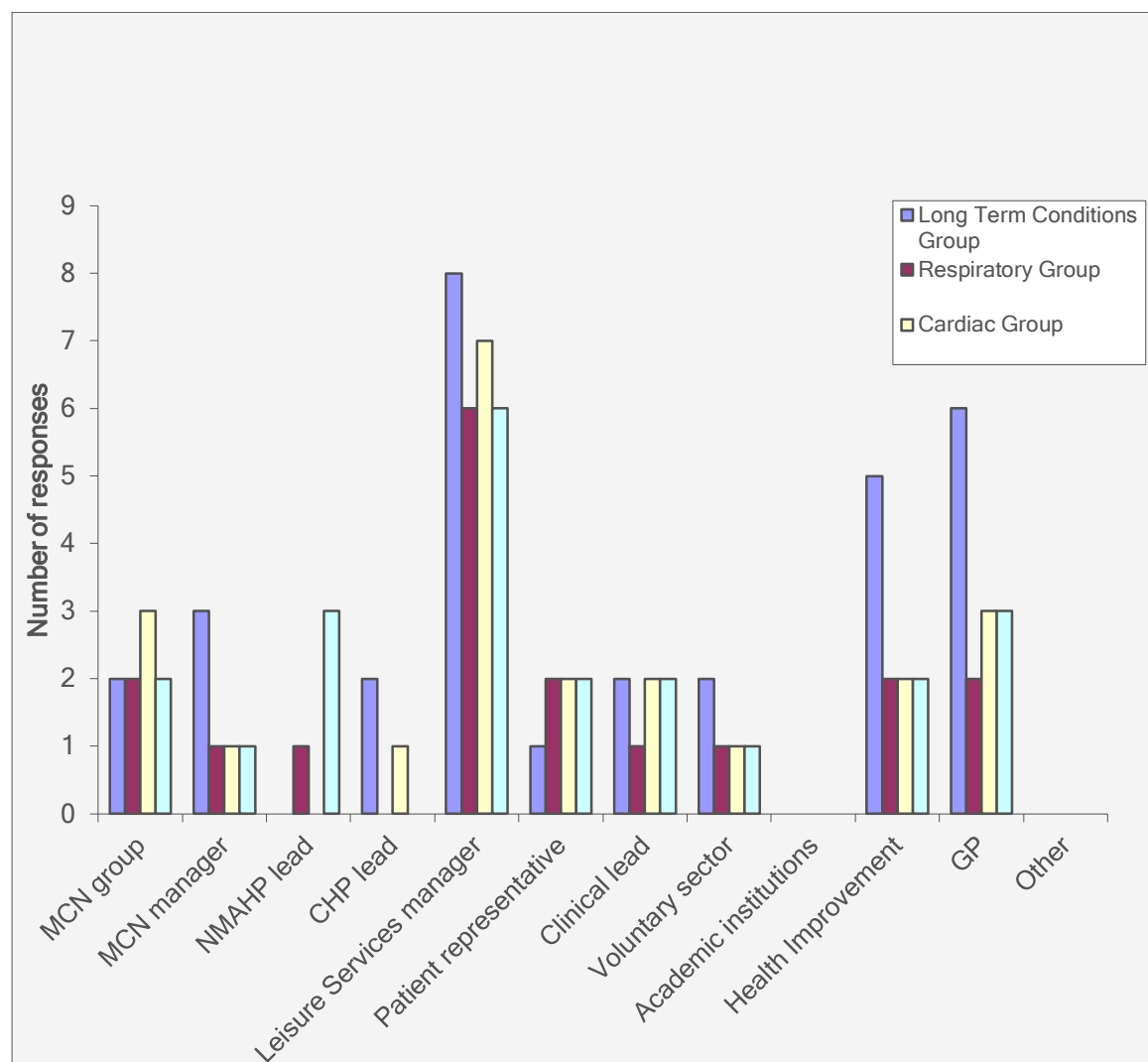
Q10. Is there a collaborative working group for exercise maintenance in your region?
Please tick any/all that apply.



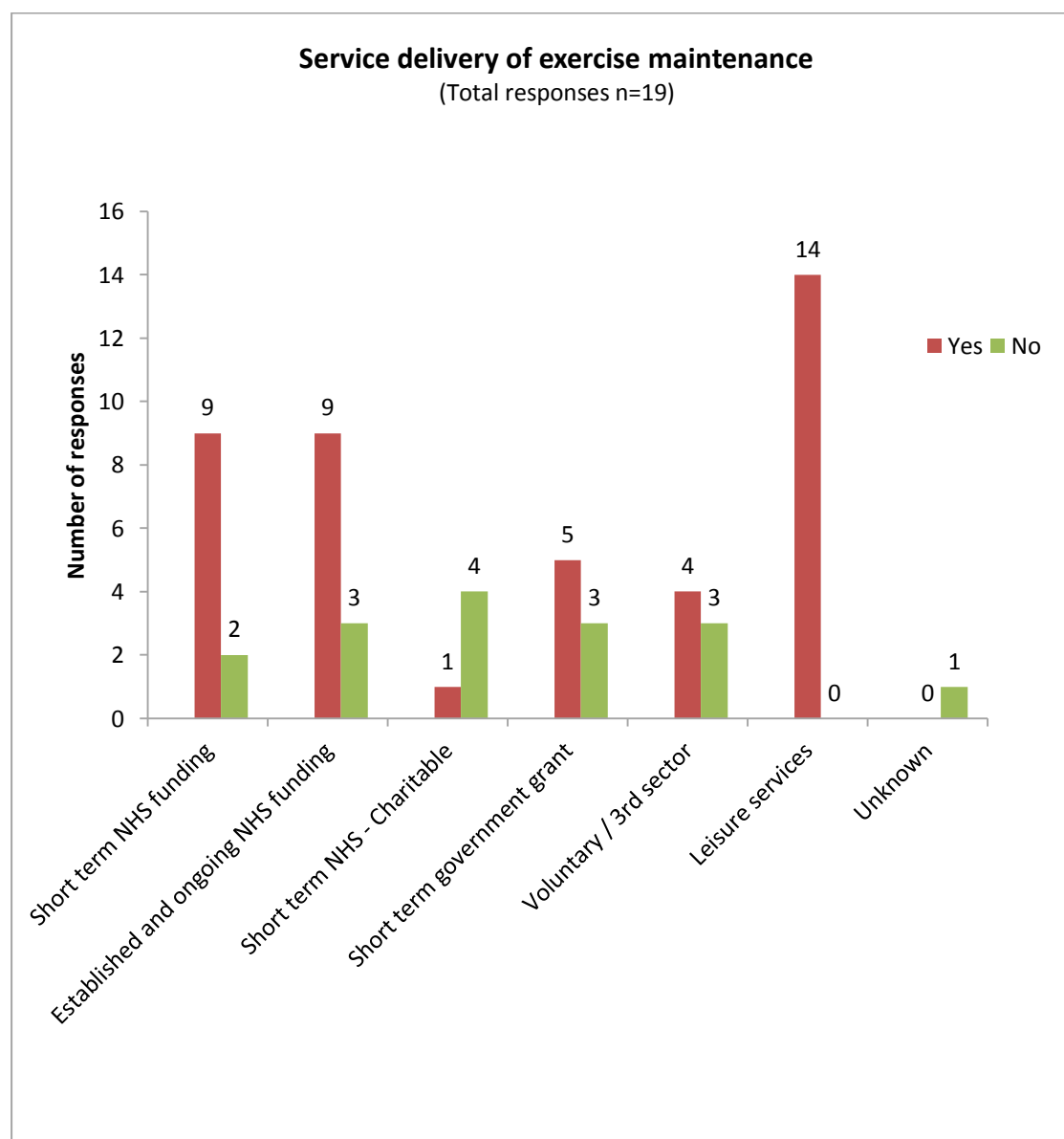
Q11. Which organisations are members of the collaborative working group for exercise maintenance in your region? Please tick any/all that apply.



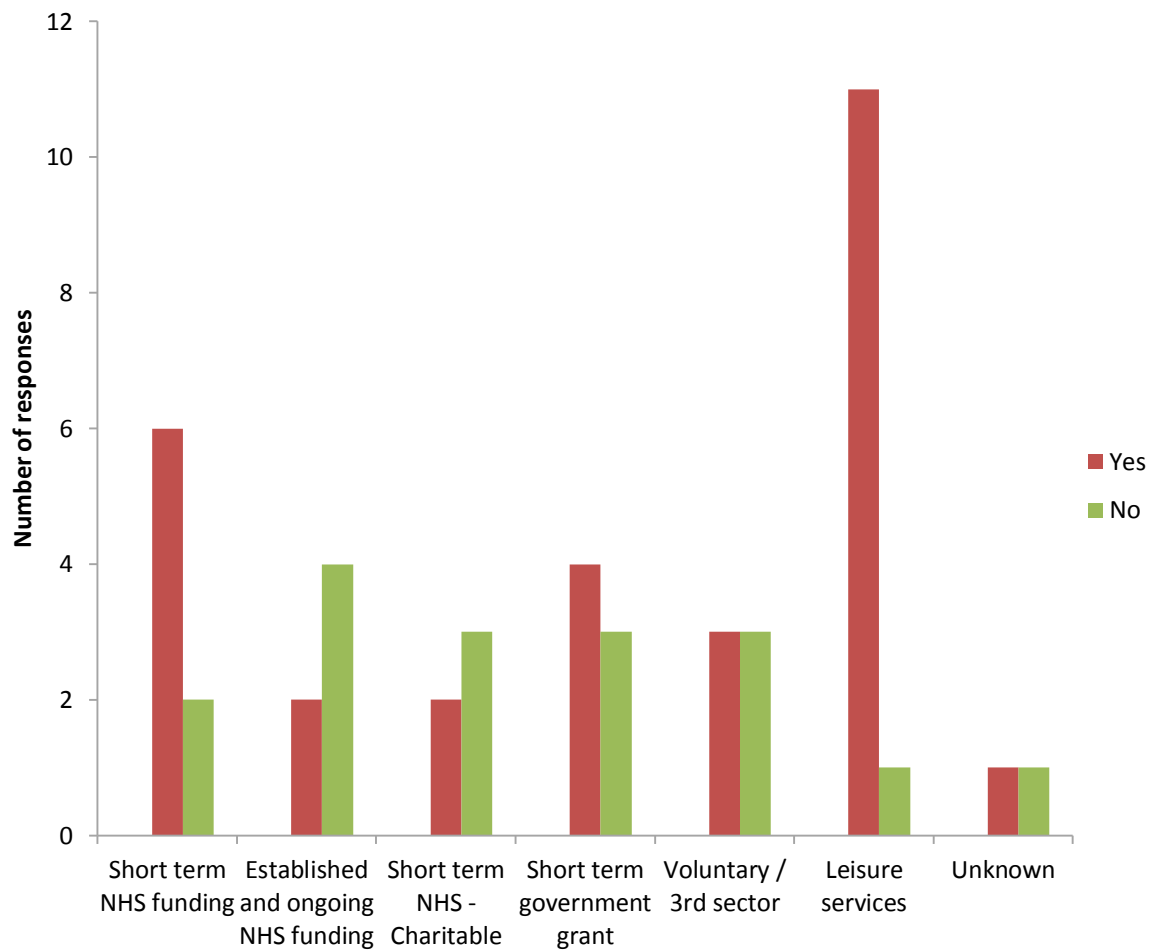
Q12. Which roles are involved in service delivery of exercise maintenance in your region? Please tick any/all that apply.



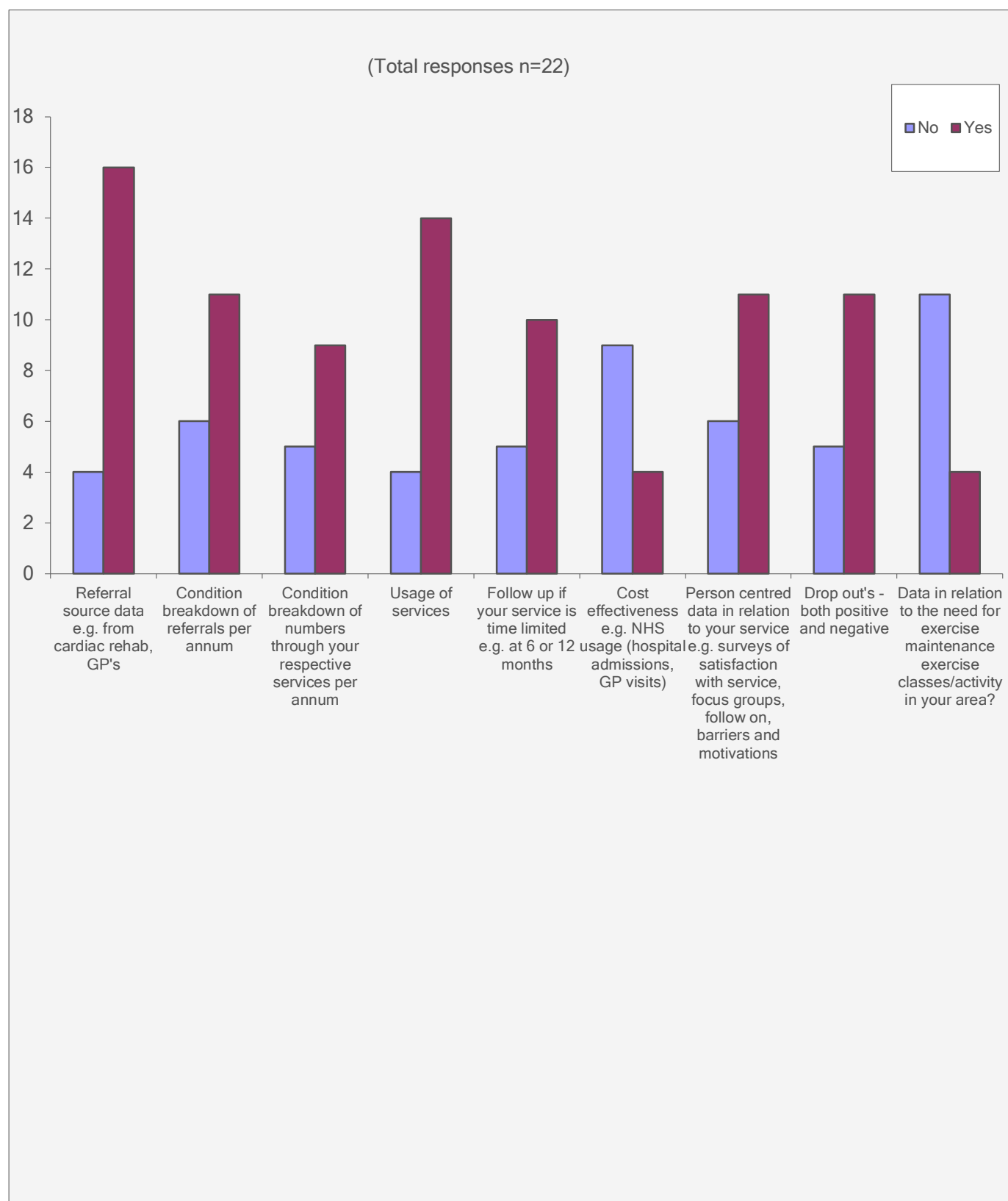
Q13. Who are the funding partners for the following in your region?



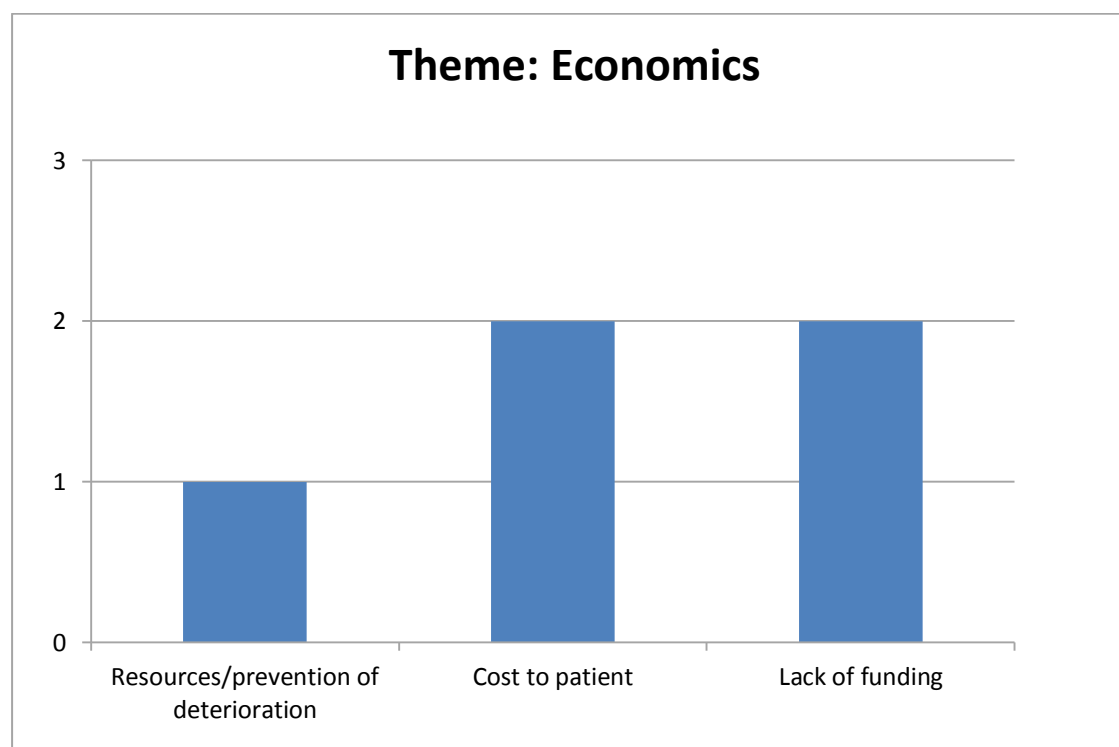
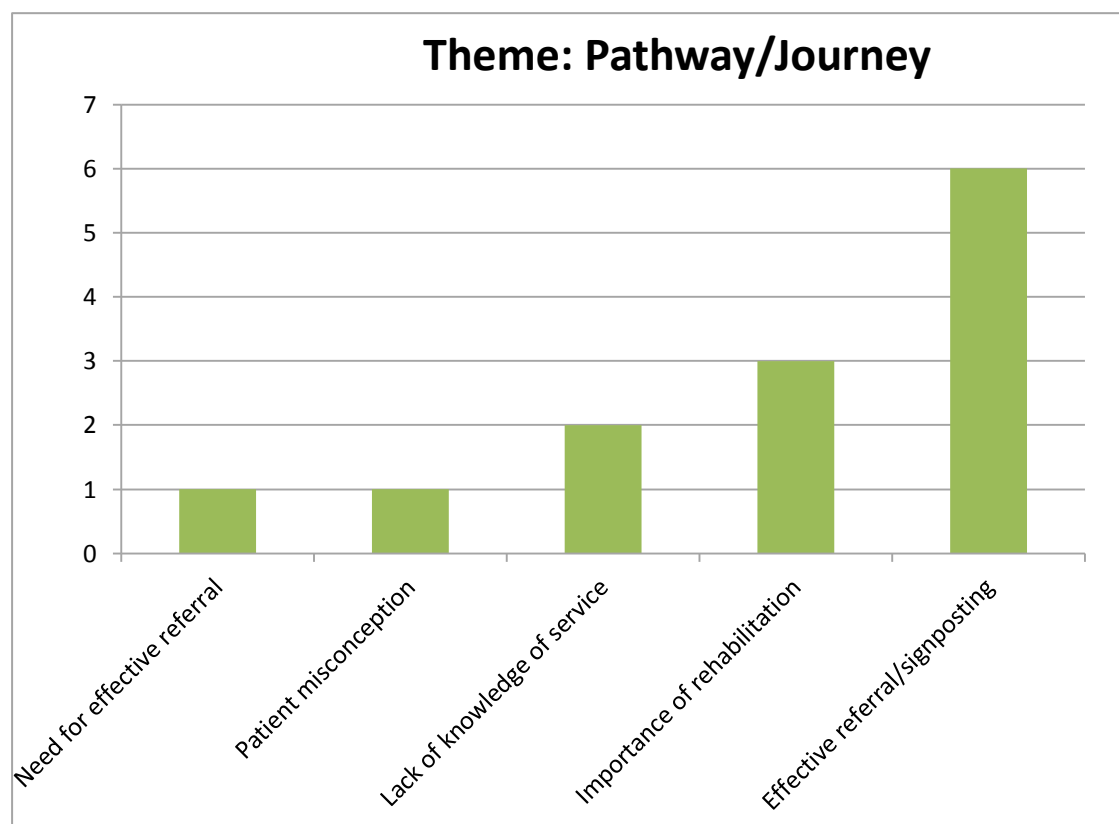
Who are the funding partners for the following in your region?
Specialist Instructor training for exercise maintenance
 (Total response n=19)



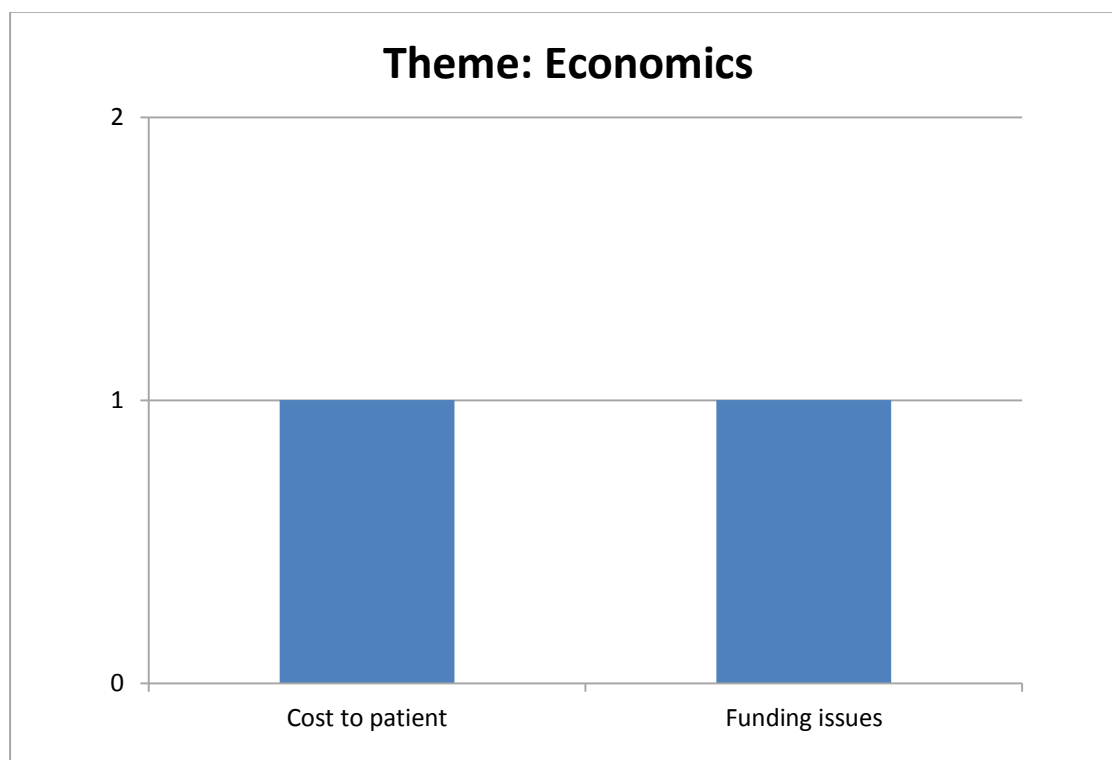
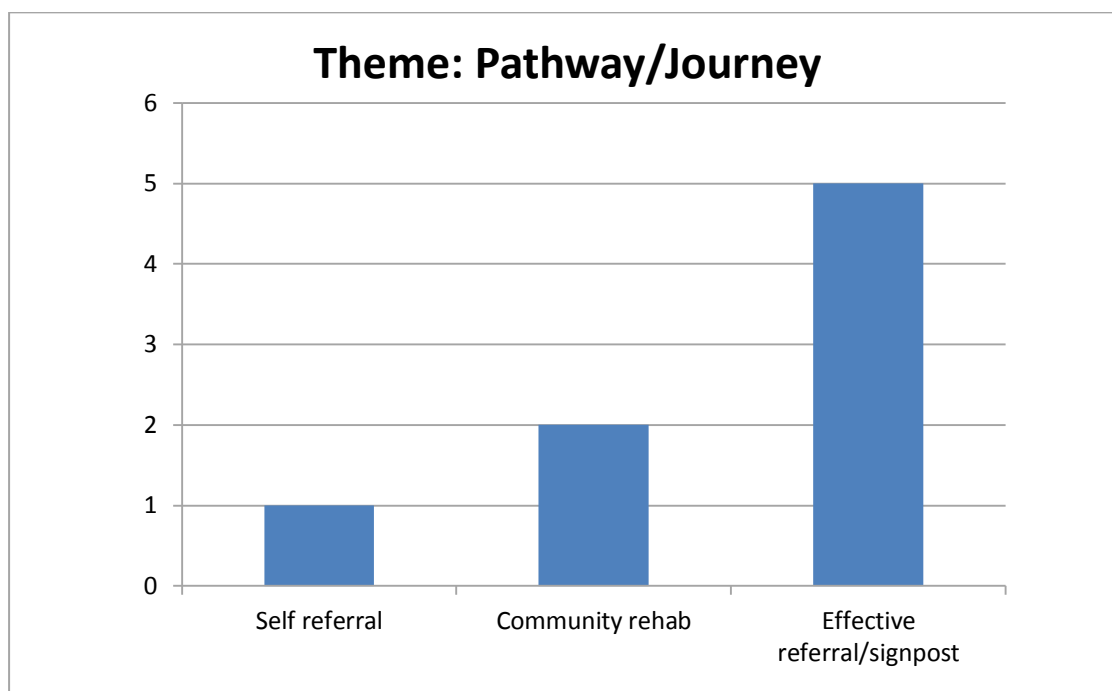
Q14. Do you collect any evaluation data for the following?



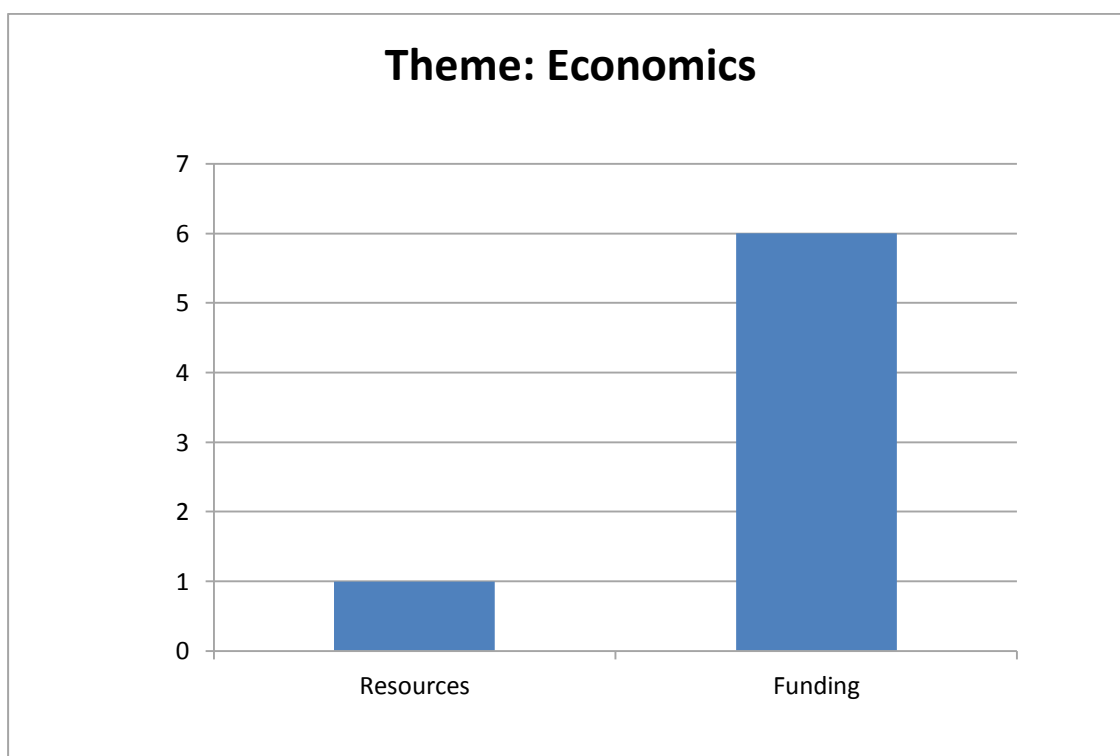
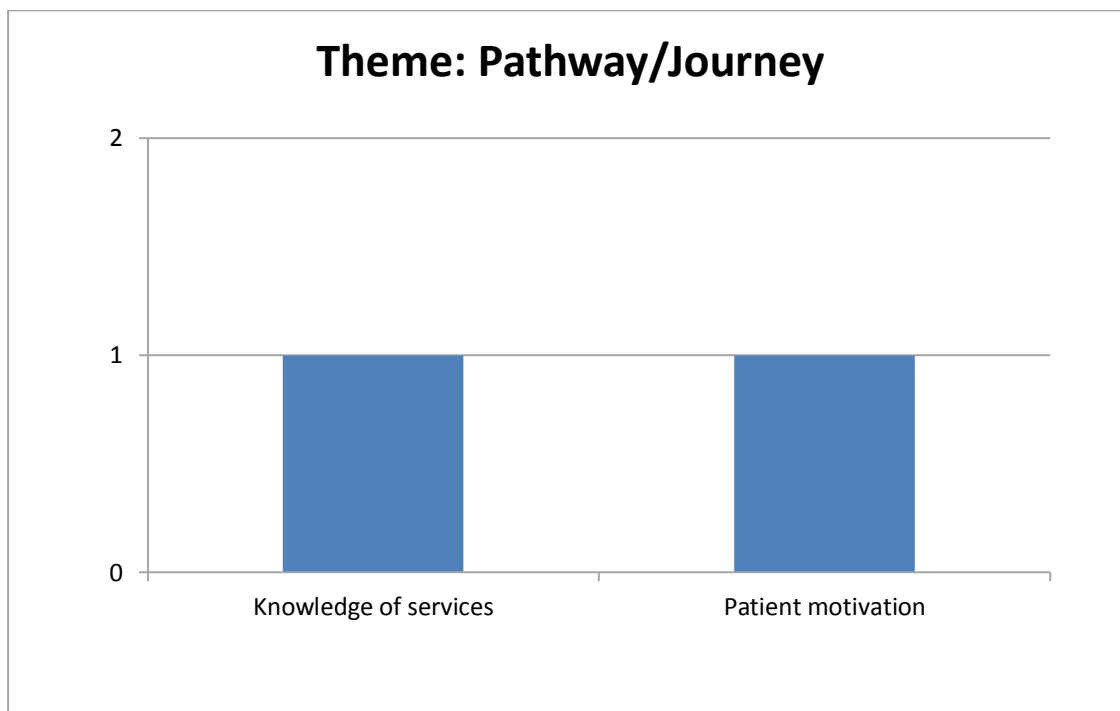
Q15. Please give a comment to SUMMARISE your understanding of access to and service provision of EXERCISE MAINTENANCE that follow on from clinical rehabilitation in your area.



Q16. Please comment on KEY SUCCESSES e.g. delivery, usage, adherence, innovators, in relation to Exercise Maintenance:



Q17. Please comment on CHALLENGES e.g. data collection, lessons learnt, in relation to Exercise Maintenance:



**RESULTS OF RESPONSES FROM CHSS AFFILIATED GROUPS SERVICE USER
QUESTIONNAIRE**

**FOR SECTIONS - ABOUT YOUR GROUP(S), PHYSICAL ACTIVITY AND HEALTH,
EXERCISE & ACTIVITY GROUPS & SUPPORT GROUPS**

Service User Survey – Total responses n= 221 from CHSS affiliated groups

Condition	Number of responses
Cardiac	n = 143
Respiratory	n = 53
Stroke	n = 25
Co – morbidities – classified as those with a combination of either a cardiac condition, a respiratory condition, or a stroke	n = 21

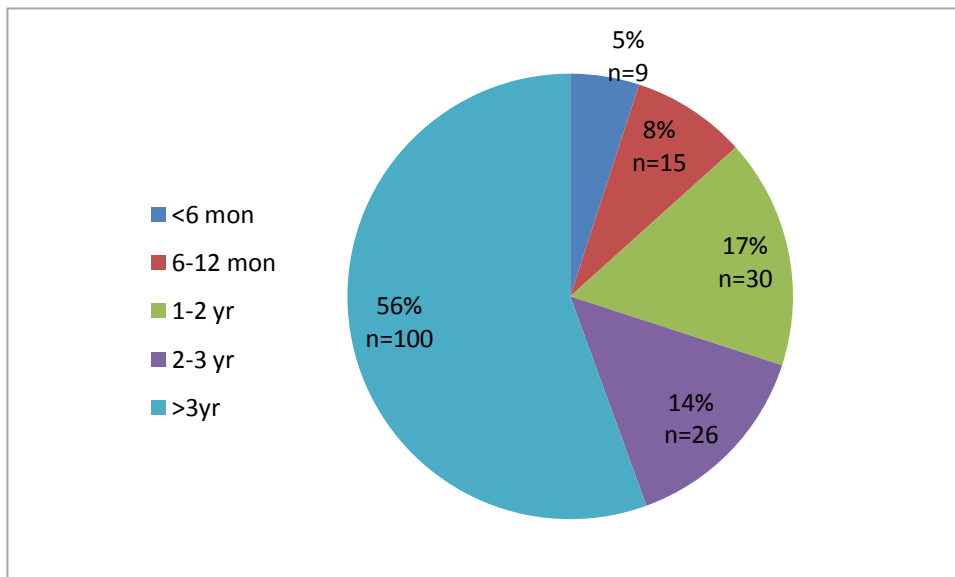
Breakdown of respondents by type of group	Number
Attending an exercise group	181
Attending a support group	106
Not attending an exercise or a support group	1

The following charts and graphs are the overall results of responses (n=221), i.e. for those with a cardiac, respiratory condition or stroke, not broken down by condition.

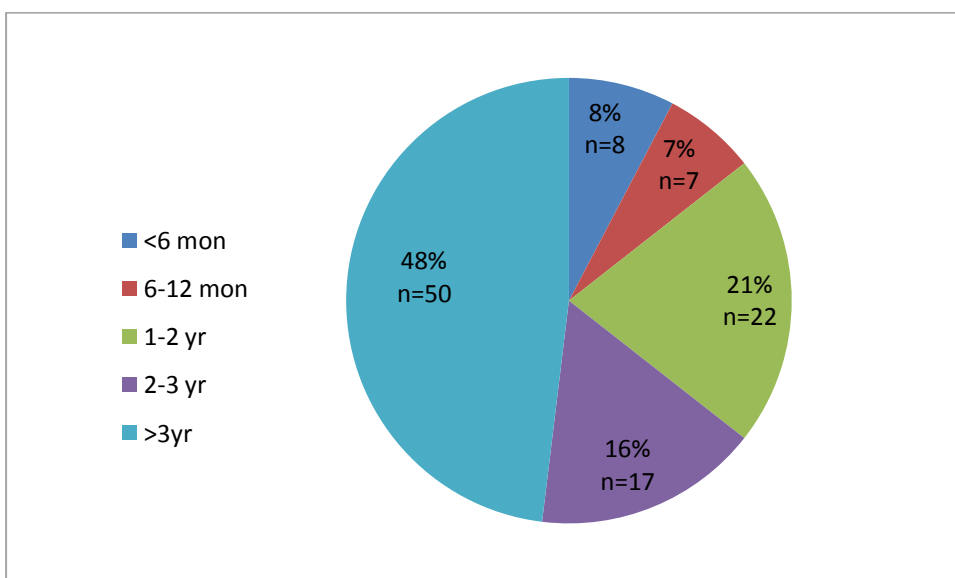
Results of responses to questions

SECTION - YOUR GROUPS

How long have you being attending an exercise class/activity group?

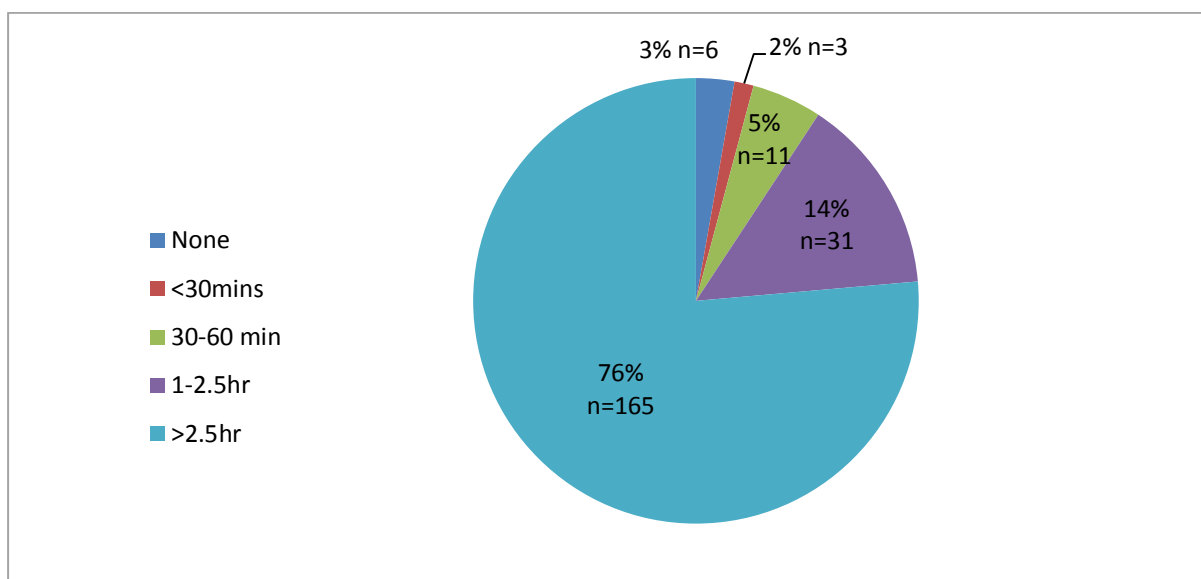


How long have you being attending a support group?

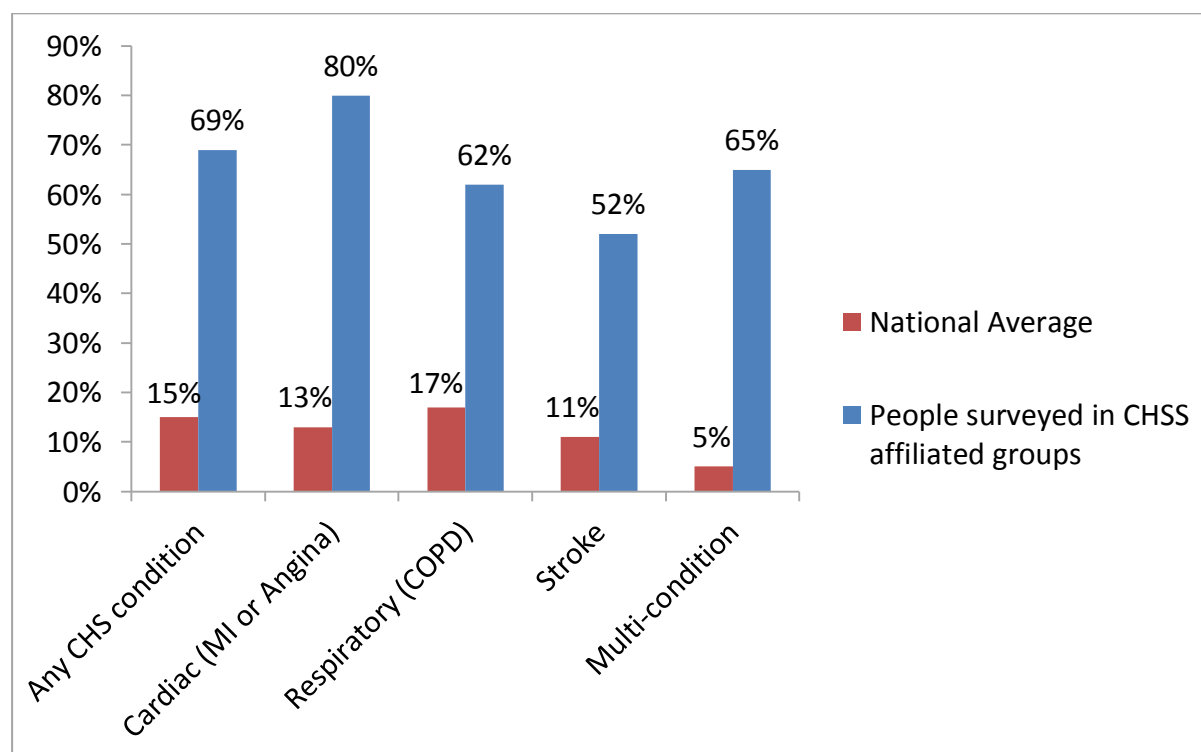


SECTION A - PHYSICAL ACTIVITY AND HEALTH

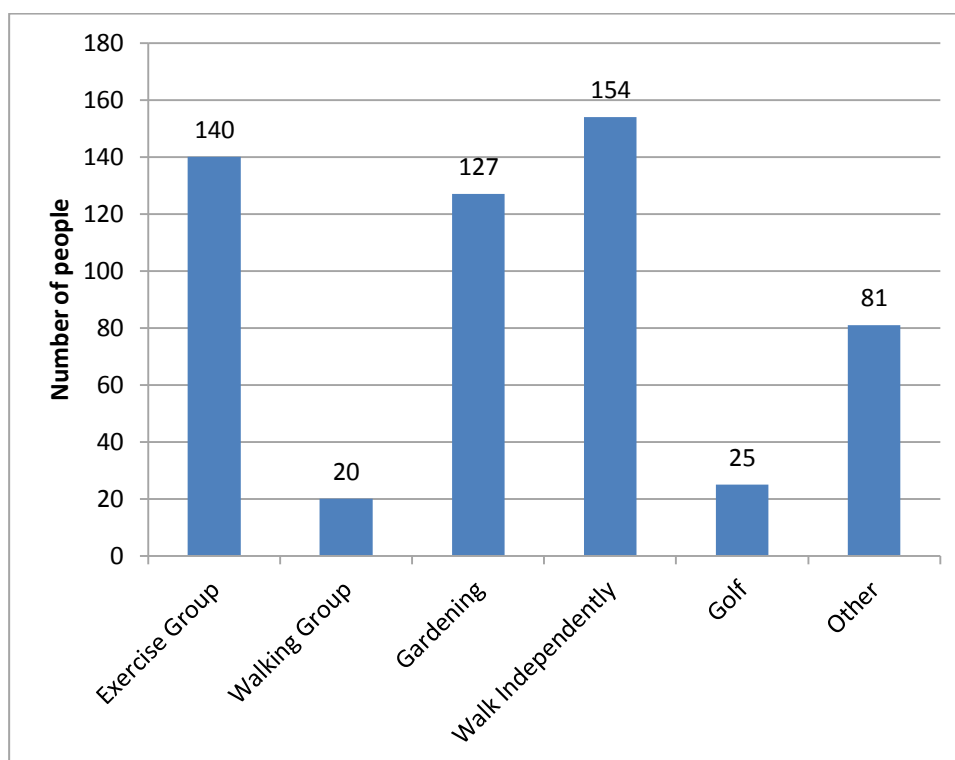
Q1. Physical activity includes walking, active household chores, and sport and leisure activity. How much time do you spend doing these activities in a week?



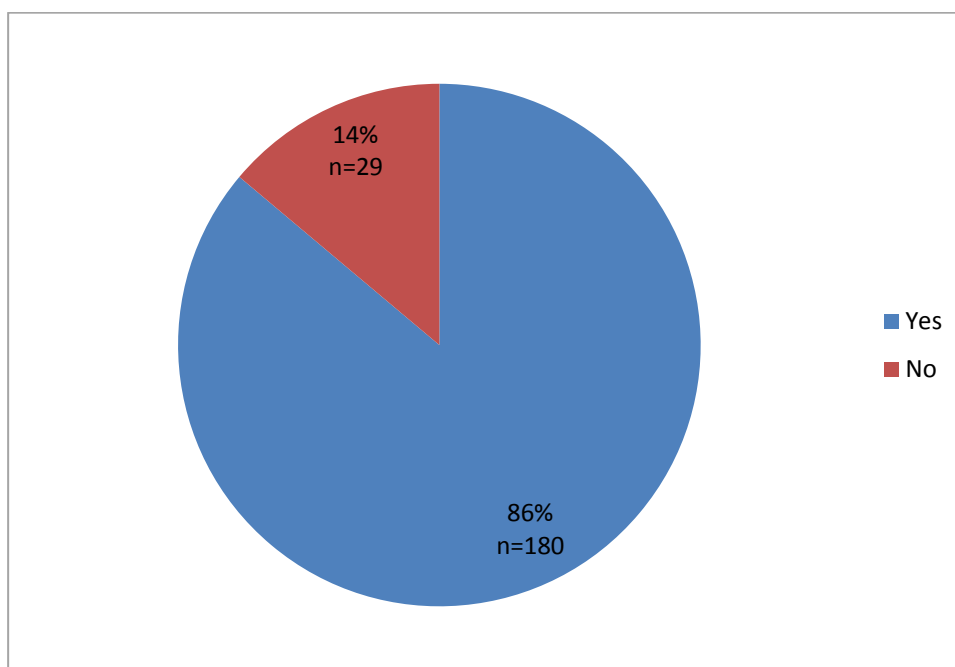
Comparison of amount of physical activity per week compared with the national averages by condition



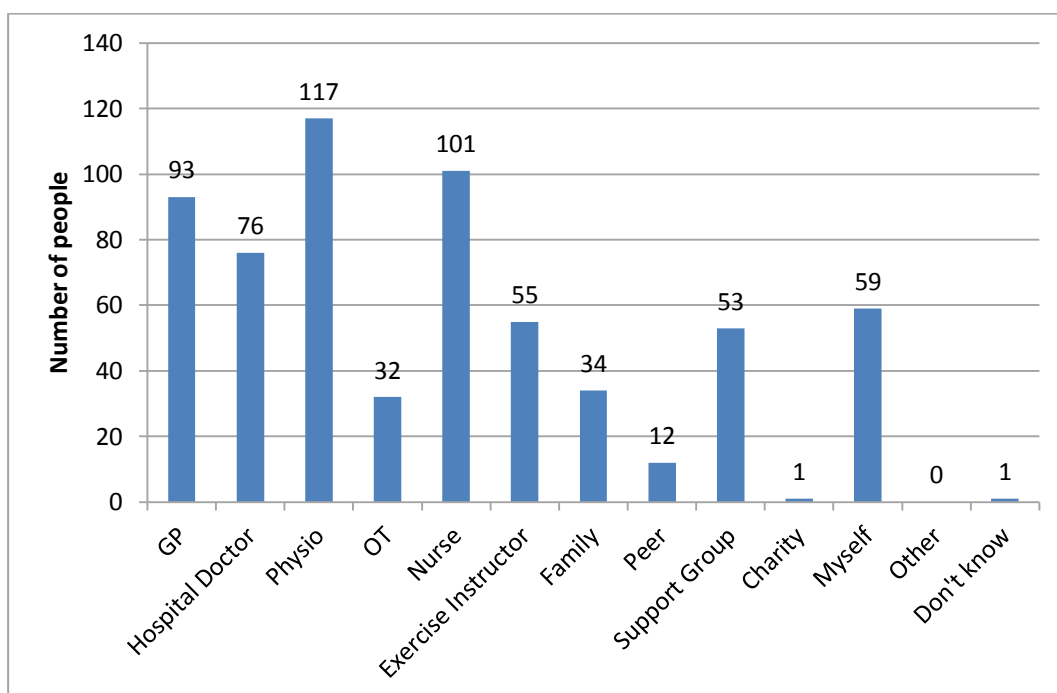
Q2. What type of physical activities are you involved in?



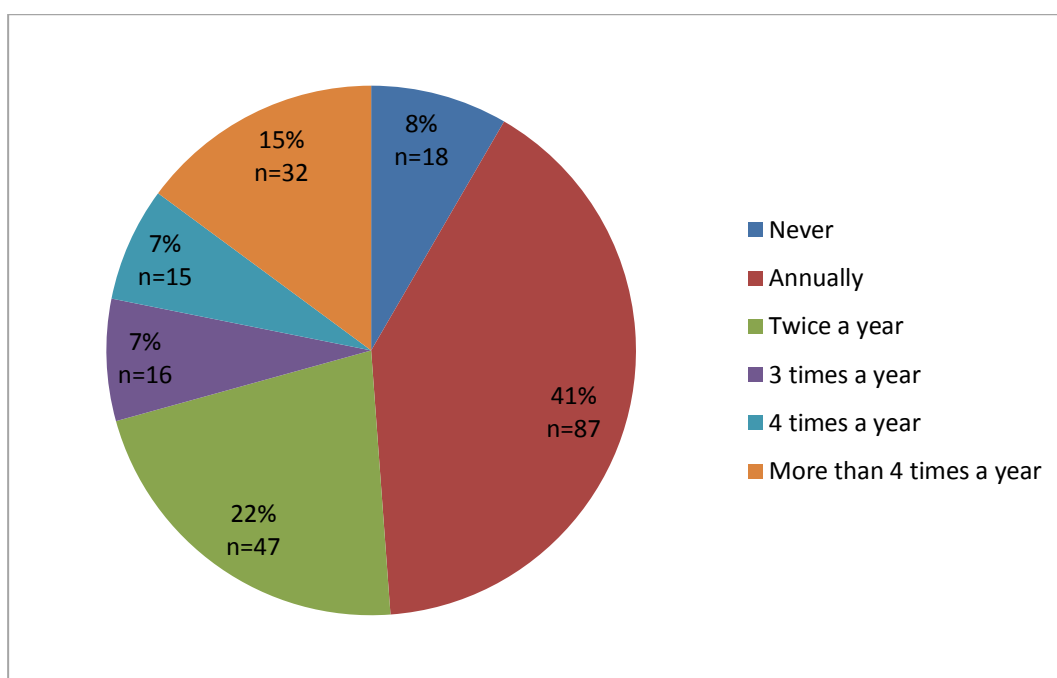
Q3. When you were seen by health care services (NHS) for your condition, were you advised about the importance of physical activity?



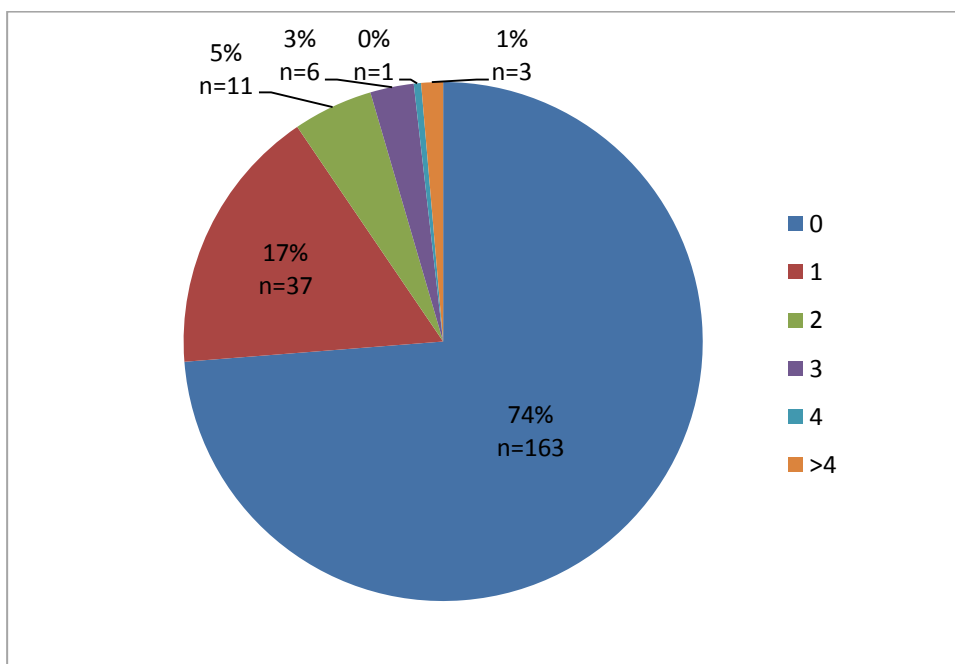
Q4. Who talked to you about the importance of physical activity/exercise?



Q5. How often do you visit your GP?

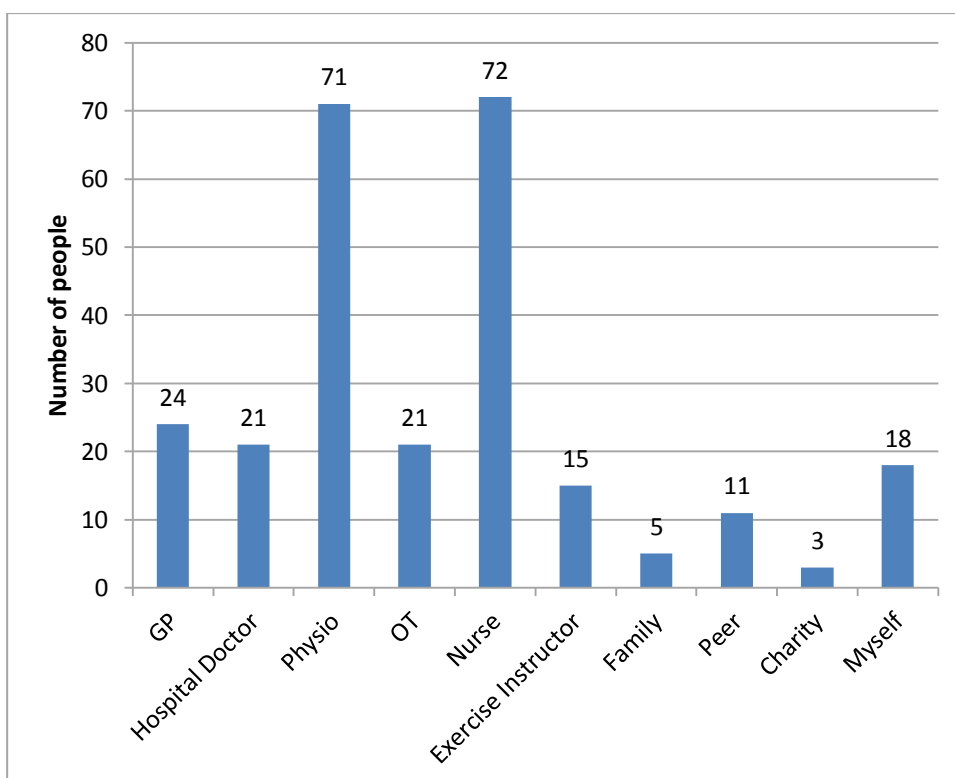


Q6. How many hospital admissions have you had in the last year?

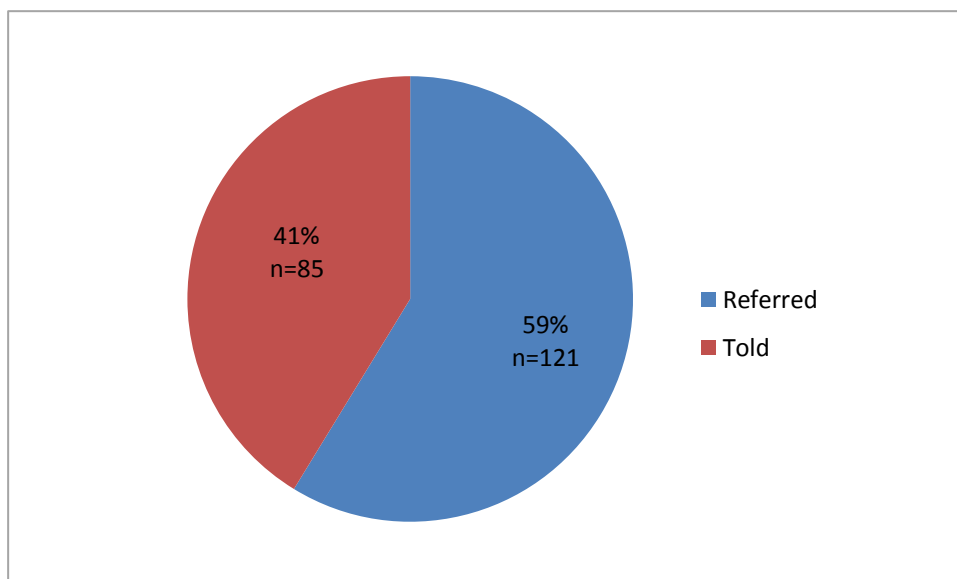


SECTION B – EXERCISE CLASS/ ACTIVITY GROUPS

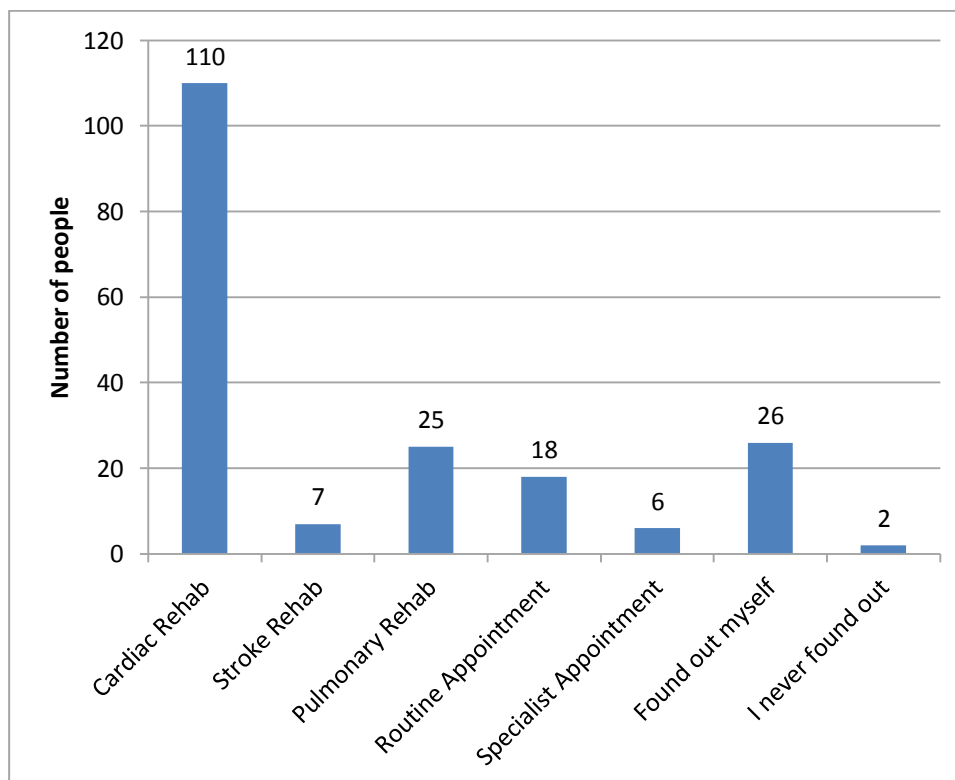
Q7. How did you find out about an exercise class suitable for your condition in your area?



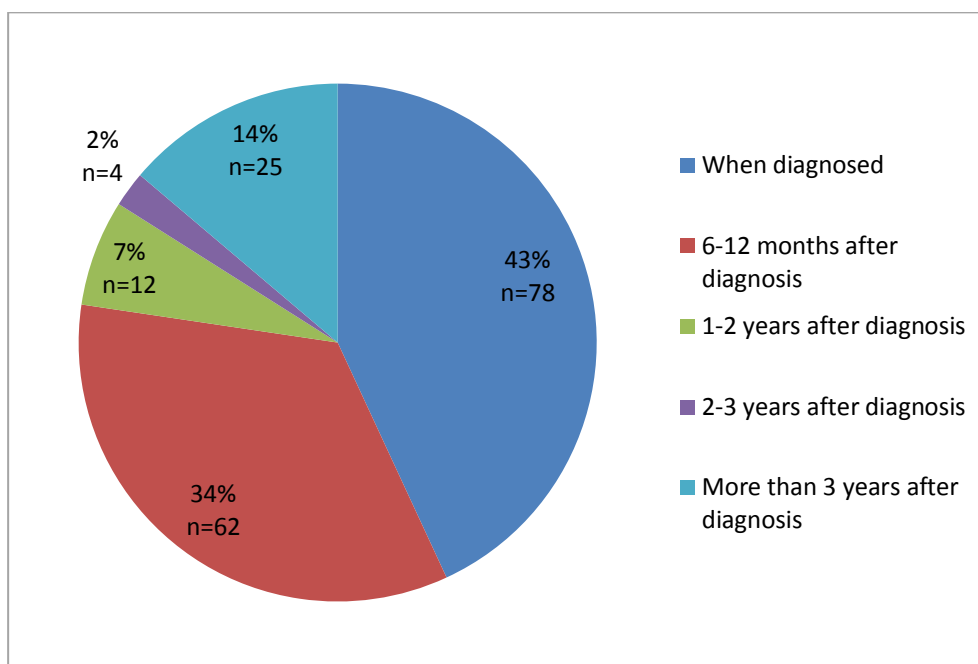
Q8. Did a Health service/NHS professional (e.g. doctor, nurse, and physiotherapist) formally refer you to an exercise maintenance class or tell you about an exercise maintenance class?



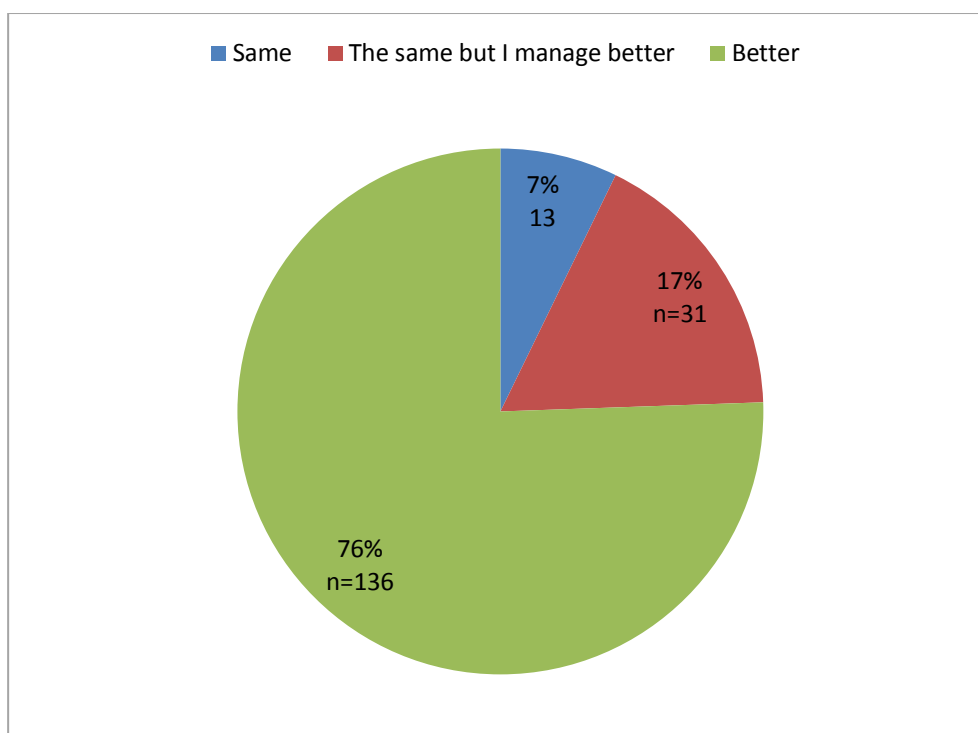
Q9. Where did you find out about your exercise class?



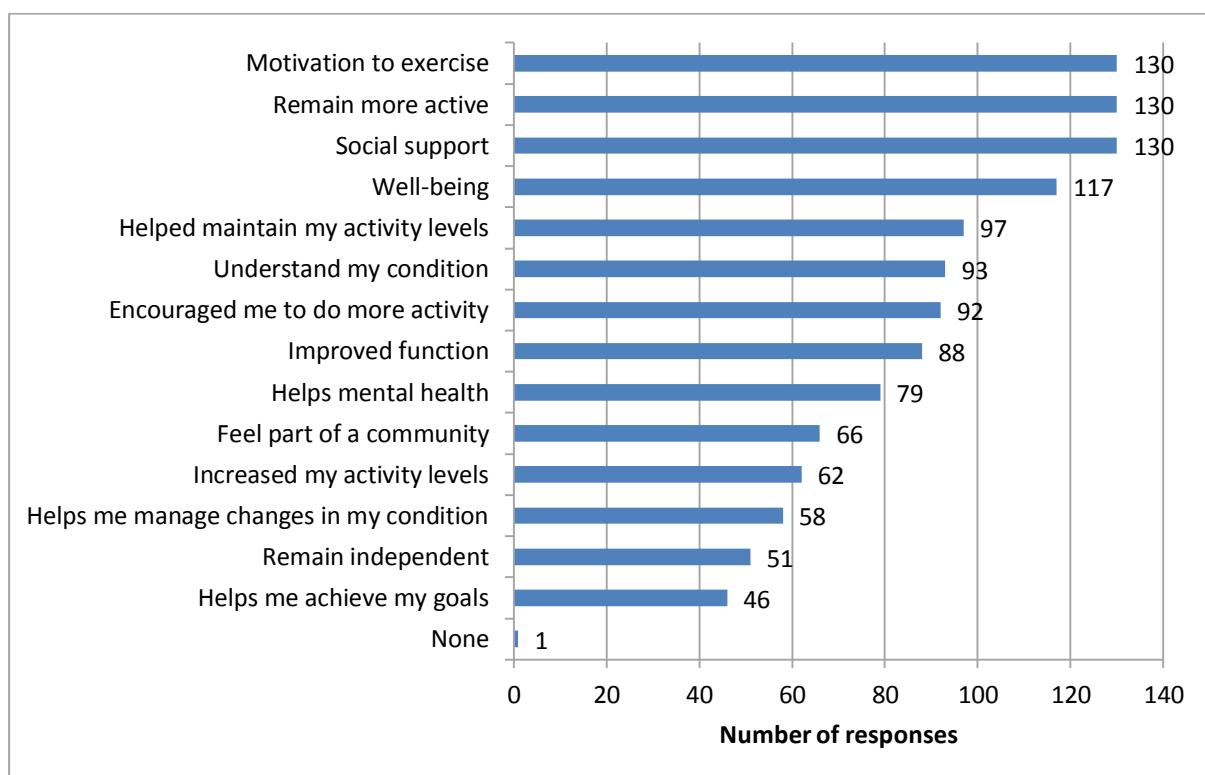
Q10. When in relation to your diagnosis did you find out about a suitable exercise class?



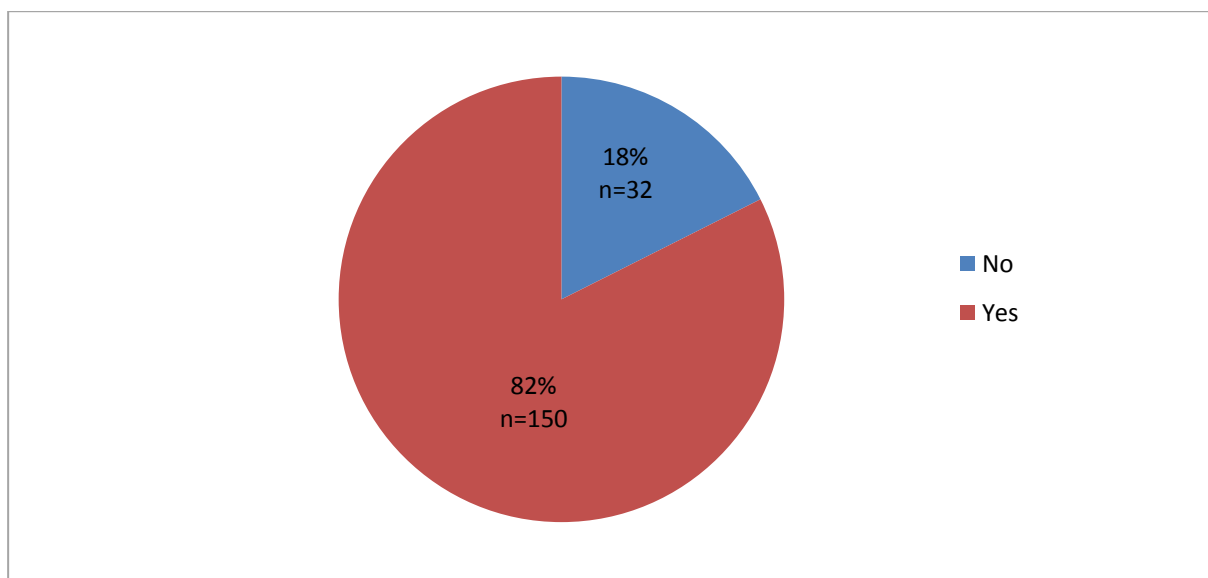
Q11. How do you feel your condition is since joining this exercise class?



Q12. What are the benefits of being part of this exercise class?

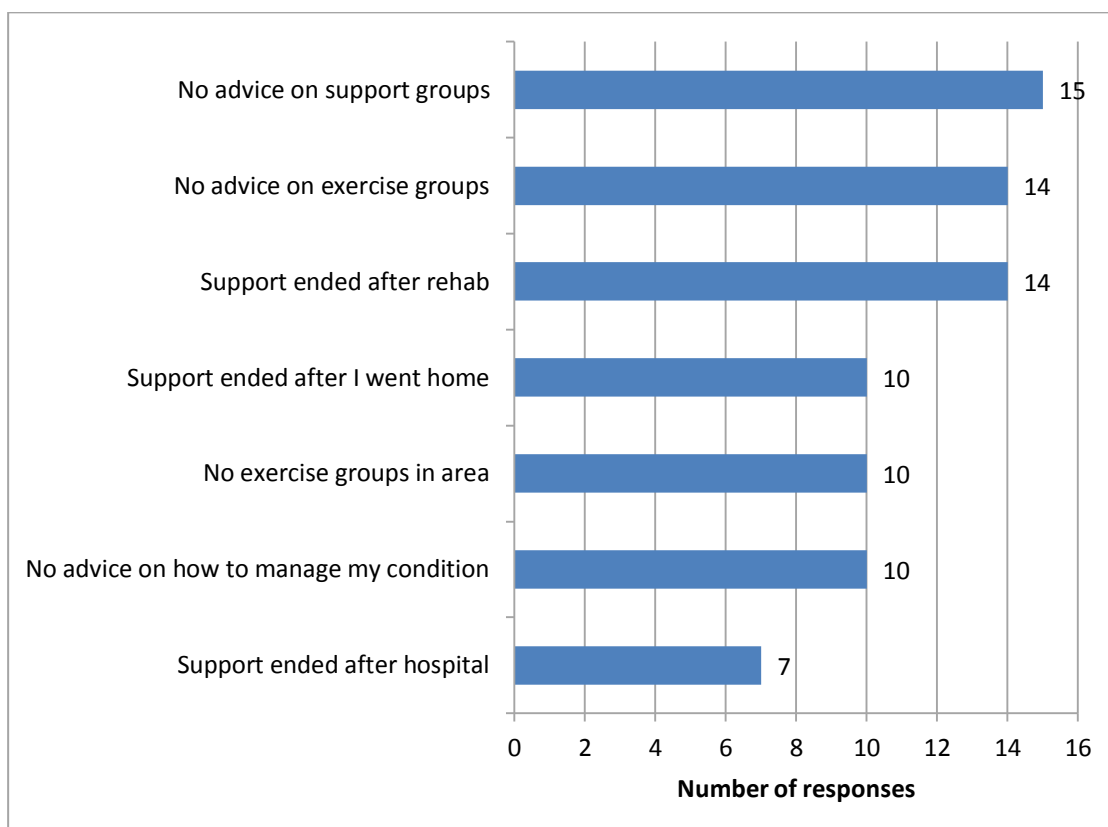


Q13. - Was there an easy move from hospital health care services to community support (including maintenance exercise/activity and advice on self management?)



If the answer to the above question was no, respondents were asked Q14

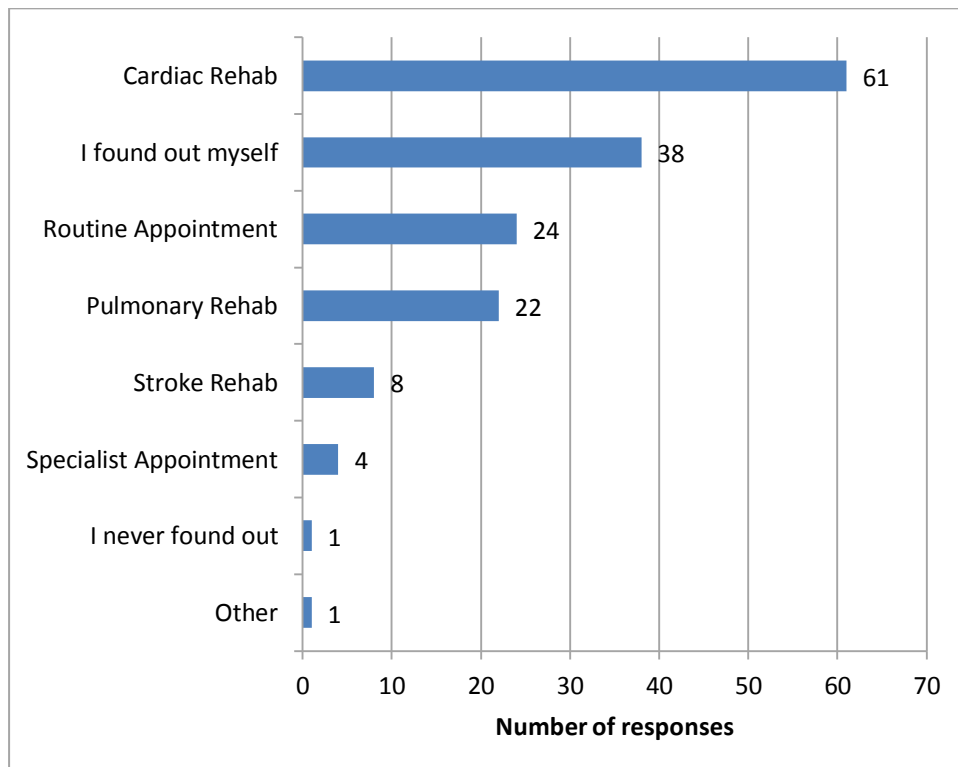
Q14. What were the issues that prevented an easy transition to community support?



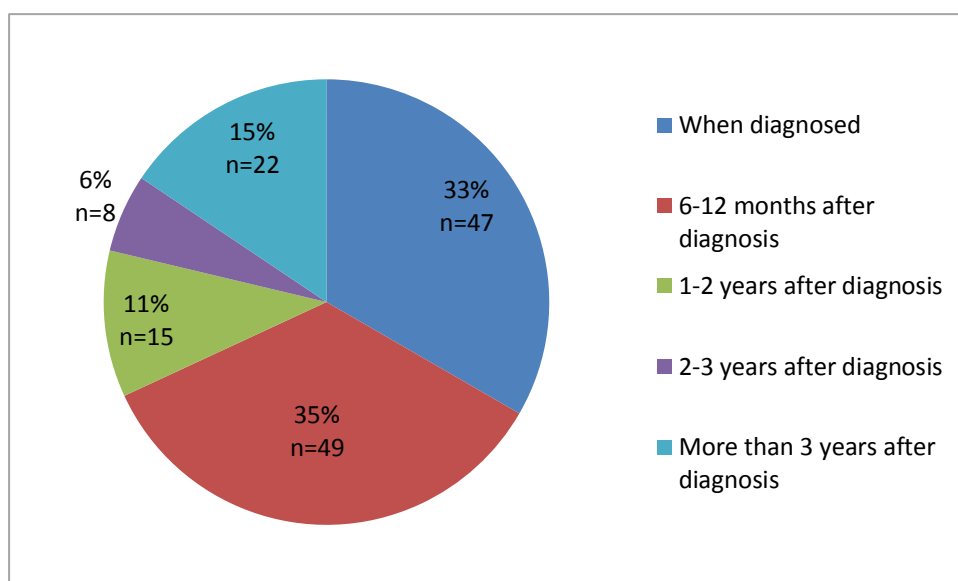
RESULTS OF RESPONSES FROM CHSS AFFILIATED GROUPS SERVICE USER QUESTIONNAIRE

FOR SECTION C– SUPPORT GROUPS

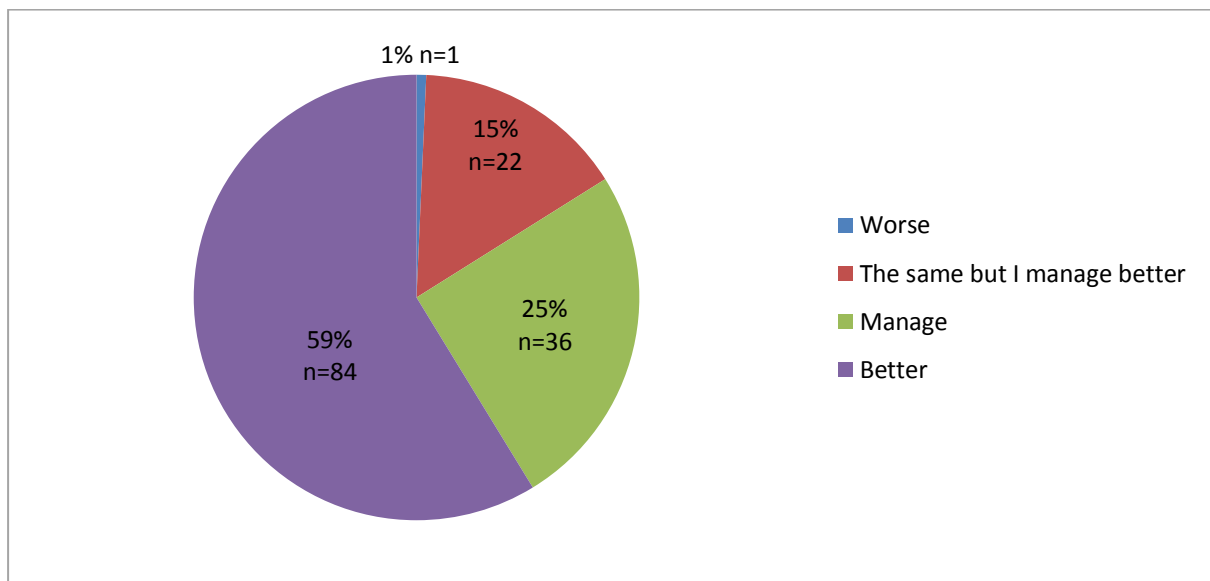
Q15. Where did you find out about your support group?



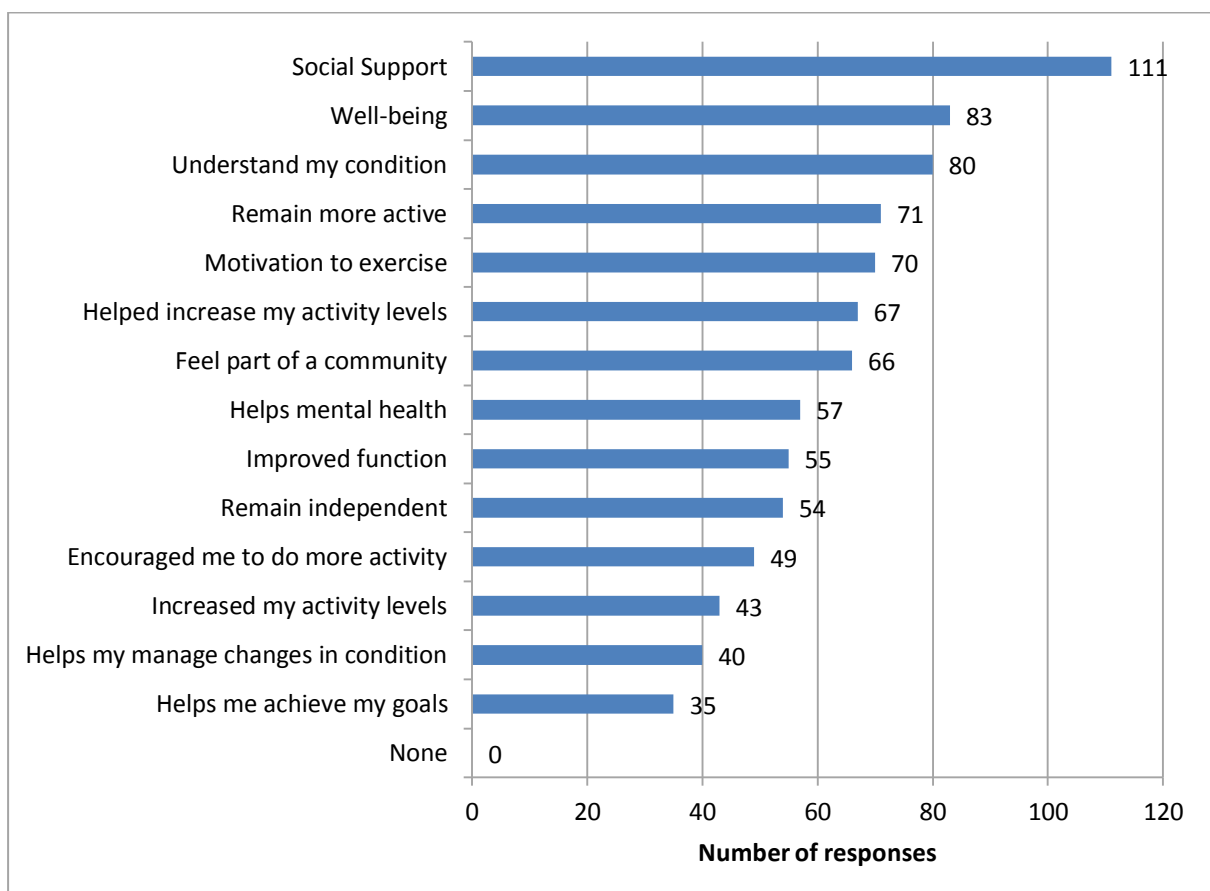
Q16. When in relation to your diagnosis did you find out about a suitable support group?



Q17. How do you feel your condition is since joining this support group?

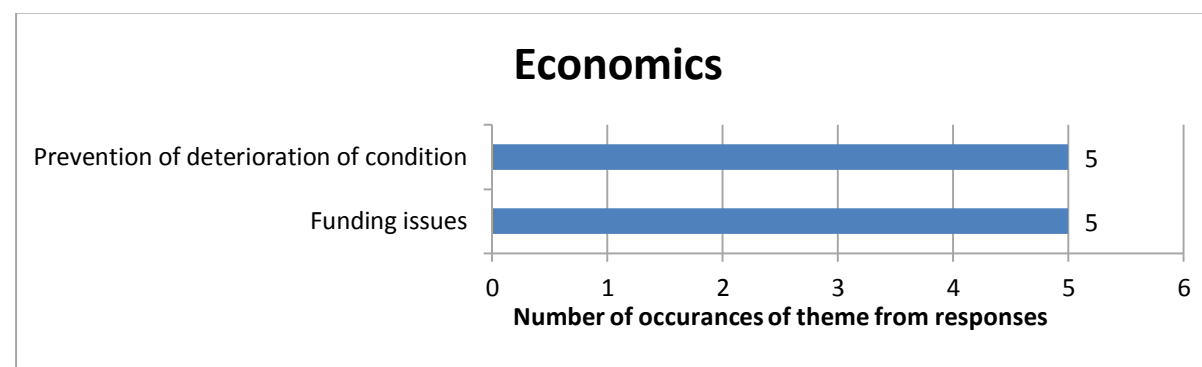
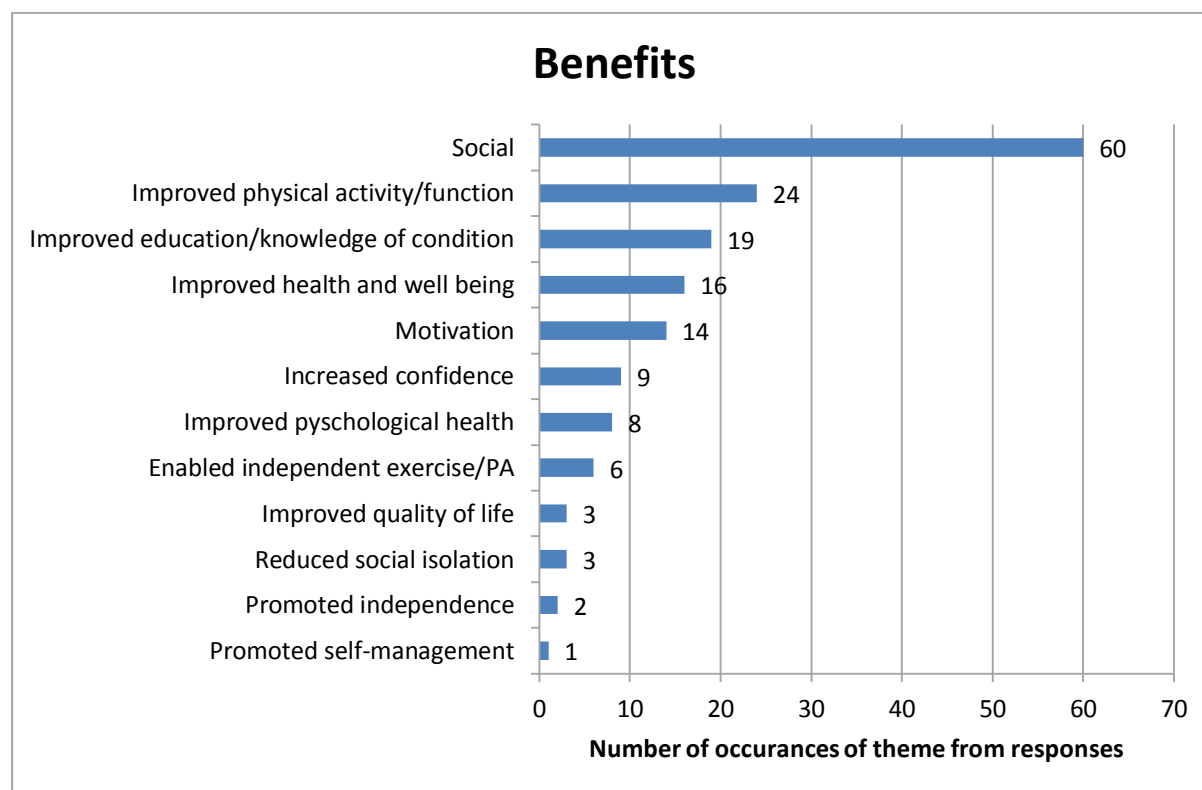


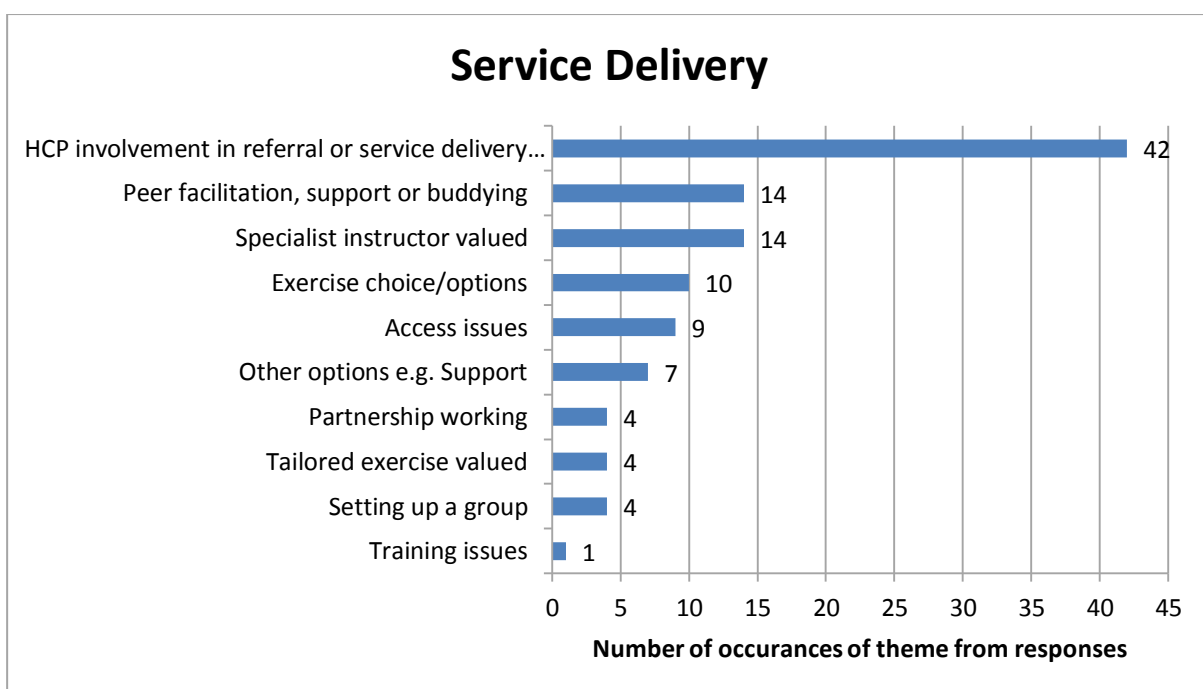
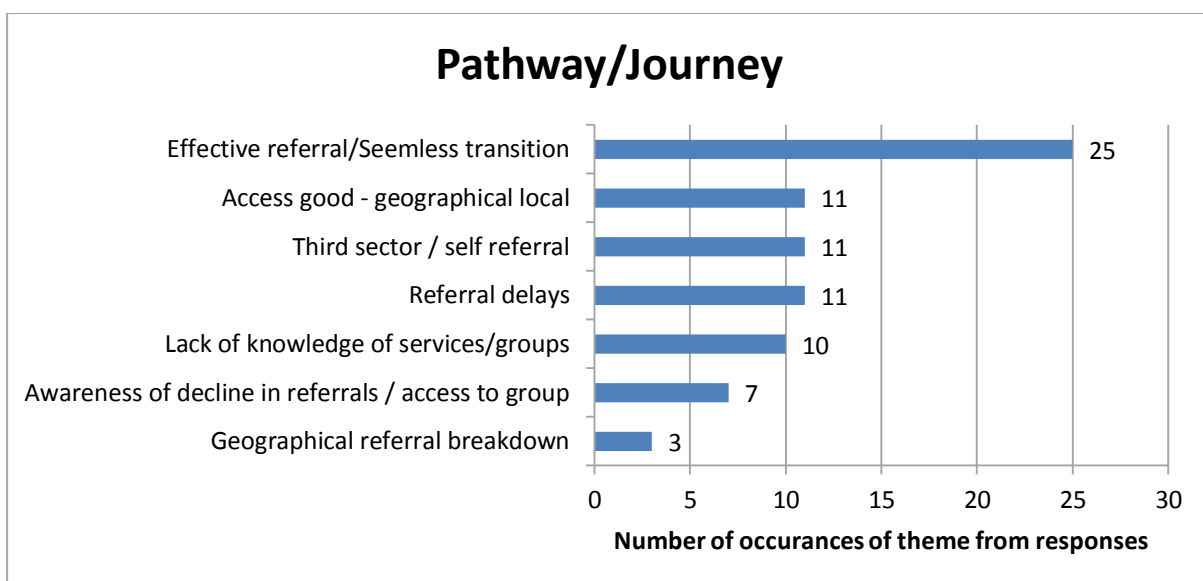
Q18. What are the benefits of being part of this support group?



Q19. Please summarise your experiences of access to and provision of maintenance exercise/activity groups or support groups in you region in relation to our condition.

Key themes from the free text comments to the above question:





Questionnaires sent to HCPs, GPs, service providers (mainly leisure) and service users are available on request. Please contact Sarah Florida-James: sarah.florida-james@chss.org.uk

APPENDIX 6 – MEETINGS/FOCUS GROUPS WITH SERVICE USERS AND POTENTIAL SERVICE USERS

SUMMARY OF GROUP MEETINGS IN BORDERS REGION IN TWO DIFFERENT GEOGRAPHICAL LOCATIONS (ONE IN A DEPRIVATION AREA)

BORDERS POTENTIAL SERVICE USERS

Individuals considering joining a CHSS support group, completers of cardiac rehabilitation)
(n=9)

Individuals considering joining a CHSS support group, completers of pulmonary rehabilitation
(n=2)

BARRIERS

1) SETTING UP A GROUP

- Health and Safety issues
- Venue – where
- Equipment – storage and use
- Forming a committee - Volunteers

2) DELIVERY

- where, transport links and travel to the class
- Accessibility for all in the region who wish to attend

3) COST

- Space/ Venue
- Instructor
- Potential set up grant from CHSS requires committee

4) KNOWLEDGE OF CLASSES

- Identification of groups in the community

5) EXERCISE INTENSITY

- „how to“ and „how much“

6) INDIVIDUALISED TAILORED EXERCISE

- Like in cardiac rehab and would like this to continue

USERS SUMMARY:

Want to continue exercising in a group but WHERE and HOW BARRIERS

MOTIVATIONS/ENABLERS

SOCIAL AND PEER SUPPORT increases confidence and develops in Cardiac Rehabilitation (CR)

SUPERVISION/DELIVERY likes supervision in CR

SUMMARY OF GROUP MEETING IN LANARKSHIRE REGION

LANARKSHIRE SERVICE USERS

Members of CHSS cardiac support group exercising in leisure provided class (n=17)

BARRIERS

KNOWLEDGE OF CLASSES

- Knowing about classes
- fear of exercise, „how to“ and „how much“

MOTIVATIONS/ENABLERS

SOCIAL

Social and peer support increases confidence

SUPERVISION/DELIVERY

Instructor relationship with group important

SEAMLESS TRANSITION

Link between NHS and Local Authority

Maintenance classes follow times of community rehab and pulmonary rehab

Visit from peers to „sell“ service/support

TAILORED EXERCISE

Different levels of exercise intensity (like condition specific rehab)

Social bonds from „mainstream“ rehab

COST

„Free“ / subsidised exercise classes

IMPROVEMENTS

KNOWLEDGE and awareness of groups could be improved, from GPs, HCP and nurses

TRAINING, instructors not trained in neighbouring health board areas

TAILORED EXERCISE, goal setting and progression /regression as appropriate from hospital through all stages of rehabilitation into community

SUMMARY OF GROUP MEETING IN FIFE REGION WOMENS ETHNIC GROUP

FIFE ETHNIC GROUP POTENTIAL SERVICE USERS

Members of a women's ethnic (Muslim) group (n=20) wishing to be more active

Health needs/conditions of attendees:

Healthy - healthy wanting to maintain health and wellbeing and increase physical activity, women wanting to address weight management and diet

Long term conditions – x1 lady with a heart condition and who had had a stroke, x 1 lady with a asthma diabetes and fluctuating blood pressure, x 1 lady with heart and diabetes, x 2 older ladies with mobility issues walking with mobility aids, x 2 ladies had low back pain and other musculoskeletal complaints were identified e.g. knee pain

Wider community health issues – it was identified within the wider Muslim community that diabetes was an issue and other ladies not able to attend today had long term conditions in particular chest conditions and that a large proportion of ladies within the group were elderly.

Summary of Discussion in relation to PARCS Project Physical Activity/Exercise - Barriers, Motivators & Enablers

- **Health Challenges – level, intensity & specifics of exercise in relation to long term conditions & health concerns - was a major barrier.** The group reported **high incidence of long term conditions within their community** – diabetes, respiratory (chest) and cardiac (heart) conditions, stroke, musculoskeletal problems - low back pain, arthritis, knee pain and mobility issues and often individuals co-morbidities (many conditions)
- **Health Care Professional Support** - this is valued as part of the patient pathway/journey of those with long term conditions and advice in terms of activity is often adhered to
- **Move from Health Care (NHS) to Community** - 2 ladies with long term conditions reported **differing experiences**. One lady who was a stroke survivor was given advice and information and support in the community (visits from health care professionals), the other lady (cardiac and other long term conditions reported having to go to her GP to ask what services were available and ask to be referred to these in relation to her need. Within the Muslim community **when people leave NHS care the family and wider community support them (shift of care to the community)**, there is a desire to support those with health conditions more effectively through education as to how best to deliver this. **Want to exercise within the community.**

- **Specialist Instructor** – a female specialist instructor would be ideal to lead the group and tailor individual exercise to individual's specialist health needs. Previously an instructor from Fife Leisure has successfully led classes and this was well received was of benefit to all
- **Culturally Sensitive Issues** - swimming held in a local high school swimming pool at a time where the pool can be screened off to allow appropriate Islamic dress and women only. Exercise class held in the mosque to tailor to Islamic, gender specific & community/ social needs.
- **Sustained Funding & Service Delivery – cost of venue & instructor** - although cost is not cited as an issue learning from previous initiatives is that when the service is offered at no cost attendance was high (peaked at 20 plus ladies for previous tailored swim sessions), once this funding ceased there was poor attendance and therefore no ongoing service provision once the classes has a cost attached at £2-£3 per class
- **Frequency of Delivery - Regular & Continuous** – the group identified the need for a regular class that was continuous, i.e. not stopped and starting as funding dictates and ideally weekly
- **Type of Exercise** – **swimming** sessions or **moderate intensity exercise class** would best meet the needs of this group
- **Environment - Timings & Location – local and within Muslim Community-** to enable those who work to attend, to fit with Islamic faith (older children attending Koran lessons) and local in Mosque of local high school for ease of access. 5.30 – 7.00pm identified as best time frames for classes. It would be best if children could be present and to allow those with children to attend. It would be best delivered. Only one lady reported going to mainstream leisure services provided classes (for over 50's) this she did after advice and encouragement from a health care professional.
- **Gender Specific Issues** – responsibilities for childcare as well as work commitments mean women often put their family's needs before their health needs, physical activity/exercise would have to be harmonious with these
- **Social Aspect** – **is important**, both **within this group** by meeting and exercising together and by offering support to the **wider Muslim community** to those with health needs. This group would like to be educated and involved in managing health concerns and ongoing health conditions and to support each other with this.
- **Education & Self Management** – an education component is **needed and would be beneficial** and this would **best be delivered during exercise classes**. Previous initiatives showed that people did not attend education only sessions. Previously a dietician attended the group and this was well received with the information is still being utilised
- **Lesson learnt** – (from previous initiatives) **Service delivery key themes – collaborative approach, sustainable funding and delivery, tailored exercise, specialist instructor led & local access, cost** relates to attendance, deliver service locally within the Muslim community (culturally sensitive) by a specialist instructor, individually tailored exercise within a group setting suitable for all, at a suitable time, make any initiative sustainable, incorporate education with exercise, social aspect important.

EXERCISE COMPONENT AS PART OF DUMFERMLINE MUSLIM WOMEN'S GROUP

OUTCOME - Group agreed that there was a **need and a want for supervised, moderate physical activity/exercise that meets the needs of each individual within a group exercise session. These group sessions would try to meet the needs of all people**, of different ages and different health needs: - those who are healthy, those with health concerns (e.g. weight loss) and those who have long term conditions (e.g. chest, heart and stroke problems). The physical activity/exercise session would if possible include **health education (e.g. advise on diet, and other information you need to know to look after yourself). To do this would require lasting money to make sure the group can keep going.** This exercise and education group could be **part of the up and running Muslim Women's group, working with other groups such as Chest, Heart & Stroke Scotland and NHS Health Project Worker.** This could happen by everyone working together to help make the most of the social set up and support already here in this group of Muslim Women and the others people in the Muslim community.

APPENDIX 7 - OVERVIEW PROFILES BY HEALTH BOARD REGION

AYRSHIRE & ARRAN

Service User „The weekly exercise classes have become an important part of my life... the support and help received from the group. I would recommend such groups to anyone...”

Cardiac Health Care Professional (HCP) „Always works well. Variety of classes to suit all abilities”

Neurological HCP „I can see a difference in the types of exercise for stroke patients throughout Ayrshire. In the North there is an exercise classes...for stroke patients which has been very beneficial.....there is no similar service in the East or South ...”

Service Provider „We were finding it more and more challenging to provide disease specific classes so we consulted with a range of Physiotherapists and implemented a circuit based class which would be suitable for a whole range of participants - cardiac rehab, MS, COPD, etc”... „The overall tracking, adherence and analysis of improvements have proved to be too challenging for anyone in the current team to be able to do.”

BOARD PROFILE

Total Board Population ⁽¹⁾	373,190
Urban/ Rural ^(2,3)	296,040 / 77,150 (79% / 21%)

PREVELANCE & STRUCTURED CLINICAL REHABILITATION

Condition	CHD	COPD	Stroke
Prevalence ⁽⁴⁾	20,360	9,783	9,657
Hospital Discharges ⁽⁵⁾ (number of patients)	2,011	1,335	728
Cardiac Rehabilitation ⁽⁶⁾ (numbers referred following a heart attack or revascularisation procedure and as a percentage of eligible patients)	831 (79.9%)		
Pulmonary Rehabilitation ⁽⁷⁾ (estimated total number of patients per year)		704	
Stroke Rehabilitation (number of patients per year)			Not collected by ISD

AVAILABILITY OF EXERCISE MAINTENANCE (EM)

Known numbers participating in community based maintenance exercise/physical activity (snapshot/estimated per annum) ⁽⁸⁾	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults/ Older Adults Activities
Leisure services provided (attendances)	400 * (one out of 3 known providers)					
CHSS affiliated groups (attendees, 2014)		80		10-15		
Total Known (attendances/attendees)	400	80		10-15		

* Figure for East Ayrshire (per annum), numbers going through the service per year, the assumption was made this was attendances unless otherwise indicated. The data is likely to be an under-representation of the actual situation as data was not available from all Local Authority areas within Ayrshire & Arran

SERVICE DELIVERY OF EM

Aspects of Delivery	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults	Other: Third Sector/ Charity Affiliated
Type of Delivery (Generic/LTC or Condition Specific*)	Yes	Yes	Some regions	Some regions	Yes	Yes	Some regions
Established Pathways to Exercise Maintenance	Some regions	Some regions	Some regions	Some regions	Some regions	Some regions	
Earliest year a Scheme Commenced	2006				2006	2006 one region	2006
Service Co-ordinator	Yes	Yes	Yes	Yes	Yes	Yes	Some regions

*Yes/No here indicates stakeholder responses to the question what types of follow on maintenance class are available in your region generic long term conditions class, a cardiac specific class, a respiratory specific class etc (details of data sources and synthesis in the reference section below)

REFERRAL TO EM

Single Point of Referral for all Long Term Conditions to Exercise Maintenance	No. There is a single point of contact and service co-ordinator in each Local Authority/Community Health Partnership area North, East & South.
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DATA COLLECTION FOR EM

Data Collector	Not Collected	Leisure Services	Commissioned By Third Sector/ Other	NHS – HCP	Other
Data Collected					
Follow up data		Yes (2 out of 3 regions)		Some regions	
Cost effectiveness		No		No	
Person centred data		No		Some regions	

FUNDING FOR EM

Funders	Local Authority	Leisure Services	Short Term Government Grant	Short Term NHS - Charitable	Established NHS	Third Sector/ Charity
Funding partners for service delivery	One regions	Some regions	Some regions	One region	One region	One region
Funding for initial instructor/service provider training	One region	Some regions	Some regions	Some regions	No	No

GOVERNANCE OF EM

Collaborative working group(s) for governance of exercise maintenance	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
	Some regions	No	Some regions	Some regions	Some regions	Some regions

INSTRUCTORS WITH SPECIALIST TRAINING

Different regions have variation in numbers trained, overall total of known instructors shown

REPS Level 4 (9)	REPS Level 3 (9)	BACPR	Otago (Falls)	Postural Stability Instructor (Falls)	Exercise After Stroke	Wright Foundation	Seated Exercise	NHS In house	Data Sources
9-10 (i)	11	6-7 (i)	2	9-10 (i)	4	12	6	23 (Total, ii)	Leisure services (2 out of 3 known providers) MCN, Third sector - charity groups

(i) The range in total numbers indicated represents the range of responses given, i.e. lowest number response to highest number response. This number potentially indicates numbers known by the different data sources documented above or the variation in numbers of instructors in different geographical locations within the Health Board.

(ii) In house training components: dementia - n= 5, heart failure - n= 6, respiratory - n= 6, defibrillation training n=6 (total =23)

KEY CONTEXTUAL OVERVIEW - 3 Community Health Partnership (CHP) Regions

Cardiac Rehabilitation is delivered in hospital and community centres as a twelve week programme for all cardiac patients. Exit strategy includes referral to Leisure services and/or signposting to menu based options. Those not appropriate for exercise options are referred to support and self-management group(s).

Pulmonary Rehabilitation is delivered in various community centres over ten weeks. There is an option of delivery at home via a pod/tablet, with monitoring by Physiotherapist (pilot in East Ayrshire). Exit strategies refer to leisure services and signpost to local support group (s).

Stroke Rehabilitation is delivered acutely in hospital and in the community. Exit strategy to signpost/refer to Third Sector or Leisure services dependant on locality (see below).

Long Term Conditions (LTC) Exercise Maintenance is delivered pan Ayrshire and Arran as part of an exercise referral/activity for health scheme within each Local Authority (LA)/CHP region. This is delivered by Leisure services in partnership with NHS. HCP refer to North, East and South Leisure services to a generic function based exercise class. Some regions offer a 1:1 with a fitness instructor, offering a menu of exercise options with follow up. Ayrshire LTC support group is available in three locations.

Cardiac Exercise Maintenance is delivered as part of an exercise referral scheme/activity for health scheme within each LA/CHP region for LTC. Third sector (CHSS) provision in three locations, two exercising (physiotherapist led) and one support/social group.

Respiratory Exercise Maintenance, respiratory community based exercise maintenance is delivered as part of an exercise referral scheme/activity for health scheme within each LA/CHP region for LTC.

Stroke Exercise Maintenance, stroke community based exercise maintenance is delivered by the Third Sector (North) and some support is offered within Leisure (East and South). In North Ayrshire, there is a Different Strokes exercise class, led by a specialist exercise after stroke instructor. East and South Ayrshire offer a scheme to refer to the gym where a trained exercise instructor will assess and support initiation into the gym (this may not be appropriate for all patients). In East and South Ayrshire the LA and Health Board are currently training instructors in the Exercise after Stroke qualification. There are also eight social/support groups (CHSS affiliated) in six different locations.

KEY SUCCESSES

- **Service delivery**, delivery of exercise maintenance classes for LTC pan Ayrshire and Arran with menu based exercise options
- **Partnership/collaborative working**, between health and LA and across different LA's with HCP involvement
- **Pathway, effective referral /signposting**
- **Generic LTC classes**, replacement of condition specific with LTC classes

KEY CHALLENGES

- **Service Delivery, knowledge of services**, „keeping up to date with all that the three LA's offer" (MCN)
- **Partnership/collaborative working**, „Frequent communication between health & LA's (MCN)
- **Data Collection/IT systems**, to track participants and demonstrate improvement
- **Equity in service provision** across the Health Board
- **Access**, transport & availability of classes
- **Resources**, funding, sustained funding for service staff (HCP & instructors)
- **Governance**, ensuring this remains structured and sustainable
- **Funding for venues** – NHS Ayrshire and Arran have to pay for all local authority venues, and no identified budget

Data Sources/References

The HCP, service providers/leisure services and GP survey was online in 'survey monkey' format. For HCP the dissemination process for completion was for HCP via professional networks: SNNF, SSAHP forum, SPRAG, SRNF, CRIGS, CSP Scotland website/online forum, MCN Managers, HI, CHP, NMAHP leads for cascading and internally for stroke nurses in CHSS. Leisure services/service providers, via PAHA, HI, Physical Activity leads and via identification of leisure services providers from online searches along with cross checking with a previous stroke audit and gained knowledge from the PARCS scoping to that point. The GP survey was via a CHSS list of GPs who had previous contact with CHSS and then targeted identification of practices/practice managers in regions with a no/low responses rate, by sending the link to the survey via post or email. Some questionnaires were completed in paper format during face to face meetings as part of PARCS project and then inputted manually into the survey monkey format (with permission). For service users the surveys were posted out to all CHSS group leads to circulate via their respective groups. All data was protected in line with CHSS data protection and confidentiality policies and followed the ethical standards of the charity in line with charity business/service development.

All data incorporated within the CHSS PARCS scoping was collected for the period November 2012 – January 2014. The PARCS surveys were completed between August 2013 and January 2014.

The data represented in the tables above is compiled from a synthesis of data from PARC surveys - MCN, Health Care Professionals, and service provider (leisure services, third sector, and private provider) responses. The data synthesis process that was used for each question/table response was in relation to the number of definitive responses to that question (i.e. yes and no answers only, unsure responses were not included in the tally). For Yes or No responses, if all stakeholders reported Yes the table was populated with a Yes and the same process was used for No. If there was a mixed response from the different stakeholders, if the total responses for that question were high (>20) the majority response was used. If the total responses were low (below 20) if 2 or more stakeholders responded negatively (No) or positively (Yes) the answer was populated as 'some regions'. If the responses for that question were high (>20) and the results were mixed i.e. a high number of yes and a high number of no, the answer was populated as some regions. If there was only a single response either yes or no the respective response was used and populated, or populated as 'one region' (as appropriate). If no responses, the section was left blank.

The data represented in key contextual overview and quotes sections (above the tables) is a data synthesis from the PARCS surveys (as detailed above and including service users), meetings detailed below and other data sources e.g. reports, audits/evaluations, online resources (e.g. websites etc), identified as part of the PARCS (CHSS) scoping. Where information was missing e.g. nil responses the information was based on information available from other e.g. online resources. The accuracy of such information may not always be correct; the sense check detailed below was to enable a mechanism whereby any errors to be identified and corrected.

The overview profile shown above (tables and key contextual data) was circulated prior to final production to the respective Health Board MCN Managers for sense checking (checking that the information had no obvious errors). A 2 week deadline was given (due to the time limited nature of the project). A nil response within a 2 week period would lead to the assumption that the data was acceptable and required no corrections.

PARCS surveys responses in this Health Board region (or hits on web based surveys, and stakeholders represented)

- MCN, n=1
- Health Care Professionals, n= 31
- GPs, n=4
- Services Providers, n= 2 (out of 3 known leisure providers)
- Service Users, n= 13 (engagers in CHSS affiliated groups)

Meetings as part of PARCS CHSS scoping in this Health Board region

Face to Face Meetings with:

- X 2 Lead Health Care Professionals

Other correspondence and/or meetings with 3rd sector service providers – CHSS & other 3rd sector providers

References

ISD statistics provided by ISD

1. Source: 2012 mid-year population estimates (National Records of Scotland (NRS)) (<http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html>)
2. Source: 2011/12 version of the Urban Rural Classification (Scottish Government) and the 2012 mid-year population estimates (National Records of Scotland).
3. Urban areas are settlements of over 3,000 people. Rural areas are settlements of fewer than 3,000 people. More details can be found here: <http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification>
4. Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp>
5. Source: SMR01 (ISD), extracted February 2014. Number of patients discharged from hospital during calendar year 2012.
6. Source: Cardiac Rehabilitation in Scotland (2011/12) publication. The full publication and data tables can be found here: <https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf>

Statistics from other sources (as not collected by ISD)

7. Health Improvement Scotland Costing Report – Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) http://www.healthcareimprovementscotland.org/our_work/longterm_conditions/copd_implementation/implementing_copd_standards.aspx

8. These figures were based on responses to the PARCS survey (CHSS scoping) from services providers (this could include leisure, third sector, private). The year (i.e. 2012 -2013) from some providers was not completed. The figures are therefore intended to give a snapshot/estimate of numbers in services. Also in some regions more than one provider was identified but only one or some of the providers responded. In some regions attendance fluctuated in numbers particularly in third sector groups, so figures were based on averages or the range if given. The figure provided is not a definitive figure but intended to give a best estimate based on the information available and only represents service providers and initiatives that the PARCS scoping was able to identify within the time limited constraints of the project and the data available.
9. **Register of Exercise Professionals (REPs)** is an independent, public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REP's provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards. **DEFINITION OF REPS LEVEL 3:** The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions this includes Respiratory Conditions: Asthma and Chronic obstructive pulmonary disease (COPD). Musculoskeletal Conditions, Cardiovascular Conditions, Hypertension, Hypercholesterolaemia, Psychological/Mental Health Conditions, Metabolic/Immunological Conditions e.g. Diabetes Type 1 and Type 2 and obesity. **DEFINITION OF REPS LEVEL 4:** The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the affects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease. <http://www.exerciseregister.org/resources/exercise-referral>

BORDERS

Service User „Lack of information re exercise groups or support groups...”

Health Care Professional (HCP) „Largely with the support of CHSS, progress has been made in providing exercise maintenance, but this has been limited largely to respiratory. Plans are underway to develop exercise post stroke skills throughout Leisure. Overall access is still very limited & must improve”

Leisure Provider „We have been trying to establish a group for the last two years... We were frustrated that there was no sustainability with any of the groups after initial funding so we decided to start our own group with all partners involved, so we could have a exercise programme/ rehab for all... Chest Heart and Stroke Scotland were vital in this process...”

BOARD PROFILE

Total Board Population ⁽¹⁾	113,710
Urban/ Rural ^(2,3)	57,132 / 56,578 (50% / 50%)

PREVELANCE & STRUCTURED CLINICAL REHABILITATION

Condition	CHD	COPD	Stroke
Prevalence ⁽⁴⁾	5,798	2,579	2,917
Hospital Discharges ⁽⁵⁾ (number of patients)	568	236	244
Cardiac Rehabilitation ⁽⁶⁾ (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	153* (44.9%)		
Pulmonary Rehabilitation ⁽⁷⁾ (estimated total number of patients per year)		199	
Stroke Rehabilitation (number of patients Per year)			Not collected by ISD

*likely to be an underrepresentation due to insufficient data available at time of collection

AVAILABILITY OF MAINTENANCE EXERCISE (EM)

Known numbers participating in community based maintenance exercise/physical activity (snapshot/estimated per annum) ⁽⁸⁾	Long Term Conditions (LTC)	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults/ Older Adults Activities
Leisure services provided (attendances)					60 (one provider) i)	0
CHSS affiliated groups (attendees, 2014)	28 *	8	16			
Private sector provided (Attendees)					20 i)	20 i)
Total Known (attendances/attendees)	28	8	16		80	20

i) Figures provided were numbers (per annum) going through the service per year, the assumption was made this was attendances at leisure and attendees for private providers, unless otherwise indicated by the data source.

*Two stroke service users within this group

SERVICE DELIVERY OF EM

Aspects of Delivery	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults	Other: Third Sector/ Charity Affiliated
Type of Delivery (Generic/LTC or Condition Specific *)	Some regions	Some regions	Some regions	No	Some regions	Some regions	Some regions
Established Pathways to Exercise Maintenance	Some regions	Some regions	Some regions	No	Some regions	Some regions	Some regions
Earliest year a Scheme Commenced	2013	2006	2010	N/A	2013	2013	2011
Service Co-ordinator			One region		One region	One region	

*Yes/No here indicates stakeholder responses to the question what types of follow on maintenance class are available in your region generic long term conditions class, a cardiac specific class, a respiratory specific class etc (details of data sources and synthesis in the reference section below)

REFERRAL TO EM

Single Point of Referral for all Long Term Conditions to Exercise Maintenance	No. A small number of regions have a service co-ordinator.
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DATA COLLECTION FOR EM

Data Collector / Data Collected	Not Collected	Leisure Services	Commissioned By Third Sector/ Other	NHS – HCP	Other Private Provider
Follow up data		No		No	
Cost effectiveness		No		No	
Person centred data		One region		One region	One region

FUNDING FOR EM

Funders	Local Authority	Leisure Services	Short Term Government Grant	Short Term NHS - Charitable	Established NHS	Other: Third Sector/ Charity
Funding partners for service delivery	One region	Yes		Yes	One region	Yes
Funding for initial instructor/service provider training		One region		One region	One region	One region

GOVERNANCE OF EM

Collaborative working group(s) for governance of exercise maintenance	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
	Some regions		One region			One region

INSTRUCTORS WITH SPECIALIST TRAINING

Different regions have variation in numbers trained, overall total of known instructors shown

REPS Level 4 (9)	REPS Level 3 (9)	BACPR	Otago (falls)	Postural Stability Instructor (falls)	Exercise After Stroke	Wright Foundation	Seated Exercise	NHS In House	Data Sources
1	13	1-2 (i)	9	4*			11	14	Leisure Services (x 1 regional manager, 1 regional provider). Private providers x 2, HCPs

(i)The range in total numbers indicated represents the range of responses given, i.e. lowest number response to highest number response. This number potentially indicates numbers known by the different data sources documented above or the variation in numbers of instructors in different geographical locations within the Health Board.

* 3 physiotherapists also hold this qualification

KEY CONTEXTUAL OVERVIEW - 1 Community Health Partnership (CHP) Region

Cardiac Rehabilitation is delivered at the Borders General Hospital (BGH). Exit strategy is to signpost to the one maintenance group available in one area. All acute coronary and surgical patients who are referred to the service are comprehensively assessed by the team and offered appropriate ongoing support/advice.

Pulmonary Rehabilitation (PR) was delivered in both health care and community settings on a rolling programme throughout the Borders. Community delivered PR is a driver for establishment of maintenance classes. Exit strategy was signposting to Third Sector groups where available. Currently there is no Pulmonary Rehabilitation being delivered.

Stroke Rehabilitation is delivered at hospital (BGH) and in the community.

Long Term Conditions Exercise (LTC) Maintenance is delivered as a generic LTC exercise maintenance classes in some geographical areas by different providers: Third Sector (CHSS affiliated) and independent/private sectors. In one region there is an NHS/Leisure/Third Sector (CHSS) partnership. Falls classes are more established and are delivered more widely, as are older adult's classes. No exercise referral scheme is available; a previous GP exercise referral scheme was successful in long term adherence (3-5 years) (10)

Cardiac Exercise Maintenance is delivered by Third Sector (CHSS affiliated) delivery in one location, which was initially led by a HCP, now peer led.

Respiratory Exercise Maintenance is delivered by Third Sector (CHSS affiliated groups) in two locations in two locations which are peer led.

Stroke Exercise Maintenance plans are underway to develop exercise post stroke skills throughout Leisure.

KEY SUCCESSES

- **Service delivery, service provision need identified**, workforce planning toward this. Staff appointed to work across Leisure and Health to develop services and collaborative meetings with multiple stakeholders
- **Third Sector key service provider, with value of peer support** demonstrated
- **Knowledge of services**, awareness of Third Sector (CHSS affiliated) exercise maintenance groups by HCP, with signposting and a directory of Borders based community activities
- **Behavioural change support**, the Lifestyle Adviser Support Service (LASS) offers support and advice to people (over 16 years) wishing to make a lifestyle change to improve their health, situated in primary care with referral from HCP, leisure services, other community services and option of self-referral
- **Training of specialist instructors** , need identified and training underway in exercise after stroke
- **Well established falls pathway with community maintenance classes**

KEY CHALLENGES

- **Service delivery, service provision/development need**, for greater geographical coverage, access and service planning
- **Service delivery and design**, organisational and operational challenges
- **Access**, transport and some regions socioeconomic (cost to service user)
- **Data collection/IT/Information transfer**, between, and by, health and Leisure
- **Resources, funding & staffing**
- **Sustainability**, Third Sector groups often lack support and sustainability without wider partnership working, i.e. setting up a group, ensuring ongoing referrals, finding a venue, finding an appropriate lead for an exercise class e.g. specialist instructor

Data Sources/References

The HCP, service providers/leisure services and GP survey was online in 'survey monkey' format. For HCP the dissemination process for completion was for HCP via professional networks: SNNF, SSAHP forum, SPRAG, SRNF, CRIGS, CSP Scotland website/online forum, MCN Managers, HI, CHP, NMAHP leads for cascading and internally for stroke nurses in CHSS. Leisure services/service providers, via PAHA, HI, Physical Activity leads and via identification of leisure services providers from online searches along with cross checking with a previous stroke audit and gained knowledge from the PARCS scoping to that point. The GP survey was via a CHSS list of GPs who had previous contact with CHSS and then targeted identification of practices/practice managers in regions with a no/low responses rate, by sending the link to the survey via post or email. Some questionnaires were completed in paper format during face to face meetings as part of PARCS project and then inputted manually into the survey monkey format (with permission). For service users the surveys were posted out to all CHSS group leads to circulate via their respective groups. All data was protected in line with CHSS data protection and confidentiality policies and followed the ethical standards of the charity in line with charity business/service development.

All data incorporated within the CHSS PARCS scoping was collected for the period November 2012 – January 2014. The PARCS surveys were completed between August 2013 and January 2014.

The data represented in the tables above is compiled from a synthesis of data from PARC surveys - MCN, Health Care Professionals, and service provider (leisure services, third sector, and private provider) responses. The data synthesis process that was used for each question/table response was in relation to the number of definitive responses to that question (i.e. yes and no answers only, unsure responses were not included in the tally). For Yes or No responses, if all stakeholders reported Yes the table was populated with a Yes and the same process was used for No. If there was a mixed response from the different stakeholders, if the total responses for that question were high (>20) the majority response was used. If the total responses were low (below 20) if 2 or more stakeholders responded negatively (No) or positively (Yes) the answer was populated as '*some regions*'. If the responses for that question were high (>20) and the results were mixed i.e. a high number of yes and a high number of no, the answer was populated as *some regions*. If there was only a single response either yes or no the respective response was used and populated, or populated as '*one region*' (as appropriate). If no responses, the section was left blank.

The data represented in key contextual overview and quotes sections (above the tables) is a data synthesis from the PARCS surveys (as detailed above and including service users), meetings detailed below and other data sources e.g. reports, audits/evaluations, online resources (e.g. websites etc), identified as part of the PARCS (CHSS) scoping. Where information was missing e.g. nil responses the information was based on information available from other e.g. online resources. The accuracy of such information may not always be correct; the sense check detailed below was to enable a mechanism whereby any errors to be identified and corrected.

The overview profile shown above (tables and key contextual data) was circulated prior to final production to the respective Health Board MCN Managers for sense checking (checking that the information had no obvious errors). A 2 week deadline was given (due to the time limited nature of the project). A nil response within a 2 week period would lead to the assumption that the data was acceptable and required no corrections.

PARCS surveys responses (or hits for online surveys) in this Health Board region (or 'hits' for online surveys and stakeholders represented)

- MCN, nil
- Health Care Professionals responses, n =19
- GPs, n= 5
- Services Providers (Leisure, Third and private sector), n= 4
- Service Users (engagers in CHSS affiliated groups), n= 3

Meetings as part of PARCS CHSS scoping in this Health Board region

Face to Face Meetings with:

- Focus groups (n=11) with 2 groups leaving clinical rehabilitation wanting to keep exercising, looking to be affiliated with CHSS, in different geographical and socioeconomic regions (cardiac group, n= 9) & (respiratory group, n= 2)
- X 2 Health Care Professional Leads, x 1 Health Service
- Other correspondence, (emails and telecoms), with other private and Third Sector (CHSS) providers.

References

ISD statistics provided by ISD

1. Source: 2012 mid-year population estimates (National Records of Scotland (NRS)) (<http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html>)
2. Source: 2011/12 version of the Urban Rural Classification (Scottish Government) and the 2012 mid-year population estimates (National Records of Scotland).
3. Urban areas are settlements of over 3,000 people. Rural areas are settlements of fewer than 3,000 people. More details can be found here: <http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification>
4. Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp>
5. Source: SMR01 (ISD), extracted February 2014. Number of patients discharged from hospital during calendar year 2012.
6. Source: Cardiac Rehabilitation in Scotland (2011/12) publication. The full publication and data tables can be found here: <https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf>

Statistics from other sources (as not collected by ISD)

7. Health Improvement Scotland Costing Report – Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/copd_implementation/implementing_copd_standards.aspx

8. These figures were based on responses to the PARCS survey (CHSS scoping) from services providers (this could include leisure, third sector, private). The year (i.e. 2012 -2013) from some providers was not completed. The figures are therefore intended to give a snapshot estimate of numbers in services. Also in some regions more than one provider was identified but only one or some of the providers responded. In some regions attendance fluctuated in numbers particularly in third sector groups, so figures were based on averages or the range if given. The figure provided is not a definitive figure but intended to give a best estimate based on the information available and only represents service providers and initiatives that the PARCS scoping was able to identify within the time limited constraints of the project and the data available.
9. **Register of Exercise Professionals (REPs)** is an independent, public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REPs provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards. **DEFINITION OF REPS LEVEL 3:** The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions this includes Respiratory Conditions: Asthma and Chronic obstructive pulmonary disease (COPD). Musculoskeletal Conditions, Cardiovascular Conditions, Hypertension, Hypercholesterolaemia, Psychological/Mental Health Conditions, Metabolic/Immunological Conditions e.g. Diabetes Type 1 and Type 2 and obesity. **DEFINITION OF REPS LEVEL 4:** The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the affects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease. <http://www.exerciseregister.org/resources/exercise-referral>
10. Health Bulletin Edinburgh (2001) Sep; 59 (5):343-6 The Scottish Borders general practitioners exercise referral scheme (GPERS)

DUMFRIES & GALLOWAY

Service User – „the current groups ...are not getting many new members and unless things change will have a very limited life”

Health Care Professional (HCP) „wide area and services are varied. In Dumfries there is good local access to leisure facilities and exercise groups suitable to long term conditions. Outwith there are several exercising charitable groups but very varied”

GP – „unfortunately nearest maintenance exercise class is 30 miles away.... „

Service Provider „We do not have one dedicated Referral Instructor, so they may not be able to dedicate all their time to collating information or working with referral clients. To get a true reading of the statistics one person would need to oversee the whole process.”

BOARD PROFILE

Total Board Population ⁽¹⁾	150,830
Urban/ Rural ^(2,3)	81,055 / 69,775 (54% / 46%)

PREVELANCE & STRUCTURED CLINICAL REHABILITATION

Condition	CHD	COPD	Stroke
Prevalence ⁽⁴⁾	8,198	4,162	3,801
Hospital Discharges ⁽⁵⁾ (number of patients)	708	409	348
Cardiac Rehabilitation ⁽⁶⁾ (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	320 (97.6%)		
Pulmonary Rehabilitation ⁽⁷⁾ (estimated total number of patients per year)		270	
Stroke Rehabilitation estimated patients Per year			Not collected by ISD*

* D & G report clinical lead report difficult to estimate due to different levels of recovery

AVAILABILITY OF MAINTENANCE EXERCISE (EM)

Known numbers participating in community based maintenance exercise/physical activity (snapshot/estimated per annum) ⁽⁸⁾	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults/ Older Adults Activities
Leisure services provided						
CHSS affiliated groups (attendees, 2014)	10	150	45			
Total Known (attendees)	10	150	45			

SERVICE DELIVERY OF EM

Aspects of Delivery	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults	Other: 3rd sector/ Charity Affiliated
Type of Delivery (Generic/LTC or Condition Specific *)	Some regions	Some regions	Some regions	Some regions	Some regions	Some regions	Some regions
Established Pathways to Exercise Maintenance	Some regions	Some regions	Some regions	Some regions	Some regions	Some regions	Some regions
Earliest year a Scheme Commenced	2006 or earlier	2006 or earlier		2007	2006 or earlier	2006 or earlier	2009
Service Co-ordinator	Some regions	Some regions	Some regions	Some regions	Some regions	Some regions	Some regions

*Yes/No here indicates stakeholder responses to the question what types of follow on maintenance class are available in your region generic long term conditions class, a cardiac specific class, a respiratory specific class etc (details of data sources and synthesis in the reference section below)

REFERRAL TO EM

Single Point of Referral for all Long Term Conditions to Exercise Maintenance	No. Some regions have a regional point of contact /referral or service co-ordinator
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DATA COLLECTION OF EM

Data Collected / Data Collector	Not Collected	Leisure Services	Commissioned By Third Sector/ Other	NHS – HCP	Other: Community Health Support Worker
Follow up data		Some regions		Some regions	Yes
Cost effectiveness		No		No	
Person centred data		No		One Region	

FUNDING OF EM

Funders	Local Authority	Leisure Services	Short Term Government Grant	Short Term NHS -	Established NHS	Third Sector/ Charity
Funding partners for service delivery	Yes	Some regions	Some regions	Some regions	Some regions	Yes
Funding for initial instructor/service provider training		Some regions	Some regions			

GOVERNANCE OF EM

Collaborative working group(s) for governance of exercise maintenance	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
	Some regions	Some regions	Some regions	Some regions	Some regions	Some regions

INSTRUCTORS WITH SPECIALIST TRAINING

Different regions have variation in numbers trained, overall total of known instructors shown

REPS Level 4 (9)	REPS Level 3 (9)	BACPR	Otago (falls)	Postural Stability Instructor (falls)	Exercise After Stroke	Wright Foundation	Seated Exercise	NHS In house	Data Sources
0-1 (i)	2	1			1	1-5 (i)	1		MCN, HCP, Leisure services

(i) The range in total numbers indicated represents the range of responses given, i.e. lowest number response to highest number response. This number potentially indicates numbers known by the different data sources documented above or the variation in numbers of instructors in different geographical locations within the Health Board.

KEY CONTEXTUAL OVERVIEW - 1 CHP Region

Cardiac Rehabilitation is delivered within hospital and community settings. The exit strategy is signposting to Third Sector (CHSS) affiliated groups or Leisure services, where available.

Pulmonary Rehabilitation (PR) is delivered within hospital and community settings across Dumfries & Galloway. The exit strategy is signposting to menu based options including referral to Leisure/Local Authority (LA) services where available and CHSS affiliated groups.

Stroke Rehabilitation is delivered within hospital and community settings to post discharged patients, usually post individual rehabilitation. All stroke patients have two points of access to stroke specific exercise classes throughout Dumfries and Galloway, delivered in NHS premises which is Physiotherapist and Stroke Liaison Nurse led, over 12 weeks period. Service users are offered follow up with these HCPs at 3 and 12 months post discharge. From there referral and onward signposting is given to access ongoing exercise.

Long Term Conditions Exercise Maintenance is delivered in six regions by Leisure/LA services as part of an exercise referral/exercise on prescription scheme, accessed by HCP referral and in three regions by Third Sector (CHSS affiliated) groups, peer led exercise groups. Some Leisure/LA regions offer different exercise options e.g. walks that people can self-refer into and join.

Cardiac Exercise Maintenance is delivered in some regions by Leisure services/LA and in eight locations by Third Sector (CHSS affiliated) peer led exercise and support groups.

Respiratory Exercise Maintenance is delivered in some regions by Leisure services/LA and in two regions by Third Sector (CHSS affiliated) peer led exercise/support groups. Initially a PR maintenance class ran but it was so popular and demands for service increased that this could not be continued.

Stroke Exercise Maintenance there is no specific stroke exercise maintenance classes. There are two social/support groups (CHSS affiliated) in two different locations, peer led, with links to NHS HCPs for advice and education sessions, on invitation.

KEY SUCCESSES

- **Third Sector key service provider**, since 1990, with groups self-supporting
- **Visits to maintenance class during clinical rehabilitation**, value of visits from cardiac & pulmonary rehabilitation groups to maintenance classes to meet instructor(s)/peer(s)/understand local options

KEY CHALLENGES

- **Equity of service provision across the Health Board**
- **Initial uptake of services**, for maintenance can be poor
- **Sustainability of groups**, due to lack of new uptake/referrals
- **Access, local access needed and transport**
- **Data collection**, resources and staff time to enable this

Data Sources/References

The HCP, service providers/leisure services and GP survey was online in „survey monkey“ format. For HCP the dissemination process for completion was for HCP via professional networks: SNNF, SSAHP forum, SPRAG, SRNF, CRIGS, CSP Scotland website/online forum, MCN Managers, HI, CHP, NMAHP leads for cascading and internally for stroke nurses in CHSS. Leisure services/service providers, via PAHA, HI, Physical Activity leads and via identification of leisure services providers from online searches along with cross checking with a previous stroke audit and gained knowledge from the PARCS scoping to that point. The GP survey was via a CHSS list of GPs who had previous contact with CHSS and then targeted identification of practices/practice managers in regions with a no/low responses rate, by sending the link to the survey via post or email. Some questionnaires were completed in paper format during face to face meetings as part of PARCS project and then inputted manually into the survey monkey format (with permission). For service users the surveys were posted out to all CHSS group leads to circulate via their respective groups. All data was protected in line with CHSS data protection and confidentiality policies and followed the ethical standards of the charity in line with charity business/service development.

All data incorporated within the CHSS PARCS scoping was collected for the period November 2012 – January 2014. The PARCS surveys were completed between August 2013 and January 2014.

The data represented in the tables above is compiled from a synthesis of data from PARC surveys - MCN, Health Care Professionals, and service provider (leisure services, third sector, and private provider) responses. The data synthesis process that was used for each question/table response was in relation to the number of definitive responses to that question (i.e. yes and no answers only, unsure responses were not included in the tally). For Yes or No responses, if all stakeholders reported Yes the table was populated with a Yes and the same process was used for No. If there was a mixed response from the different stakeholders, if the total responses for that question were high (>20) the majority response was used. If the total responses were low (below 20) if 2 or more stakeholders responded negatively (No) or positively (Yes) the answer was populated as „*some regions*“. If the responses for that question were high (>20) and the results were mixed i.e. a high number of yes and a high number of no, the answer was populated as *some regions*. If there was only a single response either yes or no the respective response was used and populated, or populated as *‘one region’* (as appropriate). If no responses, the section was left blank.

The data represented in key contextual overview and quotes sections (above the tables) is a data synthesis from the PARCS surveys (as detailed above and including service users), meetings detailed below and other data sources e.g. reports, audits/evaluations, online resources (e.g. websites etc), identified as part of the PARCS (CHSS) scoping. Where information was missing e.g. nil responses the information was based on information available from other e.g. online resources. The accuracy of such information may not always be correct; the sense check detailed below was to enable a mechanism whereby any errors to be identified and corrected.

The overview profile shown above (tables and key contextual data) was circulated prior to final production to the respective Health Board MCN Managers for sense checking (checking that the information had no obvious errors). A 2 week deadline was given (due to the time limited nature of the project). A nil response within a 2 week period would lead to the assumption that the data was acceptable and required no corrections.

PARCS surveys responses in this Health Board region (or „hits“ on web based surveys, and stakeholders represented)

- MCN, n= 1
- Health Care Professionals, n=20
- GPs, n=11
- Services Providers, leisure and community health workers, n= 3
- Service Users, n=44

Meetings as part of PARCS CHSS scoping in this Health Board region

Correspondence and meetings with Third Sector providers – CHSS support workers

References

ISD statistics provided by ISD

1. Source: 2012 mid-year population estimates (National Records of Scotland (NRS)) (<http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html>)
2. Source: 2011/12 version of the Urban Rural Classification (Scottish Government) and the 2012 mid-year population estimates (National Records of Scotland).

3. Urban areas are settlements of over 3,000 people. Rural areas are settlements of fewer than 3,000 people. More details can be found here: <http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification>
4. Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp>
5. Source: SMR01 (ISD), extracted February 2014. Number of patients discharged from hospital during calendar year 2012.
6. Source: Cardiac Rehabilitation in Scotland (2011/12) publication. The full publication and data tables can be found here: <https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf>

Statistics from other sources (as not collected by ISD)

7. Health Improvement Scotland Costing Report – Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/copd_implementation/implementing_copd_standards.aspx
8. These figures were based on responses to the PARCS survey (CHSS scoping) from services providers (this could include leisure, third sector, private). The year (i.e. 2012 -2013) from some providers was not completed. The figures are therefore intended to give a snapshot estimate of numbers in services. Also in some regions more than one provider was identified but only one or some of the providers responded. In some regions attendance fluctuated in numbers particularly in third sector groups, so figures were based on averages or the range if given. The figure provided is not a definitive figure but intended to give a best estimate based on the information available and only represents service providers and initiatives that the PARCS scoping was able to identify within the time limited constraints of the project and the data available.
9. **Register of Exercise Professionals (REPs)** is an independent, public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REP's provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards. **DEFINITION OF REPS LEVEL 3:** The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions this includes Respiratory Conditions: Asthma and Chronic obstructive pulmonary disease (COPD). Musculoskeletal Conditions, Cardiovascular Conditions, Hypertension, Hypercholesterolaemia, Psychological/Mental Health Conditions, Metabolic/Immunological Conditions e.g. Diabetes Type 1 and Type 2 and obesity. **DEFINITION OF REPS LEVEL 4:** The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the affects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease. <http://www.exerciseregister.org/resources/exercise-referral>

FIFE

Service User „Since I started attending my cardiac class I have gone on to do voluntary work in seated exercise classes...for patients with MS, stroke sufferers and COPD. ..given me a new lease of life, seeing the improvement in their wellbeing is my way of saying a huge thank you to the doctors, nurses and physiotherapy staff for their care and attention”

Health Care Professional (HCP) „Active Options (Leisure services LTC exercise maintenance classes)... have been going for one year and are proving to be very popular and very successful. The co-ordinators aim to add classes in different areas as soon as demand is sufficient. Patients are happy to return to classes after exacerbations”

GP –„Patients who opt to go on to maintenance classes usually find them very useful and feel supported to take exercise safely”

Service Provider „... set up a health programme based on a person's functional ability rather than their health conditions. Clients who have had a stroke, have COPD, MD, diabetes or any cardiac condition can be referred into the programme.....Adherence is good as clients enjoy the social aspect of the class.....Strong links between Leisure services and the NHS”

BOARD PROFILE

Total Board Population ⁽¹⁾	366,220
Urban/ Rural ^(2,3)	294,126 / 72,094 (80% / 20%)

PREVELANCE & STRUCTURED CLINICAL REHABILITATION

Condition	CHD	COPD	Stroke
Prevalence ⁽⁴⁾	15,933	7,839	8,340
Hospital Discharges ⁽⁵⁾ (number of patients)	1,381	751	668
Cardiac Rehabilitation ⁽⁶⁾ (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	Not published		
Pulmonary Rehabilitation ⁽⁷⁾ (estimated total number of patients per year)		583	
Stroke Rehabilitation (estimated patients per year)			Not collected by ISD

AVAILABILITY OF EXERCISE MAINTENANCE (EM)

Known numbers participating in community based maintenance exercise/physical activity (snapshot/estimated per annum) ⁽⁸⁾	Long term conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults/ Older Adults Activities
Leisure services provided (referrals to service)	375 *	115*	103 *	55*		
CHSS affiliated groups (attendees, 2014)		30				

*Data 2012/13 – pan Fife, number of referrals to service, LTC Active Options 2. Respiratory figures are for COPD.

SERVICE DELIVERY OF EM

Aspects of Delivery	Long term conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults	Other: Third Sector/ Charity Affiliated
Type of Delivery (Generic/LTC or Condition Specific)	Yes	Yes	Some regions	Some regions	Yes	Yes	
Established Pathways to exercise maintenance	Yes	Yes	Yes	Yes	Yes	Yes	
Earliest year a scheme commenced	2012	2006			2012		
Service Co-ordinator	Yes	Yes	Yes	Yes	Yes		

*Yes/No here indicates stakeholder responses to the question what types of follow on maintenance class are available in your region generic long term conditions class, a cardiac specific class, a respiratory specific class etc (details of data sources and synthesis in the reference section below)

REFERRAL TO EM

Single Point of Referral for all Long Term Conditions to Exercise Maintenance	Yes. All referrals from NHS Fife are sent to the Health & Wellbeing Co-ordinator at Fife Sports & Leisure Trust, responsible for co-ordinating the health programmes within Fife Leisure delivered at leisure and community venues.
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DATA COLLECTION FOR EM

Data Collector / Data Collected	Not collected	Leisure services	Commissioned By Third Sector/ Other	NHS – HCP	Other
Follow up data		No			
Cost effectiveness		Yes		No	
Person centred data		Yes		No	

FUNDING FOR EM

Funders	Local Authority	Leisure Services	Short Term Government Grant	Short Term NHS - Charitable	Established NHS	Charity
Funding partners for service delivery	Yes	Yes				Yes
Funding for initial instructor/service provider training				Yes		

GOVERNANCE OF EM

Collaborative working group(s) for governance of exercise maintenance	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
		Yes	Yes	Yes	Yes	Yes

INSTRUCTORS WITH SPECIALIST TRAINING

Different regions have variation in numbers trained, overall total of known instructors shown

REPS Level ⁽⁹⁾	REPS Level 3 (9)	BACPR	Otago (falls)	Postural Stability Instructor (falls)	Exercise After Stroke	Wright Foundation	Seated Exercise	NHS In-house	Other
10-16 (i)	2-7 (i)	12-15 (i)		2		3	1		COPD =3, Cancer Rehab =12

(i)The range in total numbers indicated represents the range of responses given, i.e. lowest number response to highest number response. This number potentially indicates numbers known by the different data sources documented above or the variation in numbers of instructors in different geographical locations within the Health Board.

KEY CONTEXTUAL OVERVIEW - 3 CHP Regions

Cardiac Rehabilitation is delivered in hospital and/or the community over **ten** weeks. Exit strategy is Leisure provided community or Leisure centre based classes, followed by the offer of a referral to the specialist long term conditions (LTC) referral scheme.

Pulmonary Rehabilitation (PR) is delivered in the community throughout Fife as an eight week programme in 10 regions. Exit strategy is referral to the specialist long term conditions (LTC) referral scheme and for other community patients who may benefit.

Stroke Rehabilitation is delivered acutely in hospital and in community settings.

Long term conditions maintenance is delivered pan Fife within a specialist LTC referral scheme, Active Options 2. The service is delivered by Leisure Services with partners, NHS and Local Authority/council. Active Options 2 offers generic exercise classes based on 4 levels of functional ability for all LTC. It is accessed by HCP referral. It is delivered in wide variety of locations. It is not a time limited programme. Other options: Bums off Seats, a Fife Walking Initiative, providing free local health walk led by a trained team of volunteer walk leaders. This is a Fife Council funded project with support from Active Fife and Paths for All. Historically there was a generic exercise referral programme called Active Options 1. This programme was run with specific GP practices taking referral for patients who the GPs thought would benefit from exercise. This programme stopped in March 2013 due to lack of referrals.

Cardiac exercise maintenance is delivered as part of a community based maintenance programme (phase IV) available since 2000, as a partnership between NHS and Leisure. Third Sector provision of groups (CHSS affiliated), in two locations offering exercise classes which are Physiotherapist led, and in one location a support group. Recruitment into these groups has been challenging.

Respiratory exercise maintenance is delivered pan Fife by Leisure services within the specialist LTC referral scheme, Active Options 2. „Estimate about 50% of all PR patients/class are referred with their consent, no self referral option at a later date“ (HCP)

Stroke community based exercise maintenance is delivered pan Fife by Leisure services within the specialist LTC referral scheme, Active Options 2. Third Sector provision of three social/support groups (CHSS affiliated), in 3 locations.

KEY SUCCESSES

- **Service Provision and delivery pan Fife**, Active Options 2, since May 2012
- **Delivery of function based generic LTC classes**
- **Partnership/collaborative working**, NHS, HCP, LA, Leisure & Third Sector with a cross party working group for Active Options Leisure classes
- **Pathway, effective referral** by HCP to Leisure services
- **Specialist trained instructors** delivering classes
- **HCP involvement** into service design and delivery
- **Single point of referral and service co-coordinator**
- **Importance and value of volunteers** in assisting with delivery

KEY CHALLENGES

- **Access, transport & local access**
- **Accessing services, timing of referral & self referral option**, referral not available at a later date i.e. after the offer at the end of clinical rehabilitation
- **Data collection**, the resources staffing/time to collect data
- **Resources, funding & staffing sustainability for service delivery and workforce planning**. Although now self sustaining funding for service delivery, for some posts only there is only short term funding
- **Partnership/collaborative working**, signposting/linkage with other community groups (non Leisure)

Data Sources/References

The HCP, service providers/Leisure services and GP survey was online in „survey monkey“ format. For HCP the dissemination process for completion was for HCP via professional networks: SNNF, SSAHP forum, SPRAG, SRNF, CRIGS, CSP Scotland website/online forum, MCN Managers, HI, CHP, NMAHP leads for cascading and internally for stroke nurses in CHSS. Leisure services/service providers, via PAHA, HI, Physical Activity leads and via identification of leisure services providers from online searches along with cross checking with a previous stroke audit and gained knowledge from the PARCS scoping to that point. The GP survey was via a CHSS list of GPs who had previous contact with CHSS and then targeted identification of practices/practice managers in regions with a no/low responses rate, by sending the link to the survey via post or email. Some questionnaires were completed in paper format during face to face meetings as part of PARCS project and then inputted manually into the survey monkey format (with permission). For service users the surveys were posted out to all CHSS group leads to circulate via their respective groups. All data was protected in line with CHSS data protection and confidentiality policies and followed the ethical standards of the charity in line with charity business/service development.

All data incorporated within the CHSS PARCS scoping was collected for the period November 2012 – January 2014. The PARCS surveys were completed between August 2013 and January 2014.

The data represented in the tables above is compiled from a synthesis of data from PARC surveys - MCN, Health Care Professionals, and service provider (leisure services, third sector, and private provider) responses. The data synthesis process that was used for each question/table response was in relation to the number of definitive responses to that question (i.e. yes and no answers only, unsure responses were not included in the tally). For Yes or No responses, if all stakeholders reported Yes the table was populated with a Yes and the same process was used for No. If there was a mixed response from the different stakeholders, if the total responses for that question were high (>20) the majority response was used. If the total responses were low (below 20) if 2 or more stakeholders responded negatively (No) or positively (Yes) the answer was populated as „some regions“. If the responses for that question were high (>20) and the results were mixed i.e. a high number of yes and a high number of no, the answer was populated as some regions. If there was only a single response either yes or no the respective response was used and populated, or populated as 'one region' (as appropriate). If no responses, the section was left blank.

The data represented in key contextual overview and quotes sections (above the tables) is a data synthesis from the PARCS surveys (as detailed above and including service users), meetings detailed below and other data sources e.g. reports, audits/evaluations, online resources (e.g. websites etc), identified as part of the PARCS (CHSS) scoping. Where information was missing e.g. nil responses the information was based on information available from other e.g. online resources. The accuracy of such information may not always be correct; the sense check detailed below was to enable a mechanism whereby any errors to be identified and corrected.

The overview profile shown above (tables and key contextual data) was circulated prior to final production to the respective Health Board MCN Managers for sense checking (checking that the information had no obvious errors). A 2 week deadline was given (due to the time limited nature of the project). A nil response within a 2 week period would lead to the assumption that the data was acceptable and required no corrections.

PARCS surveys responses in this Health Board region (or hits on web based surveys, and stakeholders represented)

- MCN , n=1
- Health Care Professionals, n=18
- GPs, n= 12
- Services Providers (Leisure), n=2
- Service User's, n= 22

Meetings as part of PARCS CHSS scoping in this Health Board region

Face to face meetings with:

- Service users and non service users - Focus group with ladies ethnic group (potentially affiliating to CHSS) total n=20, including n=5, with long term conditions, (including respiratory, cardiac and stroke), n=5 with other health issues.
- Meetings with Third Sector community support worker (CHSS) and Health Project Worker

References

ISD statistics provided by ISD

1. Source: 2012 mid-year population estimates (National Records of Scotland (NRS)) (<http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html>)
2. Source: 2011/12 version of the Urban Rural Classification (Scottish Government) and the 2012 mid-year population estimates (National Records of Scotland).
3. Urban areas are settlements of over 3,000 people. Rural areas are settlements of fewer than 3,000 people. More details can be found here: <http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification>
4. Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp>
5. Source: SMR01 (ISD), extracted February 2014. Number of patients discharged from hospital during calendar year 2012.
6. Source: Cardiac Rehabilitation in Scotland (2011/12) publication. The full publication and data tables can be found here: <https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf>

Statistics from other sources (as not collected by ISD)

7. Health Improvement Scotland Costing Report – Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/copd_implementation/implementing_copd_standards.aspx
8. These figures were based on responses to the PARCS survey (CHSS scoping) from services providers (this could include leisure, third sector, private). The year (i.e. 2012 -2013) from some providers was not completed. The figures are therefore intended to give a snapshot estimate of numbers in services. Also in some regions more than one provider was identified but only one or some of the providers responded. In some regions attendance fluctuated in numbers particularly in third sector groups, so figures were based on averages or the range if given. The figure provided is not a definitive figure but intended to give a best estimate based on the information available and only represents service providers and initiatives that the PARCS scoping was able to identify within the time limited constraints of the project and the data available.
9. **Register of Exercise Professionals (REPs)** is an independent, public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REP's provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards. **DEFINITION OF REPS LEVEL 3:** The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions this includes Respiratory Conditions: Asthma and Chronic obstructive pulmonary disease (COPD). Musculoskeletal Conditions, Cardiovascular Conditions, Hypertension, Hypercholesterolaemia, Psychological/Mental Health Conditions, Metabolic/Immunological Conditions e.g. Diabetes Type 1 and Type 2 and obesity. **DEFINITION OF REPS LEVEL 4:** The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the affects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease. <http://www.exerciseregister.org/resources/exercise-referral>

FORTH VALLEY

Service Users „...enjoy having the qualified staff... who know us all and relate to everyone. A gym membership would not give me this security... discuss with others what we have all come through“ „everyone at these classes has the common issue with transportation... I feel Stirling should have some more provision for support networking local stroke victims so we can all learn from and support one another“

Health Care Professional (HCP) „...only a few continue to use, I think due to cost for some, as pulmonary patients in my area are fairly poor and would rather come to us (NHS) where it is free“

GP „Neighbouring CHP can refer to leisure centre exercise services, no access for our patients“.

GP „appears to be under resourced“ „would be good if patients could self-refer and it was integral to a patient's discharge from hospital/recovery from a condition“

Service Provider „Need more collaboration from partners in the need for and setting up of exercise maintenance classes in Stirling.....needs to be assistance in assessing the latent demand for these classes in order for us to train and provide these classes within the Stirling area“.

BOARD PROFILE

Total Board Population ⁽¹⁾	299,100
Urban/ Rural ^(2,3)	249,380 / 49,720 (83% / 17%)

PREVELANCE & STRUCTURED CLINICAL REHABILITATION

Condition	CHD	COPD	Stroke
Prevalence ⁽⁴⁾	13,911	6,356	6,534
Hospital Discharges ⁽⁵⁾ (number of patients)	1,018	588	402
Cardiac Rehabilitation ⁽⁶⁾ (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	276 (49.6%)	N/A	N/A
Pulmonary Rehabilitation ⁽⁷⁾ (estimated total number of patients per year)		527	
Stroke Rehabilitation (number of patients per year)			Not collected by ISD

AVAILABILITY OF EXERCISE MAINTENANCE (EM)

Known numbers participating in community based maintenance exercise/physical activity (snapshot/estimated per annum) ⁽⁸⁾	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults/ Older Adults Activities
Leisure services provided (referrals)						150-200 * 390 – 400**
CHSS (affiliated) groups (attendees, 2014)		390				

*figures referrals per annum (average) – Stirling via MCN

** figures referrals annum (average) – Falkirk via MC

SERVICE DELIVERY OF EM

Aspects of Delivery	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults	Other: Third Sector/ Charity Affiliated
Type of Delivery (Generic/LTC or Condition Specific*)	Some regions	Yes	Some regions	Some regions	Some regions	Yes	Falls Prevention
Established Pathways to Exercise Maintenance	Some regions	Yes	Some regions	Yes	Yes	Yes	
Earliest year a Scheme Commenced	2006 or earlier	2006 or earlier			2006 or earlier	2006 or earlier	
Service Co-ordinator	Some regions	Yes	Some regions	Some regions	Some regions	Yes	Falls Prevention

*Yes/No here indicates stakeholder responses to the question what types of follow on maintenance class are available in your region generic long term conditions class, a cardiac specific class, a respiratory specific class etc (details of data sources and synthesis in the reference section below)

REFERRAL OF EM

Single Point of Referral for all Long Term Conditions to Exercise Maintenance	No, there is a single point of referral for each Region/ service, one for Falkirk and one for Stirling.
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DATA COLLECTION OF EM

Data Collector / Data Collected	Not collected	Leisure services	Commissioned By Third Sector/ Other	NHS – HCP	Other
Follow up data		Yes		No	
Cost effectiveness		No		No	
Person centred data		Yes		No	

FUNDING OF EM

Funders	Local Authority	Leisure Services	Short Term Government Grant	Short Term NHS - Charitable	Established NHS	Third Sector/ Charity
Funding partners for service delivery		Yes	Yes			Yes
Funding for initial instructor/service provider training			Yes			Yes

GOVERNANCE OF EM

Collaborative working group(s) for governance of exercise maintenance	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
	Yes (n=1)	Yes (within ex referral, n=1)	Yes (n=1)			Yes (n=3)

INSTRUCTORS WITH SPECIALIST TRAINING

Different regions have variation in numbers trained, overall total of known instructors shown

REPS Level 4 (9)	REPS Level 3 (9)	BACPR	Otago (falls)	Postural Stability Instructor (falls)	Exercise After Stroke	Wright Foundation	Seated Exercise	NHS In-house	Data Sources
	8-12 (i)		4-5 (i)			6		1	Leisure services , MCN – Stirling & Clackmannans hire, & HCP

(i)The range in total numbers indicated represents the range of responses given, i.e. lowest number response to highest number response.

This number potentially indicates numbers known by the different data sources documented above or the variation in numbers of instructors

in different geographical locations within the Health Board.

KEY CONTEXTUAL OVERVIEW - 3 Community Health Partnership (CHP) Region

Cardiac Rehabilitation (CR) is delivered in a community Leisure setting for twelve weeks. The NHS has its own suite in Leisure (Peak Stirling).

Pulmonary Rehabilitation (PR) is delivered at Forth Valley Royal Hospital.

Stroke Rehabilitation is delivered at Forth Valley Royal Hospital and in the community.

Long Term Conditions Maintenance

- **Stirling** - within an exercise referral scheme “Active Living for Life”, delivered by Leisure services for those with inactive lifestyles and those with a diagnosed medical condition. It was established in April 2013. Accessed by a HCP referral includes initial consultation with an instructor, three, nine and twelve week review, with exit strategy to ongoing activities. “*Active Living for Life*” is Stirling’s exercise on referral scheme, but referrals from outwith the Stirling area are welcome (including Clackmannanshire and Falkirk). 68% of referrals are from the Stirling council area, 27% of referrals are from the Clackmannanshire council area and 6% of referrals are from the Falkirk Council area. “Active Living for Life” runs a programme of classes for older adults called „Active Adults” which includes Otago classes. Active Living for Life also incorporate Strength and Balance exercises into a number of their led health walks across the region in order to contribute to the Falls Prevention Strategy.
- **Falkirk** - within a physical activity referral scheme, “Active Forth”, this is open to a range of medical conditions including respiratory, cardiac and stroke. Accessed by a HCP referral and includes initial consultations with an instructor, four, eight and twelve week review. “Active Forth” links with other services, menu based options include: Otago (fall) classes, aquacize, Step Forth walking groups (in partnership with Paths for All). Self-referral is available to Step

Forth and Falls Prevention classes. 98% of active referrals are from the Falkirk council area, 2% of active referrals are from the Clackmannanshire council area. No active referrals were received from the Stirling Council area during 2014. Referrals are accepted from other areas as some member may work in the area and live elsewhere.

- **Clackmannanshire** - there is currently no formally funded exercise referral scheme in place for Clackmannanshire. However, referrals for residents of Clackmannanshire are taken by the “Active Living for Life” exercise referral scheme (based at the Peak in Stirling) and exercise classes for over 50s, mature movers & Otago (falls, strength and balance). Referrals for residents of Clackmannanshire are also taken by the “Active Forth” physical activity referral scheme (based in Falkirk). Clackmannanshire Healthier Lives community based programme offers support and advice to people in Clackmannanshire to help them make changes that can improve their health and wellbeing e.g. they can provide access to walking groups. Tullibody Healthy Living projects a voluntary project working in partnership with local volunteers and other agencies; provide local access to many healthy living activities.

Cardiac Exercise Maintenance is delivered by Leisure and Third Sector

- **Stirling** within the exercise referral scheme, Active Living for Life, and by one Third Sector (CHSS affiliated) group offering exercise (Physiotherapist led) support & education.
- **Falkirk** within the physical activity referral scheme, Active Forth and Third Sector (CHSS affiliated) groups, one exercise (Physiotherapist led) and one education and support.
- **Clackmannanshire** can access physical activity referral schemes (Active Living for Life in Stirling and Active Forth in Falkirk) & by one Third Sector (CHSS affiliated) group offering support & education. Clackmannanshire Healthier Lives community based programme offers support and advice to people in Clackmannanshire to help them make changes that can improve their health and wellbeing

Respiratory Community Based Exercise Maintenance

- **Stirling**, within the exercise referral scheme, Active Living for Life
- **Falkirk**, within the physical activity referral scheme, Active Forth
- **Clackmannanshire**, can access physical activity referral schemes (Active Living for Life in Stirling and Active Forth in Falkirk). Clackmannanshire Healthier Lives community based programme offers support and advice to people in Clackmannanshire to help them make changes that can improve their health and wellbeing

Stroke Community Based Exercise Maintenance

- **Stirling** within the exercise referral scheme, Active Living for Life
- **Falkirk**, within the physical activity referral scheme, Active Forth
- **Clackmannanshire** can access physical activity referral schemes (Active Living for Life in Stirling and Active Forth in Falkirk). Clackmannanshire Healthier Lives community based programme offers support and advice to people in Clackmannanshire to help them make changes that can improve their health and wellbeing

KEY SUCCESSES

- **Delivery of generic LTC classes**
- **Collaborative/partnership working**, a pan Forth Valley multi agency steering group to support the development and implementation of “Active Living for Life”.
- **Knowledge and information of services**, information resource produced by Falkirk Council, includes activity, health and fitness, community and support groups

- **Data, information sharing and transfer**, feedback of data to referring practitioners/ multiple agency steering group
- **Delivery of clinical rehabilitation in a community setting** (CR and PR)

KEY CHALLENGES

- **Collaborative/partnership working**
- **Data collection**, in relation to need for development of services
- **Pathways, effective referral & signposting**, some gaps identified
- **Instructor training**, developing confidence across instructors
- **Equity of service provision across the Health Board region**
- **Resources, staffing and funding** for further development of service provision

Data Sources/References

The HCP, service providers/Leisure services and GP survey was online in „survey monkey“ format. For HCP the dissemination process for completion was for HCP via professional networks: SNNF, SSAHP forum, SPRAG, SRNF, CRIGS, CSP Scotland website/online forum, MCN Managers, HI, CHP, NMAHP leads for cascading and internally for stroke nurses in CHSS. Leisure services/service providers, via PAHA, HI, Physical Activity leads and via identification of leisure services providers from online searches along with cross checking with a previous stroke audit and gained knowledge from the PARCS scoping to that point. The GP survey was via a CHSS list of GPs who had previous contact with CHSS and then targeted identification of practices/practice managers in regions with a no/low responses rate, by sending the link to the survey via post or email. Some questionnaires were completed in paper format during face to face meetings as part of PARCS project and then inputted manually into the survey monkey format (with permission). For service users the surveys were posted out to all CHSS group leads to circulate via their respective groups. All data was protected in line with CHSS data protection and confidentiality policies and followed the ethical standards of the charity in line with charity business/service development.

All data incorporated within the CHSS PARCS scoping was collected for the period November 2012 – January 2014. The PARCS surveys were completed between August 2013 and January 2014.

The data represented in the tables above is compiled from a synthesis of data from PARC surveys - MCN, Health Care Professionals, and service provider (leisure services, third sector, and private provider) responses. The data synthesis process that was used for each question/table response was in relation to the number of definitive responses to that question (i.e. yes and no answers only, unsure responses were not included in the tally). For Yes or No responses, if all stakeholders reported Yes the table was populated with a Yes and the same process was used for No. If there was a mixed response from the different stakeholders, if the total responses for that question were high (>20) the majority response was used. If the total responses were low (below 20) if 2 or more stakeholders responded negatively (No) or positively (Yes) the answer was populated as „*some regions*“. If the responses for that question were high (>20) and the results were mixed i.e. a high number of yes and a high number of no, the answer was populated as *some regions*. If there was only a single response either yes or no the respective response was used and populated, or populated as *‘one region’* (as appropriate). If no responses, the section was left blank.

The data represented in key contextual overview and quotes sections (above the tables) is a data synthesis from the PARCS surveys (as detailed above and including service users), meetings detailed below and other data sources e.g. reports, audits/evaluations, online resources (e.g. websites etc), identified as part of the PARCS (CHSS) scoping. Where information was missing e.g. nil responses the information was based on information available from other e.g. online resources. The accuracy of such information may not always be correct; the sense check detailed below was to enable a mechanism whereby any errors to be identified and corrected.

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PARCS surveys responses in this Health Board region (or hits on web based surveys, and stakeholders represented)

- MCN responses, n= 2 (1 from Falkirk and 1 from Stirling and Clackmannanshire)
- Health Care Professionals responses , n= 6
- GP responses, n= 14
- Leisure services providers, n=2
- Service users, n= 15

Meetings as part of PARCS CHSS scoping in this Health Board region

Face to Face Meetings with:

- x 1 with community engagement officer

References

ISD statistics provided by ISD

4. Source: 2012 mid-year population estimates (National Records of Scotland (NRS)) (<http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html>)
5. Source: 2011/12 version of the Urban Rural Classification (Scottish Government) and the 2012 mid-year population estimates (National Records of Scotland).
6. Urban areas are settlements of over 3,000 people. Rural areas are settlements of fewer than 3,000 people. More details can be found here: <http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification>
7. Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp>
8. Source: SMR01 (ISD), extracted February 2014. Number of patients discharged from hospital during calendar year 2012.
9. Source: Cardiac Rehabilitation in Scotland (2011/12) publication. The full publication and data tables can be found here: <https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf>

Statistics from other sources (as not collected by ISD)

10. Health Improvement Scotland Costing Report – Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/copd_implementation/implementing_copd_standards.aspx
11. These figures were based on responses to the PARCS survey (CHSS scoping) from services providers (this could include leisure, third sector, private). The year (i.e. 2012 -2013) from some providers was not completed. The figures are therefore intended to give a snapshot estimate of numbers in services. Also in some regions more than one provider was identified but only one or some of the providers responded. In some regions attendance fluctuated in numbers particularly in third sector groups, so figures were based on averages or the range if given. The figure provided is not a definitive figure but intended to give a best estimate based on the information available and only represents service providers and initiatives that the PARCS scoping was able to identify within the time limited constraints of the project and the data available.
12. **Register of Exercise Professionals (REPs)** is an independent, public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REP's provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards. **DEFINITION OF REPS LEVEL 3:** The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions this includes Respiratory Conditions: Asthma and Chronic obstructive pulmonary disease (COPD). Musculoskeletal Conditions, Cardiovascular Conditions, Hypertension, Hypercholesterolaemia, Psychological/Mental Health Conditions, Metabolic/Immunological Conditions e.g. Diabetes Type 1 and Type 2 and obesity. **DEFINITION OF REPS LEVEL 4:** The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the affects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease. <http://www.exerciseregister.org/resources/exercise-referral>

GRAMPIAN

Service Users ‘not just about exercise, it’s meeting people ... helps to talk and know you are not alone’⁽¹⁰⁾ „gives you a purpose and makes sure you get regular exercise” „discovered how much exercise I could do ...reassuring and confidence building”⁽¹⁰⁾

Health Care Professionals (HCP) „... there is very limited provision of and access to exercise maintenance in my local area.” „GP referral scheme based at Moray Leisure Centre in Elgin for all conditions. This is only available in Elgin so people in other areas of Moray are expected to travel. „

Service Provider „Pulmonary rehabilitation treatment and maintenance classes have been delivered by the NHS and (Leisure) but are hampered by a lack of funding. The same applies to the Fall Prevention classes which require more qualified Otago/Postural Stability Instructors. This is again restricted by funding to qualify instructors.”

BOARD PROFILE

Total Board Population ⁽¹⁾	573,420
Urban/ Rural ^(2,3)	385,289 / 188,131 (67% / 33%)

PREVELANCE & STRUCTURED CLINICAL REHABILITATION

Condition	CHD	COPD	Stroke
Prevalence ⁽⁴⁾	22,392	9,186	10,658
Hospital Discharges ⁽⁵⁾ (number of patients)	2,279	938	803
Cardiac Rehabilitation ⁽⁶⁾ (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	459 (35.6%)		
Pulmonary Rehabilitation ⁽⁷⁾ (estimated total number of patients per year)		650	
Stroke Rehabilitation (total number of patients per year)			Not collected by ISD

AVAILABILITY OF EXERCISE MAINTENANCE (EM)

Known numbers participating in community based maintenance exercise/physical Activity (snapshot/estimated per annum) ⁽⁸⁾	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults/ Older Adults Activities. in Moray- Be Active Life Long (BALL), and Strength and Balance (S&B) groups
Leisure services provided						
CHSS, Stroke Association and British Lung Foundation affiliated groups (attendees, 2014)		405	26 & 14	30		

Local Authority provided (Moray council – older people's development team) (attendees, 2014)						507 (BALL)i) 56 (S&B) i)
Total Known (attendees)		405	40	30		563

i) Moray Council Older people's development team figures, January 2014

SERVICE DELIVERY OF EM

Aspects of Delivery	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults	Other: Third Sector/ Charity Affiliated
Type of Delivery (Generic/LTC or Condition Specific *)	Some regions & piloting of service in others	Yes	Yes	Some regions	Some regions	Some regions	Some regions
Established Pathways to Exercise Maintenance	Some regions	Some regions	Some regions	Some region	Some regions	Some regions	Some regions
Earliest year a Scheme Commenced	2012	2002	2006 or earlier	2006 or earlier	2012	2011	2006 or earlier

*Yes/No here indicates stakeholder responses to the question what types of follow on maintenance class are available in your region generic long term conditions class, a cardiac specific class, a respiratory specific class etc (details of data sources and synthesis in the reference section below)

REFERRAL OF EM

Single Point of Referral for all Long Term Conditions to Exercise Maintenance	No, there are regional service co-ordinators/single point of contact/referral in some regions
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DATA COLLECTION OF EM

<div> Data Collector </div> <div> Data Collected </div>	Not collected	Leisure services	Commissioned By Third Sector/ Other (Grampian Cardiac Rehabilitation Association, GCRA,10)	NHS – HCP	Other
Follow up data		No	Yes	One region	
Cost effectiveness		No	Yes	No	
Person centred data		No	Yes	Two regions	

FUNDING OF EM

Funders	Local Authority	Leisure Services	Short Term Government Grant	Short Term NHS - Charitable	Established NHS	Third Sector/ Charity
Funding partners for service delivery		Yes		Yes	One region/ condition area	Yes
Funding for initial instructor/service provider training				Yes	One region/ condition area	Yes

GOVERNANCE FOR EM

Collaborative working group(s) for governance of exercise maintenance	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
	Some regions	Yes (Working group for pilot)	Yes	Yes	Yes	

INSTRUCTORS WITH SPECIALIST TRAINING

(Different regions have variation in numbers trained, overall total of known instructors shown)

REPS Level 4 ((9)	REPS Level 3 (9)	BACPR	Otago (falls)	Postural Stability Instructor (falls)	Exercise After Stroke	Wright Foundation	Seated Exercise	NHS In-house	Data Sources
		14	3-6 (i)	2	2				HCP, Third Sector - GCRA (CHSS affiliated), Different strokes, private provider, Leisure, active ageing & MCN

(i)The range in total numbers indicated represents the range of responses given, i.e. lowest number response to highest number response.

This number potentially indicates numbers known by the different data sources documented above or the variation in numbers of instructors in different geographical locations within the Health Board.

KEY CONTEXTUAL OVERVIEW - 3 CHP Regions

Cardiac Rehabilitation is delivered in both health care and community settings in Aberdeen and is hospital based in Moray.

Pulmonary Rehabilitation is delivered in both health care and community settings.

Stroke Rehabilitation is delivered in hospital and community hospitals and by community therapy services.

Long Term Conditions (LTC) Exercise Maintenance

- **Differing service provision for LTC, across the three distinct CHP regions.** For LTC generic classes, a feasibility pilot is in progress, via pan Grampian multidisciplinary steering group (Active for Life). Post falls/older adults" classes are delivered by Leisure services, Third Sector and independent groups with large pan Grampian reach.
- **Other condition specific exercise maintenance classes** (e.g. multiple sclerosis, Parkinson"s, dementia and cancer) are delivered by Leisure services, Third Sector & independent groups, largely one group for each condition delivered in some locations in Grampian
- **Exercise referral**, three regions have an exercise on referral programme.

- **Moray has referral to Leisure services from all specialities of clinical rehabilitation** for ongoing maintenance.

Cardiac Exercise Maintenance Classes, delivered since 2002 by Third Sector affiliated provider, Grampian Cardiac Rehabilitation Association (GCRA) (CHSS affiliated group), with thirty four classes across Aberdeen and Aberdeenshire. Classes delivered for the last 12 years by the University of Aberdeen, at Aberdeen Sports Village. In Moray this is Leisure services provided within LTC (see above).

Respiratory Exercise Maintenance Classes are delivered by Leisure services and independent groups, with variation pan Grampian. In Aberdeen, Leisure services classes, with referral from pulmonary rehabilitation and signposting to British Lung Foundation (BLF), Breathe Easy support groups. In Moray, Third Sector (CHSS affiliated) support group and independent group(s) led by a private exercise instructor(s).

Stroke Exercise Maintenance Classes are delivered by Third Sector (including two CHSS affiliated groups & one Stroke Association group) in three locations across Aberdeen and Aberdeenshire. The MCN in Grampian has applied for funding for pan Grampian training for Physiotherapists and instructors in exercise after stroke qualification, collaborating with mainstream Leisure services to offer to offer this.

KEY SUCCESSES

- **Collaborative/partnership working**, pan Grampian for LTC service piloting/development
- **Pathway, effective referral in Moray** with referral to Leisure services from all specialities of clinical rehabilitation to maintenance
- **Well established falls, older adults and cardiac programmes**

KEY CHALLENGES

- **Equitable service provision and delivery Pan Grampian for LTC**
- **Resources, funding & staffing** to deliver core clinical services as well as exercise maintenance, lack of funding for service delivery
- **Instructor training**, lack of funding for instructor training
- **Data collection**, resources staff and time, to enable this
- **Knowledge of services**, often inconsistent, and includes compiling directories, with previous efforts to develop and maintain such directories non sustainable, due to resources staffing/time
- **Access**, local service provision, transport, access for those housebound, and timing of offer of services to suit user need, i.e. may not always coincide with service user exiting clinical rehabilitation
- **Collaborative/partnership working**, understanding, addressing and accommodating differing perspectives and ways of working
- **Community delivered clinical rehabilitation**, investing in Pulmonary Rehabilitation and delivering this in the community was and is a driver to the establishment of maintenance classes

Data Sources/References

The HCP, service providers/leisure services and GP survey was online in „survey monkey“ format. For HCP the dissemination process for completion was for HCP via professional networks: SNNF, SSAHP forum, SPRAG, SRNF, CRIGS, CSP Scotland website/online forum, MCN Managers, HI, CHP, NMAHP leads for cascading and internally for stroke nurses in CHSS. Leisure services/service providers, via PAHA, HI, Physical Activity leads and via identification of leisure services providers from online searches along with cross checking with a previous stroke audit and gained knowledge from the PARCS scoping to that point. The GP survey was via a CHSS list of GPs who had previous contact with CHSS and then targeted identification of practices/practice managers in regions with a no/low responses rate, by sending the link to the survey via post or email. Some questionnaires were completed in paper format during face to face meetings as part of PARCS project and then inputted manually into the survey monkey format (with permission). For service users the surveys were posted out to all CHSS group leads to circulate via their respective groups. All data was protected in line with CHSS data protection and confidentiality policies and followed the ethical standards of the charity in line with charity business/service development.

All data incorporated within the CHSS PARCS scoping was collected for the period November 2012 – January 2014. The PARCS surveys were completed between August 2013 and January 2014.

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The data represented in key contextual overview and quotes sections (above the tables) is a data synthesis from the PARCS surveys (as detailed above and including service users), meetings detailed below and other data sources e.g. reports, audits/evaluations, online resources (e.g. websites etc), identified as part of the PARCS (CHSS) scoping. Where information was missing e.g. nil responses the information was based on information available from other e.g. online resources. The accuracy of such information may not always be correct; the sense check detailed below was to enable a mechanism whereby any errors to be identified and corrected.

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PARCS surveys responses in this Health Board region (or „hits“ on web based surveys, and stakeholders represented)

- MCN, n= 1
- Health Care Professionals, n= 20
- GPs, n= 10
- Services providers, Leisure, n=1, Third sector n=1, Private provider, n=1

Meetings as part of PARCS CHSS scoping in this Health Board region

Face to Face Meetings with:

- X 1 Lead Health Care Professional
- X 2 Health Improvement
- X 3 Active for Life group – including NHS - HCPs, Third Sector, Leisure services and Local Authority

Other communications (email correspondence & telephonic meetings/communications)

- X 1 Leisure services
- X 5 Health Improvement

References

ISD statistics provided by ISD

1. Source: 2012 mid-year population estimates (National Records of Scotland (NRS)) (<http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html>)
2. Source: 2011/12 version of the Urban Rural Classification (Scottish Government) and the 2012 mid-year population estimates (National Records of Scotland).
3. Urban areas are settlements of over 3,000 people. Rural areas are settlements of fewer than 3,000 people. More details can be found here: <http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification>
4. Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp>
5. Source: SMR01 (ISD), extracted February 2014. Number of patients discharged from hospital during calendar year 2012.
6. Source: Cardiac Rehabilitation in Scotland (2011/12) publication. The full publication and data tables can be found here: <https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf>

Statistics from other sources (as not collected by ISD)

7. Health Improvement Scotland Costing Report – Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) http://www.healthcareimprovementscotland.org/our_work/long_termconditions/copd_implementation/implementing_copd_standards.aspx
8. These figures were based on responses to the PARCS survey (CHSS scoping) from services providers (this could include leisure, third sector, private). The year (i.e. 2012 -2013) from some providers was not completed. The figures are therefore intended to give a snapshot estimate of numbers in services. Also in some regions more than one provider was identified but only one or some of the providers responded. In some regions attendance fluctuated in numbers particularly in third sector groups, so figures were based on averages or the range if given. The figure provided is not a definitive figure but intended to give a best estimate based on the information available and only represents service providers and initiatives that the PARCS scoping was able to identify within the time limited constraints of the project and the data available.
9. **Register of Exercise Professionals (REPs)** is an independent, public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REP's provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards. **DEFINITION OF REPS LEVEL 3:** The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions this includes Respiratory Conditions: Asthma and Chronic obstructive pulmonary disease (COPD). Musculoskeletal Conditions, Cardiovascular Conditions, Hypertension, Hypercholesterolaemia, Psychological/Mental Health Conditions, Metabolic/Immunological Conditions e.g. Diabetes Type 1 and Type 2 and obesity. **DEFINITION OF REPS LEVEL 4:** The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the affects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease. <http://www.exerciseregister.org/resources/exercise-referral>
10. (Gray, 2010). Grampian Cardiac Rehabilitation Association Phase IV Evaluation, undertaken by Robert Gordon University, report generated/research unpublished). This was an evaluation of exercise class members, n = 319, male, n= 173, average age 68, female, n=144, average age 69, and ex GCRA members, n= 68, average time since attendance 15 months.

GREATER GLASGOW & CYLDE

Service User „I believe that if the rehabilitation team had not told me of the groups and encouraged me to take part I would have struggled to find out about alternatives myself. I also believe that I wouldn't feel better and may in fact have had further complications.”

Health Care Professional (HCP) „I think access to exercise maintenance classes is good in this area. There are a variety of levels of classes for our patients to attend, a variety of locations and times...” „...the exercise instructors are also able to signpost people to alternative community resources that may be of benefit to sustain long term adherence to exercise” “I have been closely involved in many projects over many years that sought to develop and enhance .. services and adherence... until the MCN and Health Board fully funded a comprehensive staff and service delivery programme things were always piecemeal and temporary. This seems to me to be the biggest driver in long term successful services”

Service Provider „Extremely high uptake of Vitality service among users with chronic conditions”

BOARD PROFILE

Total Board Population ⁽¹⁾	1,213,973
Urban/ Rural ^(2,3)	1,188,022 / 25,951 (98% / 2%)

PREVELANCE & STRUCTURED CLINICAL REHABILITATION

Condition	CHD	COPD	Stroke
Prevalence ⁽⁴⁾	55,686	31,201	27,295
Hospital Discharges ⁽⁵⁾ (number of patients)	4,879	3,777	2,044
Cardiac Rehabilitation ⁽⁶⁾ (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	1,771 (61.2%)		
Pulmonary Rehabilitation ⁽⁷⁾ (estimated total number of patients per year)		1,916	
Stroke Rehabilitation (number of patients per year)			Not collected by ISD

AVAILABILITY OF EXERCISE MAINTENANCE (EM)

Known numbers participating in community based maintenance exercise/physical activity (snapshot/estimated per annum) ⁽⁸⁾	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic Ex Ref generic	Exercise Referral Older Adults/ Older Adults Activities (Silver Deal) ^(iv)
Leisure services provided (referrals to service)		419 ⁽ⁱ⁾	338 ⁽ⁱⁱ⁾		5,286 ⁽ⁱⁱⁱ⁾	
Leisure services provided (attendances)	61,667 ^(IV)					
CHSS affiliated groups (attendees in 2014)		230	20			
Local Authority, Leisure & Housing Association partnership - Silver Deal (numbers registered) ^(iv)						1,500 ^(v)

(i) Live Active figures, referrals to service from April 2012 to March 2013

- (ii) 338, is the figure referred from Pulmonary Rehabilitation to either Live Active or Vitality schemes. Figures from PARCS qualitative/economic report.
- (iii) Live Active figures, this number will include a proportion of stroke and respiratory patients
- (iv) Vitality figures for attendances, April 2012- December 2012
- (v) Silver Deal figures for numbers registered. Silver Deal is a partnership between Glasgow Housing Association and Glasgow Life that provides free regular, coach-led physical activity and arts sessions in GHA Sheltered Housing Complexes.
- (iv) 1,500 is the number registered on Silver Deal programme
http://www.scotland.gov.uk/Topics/Built_Environment/Housing/access/ROOPH/casestudies/preventativesupport/ghasda

SERVICE DELIVERY OF EM

Aspects of Delivery	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults	Other: Third Sector/ Charity
Type of Delivery (Generic/LTC or Condition Specific *)	Yes	Yes	Yes	Some regions	Yes	Yes	
Established Pathways to Exercise Maintenance	Yes	Yes	Yes	Some regions	Yes	Yes	
Earliest year a Scheme Commenced	2006 or earlier	2006 or earlier	2006 or earlier	2006 or earlier	2006 or earlier	2006 or earlier	2006 or earlier
Service Co-ordinator	Yes	Yes	Yes	Yes	Yes	Yes	

*Yes/No here indicates stakeholder responses to the question what types of follow on maintenance class are available in your region generic long term conditions class, a cardiac specific class, a respiratory specific class etc (details of data sources and synthesis in the reference section below)

REFERRAL TO EM

Single Point of Referral for all Long Term Conditions to Exercise Maintenance	No. There is a no single referral point; there is standardised pan GGC referral process with referral to each individual provider. Live Active, Vitality and Silver Deal (sheltered housing) have service co-ordinators.
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DATA COLLECTION FOR EM

Data Collector	Not collected	Leisure services	Commissioned by academic institution	NHS – HCP	Other
Data Collected					
Follow up data		Yes		Yes	
Cost effectiveness		One region		No	
Person centred data		One region		Some regions	

FUNDING FOR EM

Funders	Local Authority	Leisure Services	Short Term Government Grant	Short Term NHS - Charitable	Established NHS	Third Sector/ Charity
Funding partners for service delivery	Yes	Yes			Yes	Yes
Funding for initial instructor/service provider training				Yes		

GOVERNANCE OF EM

Collaborative working group(s) for governance of exercise maintenance	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
		Yes	Yes	Yes	Yes	Yes

INSTRUCTORS WITH SPECIALIST TRAINING

Different regions have variation in numbers trained, overall total of known instructors shown

REPS Level 4 (9)	REPS Level 3 (9)	BACPR	Otago (Falls)	Postural Stability Instructor (Falls)	Exercise After Stroke	Wright Foundation	Seated Exercise	NHS In house	Data Sources
2-44 (i)	2-25 (i)	2-35 (i)	6-10 (i)	3-44 (i)	3-20 (i)	0-4 (i)		35-44 (ii)	PARCS scoping/ meetings, surveys -HCPs, & Leisure services

(i) The range in total numbers indicated represents the range of responses given, i.e. lowest number response to highest number response.

This number potentially indicates numbers known by the different data sources documented above or the variation in numbers of instructors in different geographical locations within the Health Board.

(ii) NHS/ In House - All instructors have at least 2 of the Vitality competency certificates (This is the NHS in house training, in conjunction with Health Improvement Lead, osteoporosis, neurological diseases – stroke, multiple sclerosis, Parkinson's, chronic obstructive pulmonary disease, vitality certificate. The majority of instructors have all four competency certificates if they are teaching the Strength and Balance circuit)

KEY CONTEXTUAL OVERVIEW - 6 CHP Regions

Cardiac Rehabilitation is delivered by the NHS in hospital and community based settings with an exit strategy to refer to the Exercise Referral Scheme (ERS) Live Active or Vitality or independent activity as appropriate.

Pulmonary Rehabilitation (PR) is delivered by the NHS in seventeen venues, three hospitals, fourteen community venues, as a six week program. Exit Strategy is referral to ERS Live Active or Vitality classes or other appropriate options e.g. higher level exercise, support groups or Live Active one to one support.

Stroke Rehabilitation is delivered in by the NHS hospital and community based settings with an exit strategy to refer to ERS Live Active or Vitality.

Long term conditions exercise maintenance is delivered pan GGC within the Exercise Referral Scheme (ERS), Live Active. There is a specialist component Vitality, for long term

conditions (LTC). It is delivered by Leisure services, with support from NHS. Live Active offers 12 months 1-2-1 behavioural change support via face to face & telephone consultations & individually tailored activity goals & support. The LA also provides supervised exercise sessions, gym sessions and health led walks. Vitality is for adults with LTC (including heart disease, pulmonary or stroke) and offers generic exercise classes based on four levels of functional ability, delivered by specialist instructors. Physiotherapists & Nursing staff have worked in partnership with service co-ordinator & exercise instructors to design exercise programmes within Vitality. Access is via self-referral (with screening), referral from Primary Care or HCP, from Live Active Referral Scheme or directly from an NHS rehabilitation service. Self-referral initiated in 2011.

Cardiac exercise maintenance is delivered within ERS and Vitality and can be supported by Live Active. Third Sector (CHSS affiliated) exercise groups, in five locations all specialist instructor or Physiotherapist led.

Respiratory exercise maintenance is delivered within ERS and Vitality and can be supported by Live Active. PR also signpost to two Third sector (CHSS affiliated) support groups.

Stroke exercise maintenance is delivered within ERS and Vitality and can be supported by Live Active.

KEY SUCCESSES

- **Service provision and delivery of the Vitality scheme for LTC pan GGC**
- **Service provision well established**, Live Active commenced in 1997 under the umbrella of GP exercise referral
- **Replacement of condition specific classes with LTC classes** (Vitality)
- **Tailored exercise, offering appropriate and varied levels of activity**
- **Instructors with specialist training**
- **Menu based options available**
- **Service co-ordinator (s)** for service delivery
- **Partnership working**, Vitality is a quality assured programme delivered by Local Authority and Leisure services with support from NHS GGC
- **HCP involvement in service design and delivery**
- **Knowledge of services**, good awareness of services available and referral by HCP
- **Effective referral and signposting to services** by HCP
- **Pathway, referral**, simplification of the referral process and developed into offering self-referral
- **Timetabling of rehabilitation and exercise maintenance classes** i.e. PR and maintenance class timings are linked
- **Delivery within the housing association, including sheltered housing** for older adults is beneficial, increasing attendance, improving physical activity, health and mobility

KEY CHALLENGES

- **Data collection/IT systems**, to track participants and stratify by condition (out with cardiac this can be done, but is not at present a streamlined reporting measure). Data transfer between agencies NHS and local authority. No database for continuation from rehabilitation to maintenance
- **Monitoring/adherence and follow up of non-attendance**, funding and staff resources for this

- **Service development to expand services based on user need**, Vitality wish to ensure engagement of participants who cannot speak English
- **Access, transport and local access** for the infirm/housebound, issues of transport to maintenance class
- **Social isolation** for those with LTC

Data Sources/References

The HCP, service providers/leisure services and GP survey was online in „survey monkey“ format. For HCP the dissemination process for completion was for HCP via professional networks: SNNF, SSAHP forum, SPRAG, SRNF, CRIGS, CSP Scotland website/online forum, MCN Managers, HI, CHP, NMAHP leads for cascading and internally for stroke nurses in CHSS. Leisure services/service providers, via PAHA, HI, Physical Activity leads and via identification of Leisure services providers from online searches along with cross checking with a previous stroke audit and gained knowledge from the PARCS scoping to that point. The GP survey was via a CHSS list of GPs who had previous contact with CHSS and then targeted identification of practices/practice managers in regions with a no/low responses rate, by sending the link to the survey via post or email. Some questionnaires were completed in paper format during face to face meetings as part of PARCS project and then inputted manually into the survey monkey format (with permission). For service users the surveys were posted out to all CHSS group leads to circulate via their respective groups. All data was protected in line with CHSS data protection and confidentiality policies and followed the ethical standards of the charity in line with charity business/service development.

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PARCS surveys responses in this Health Board region (or hits on web based surveys, and stakeholders represented)

- MCN, nil
- Health Care Professionals, n= 58
- GPs, n= 15
- Services providers (Leisure), n= 3
- Service users, n=21

Meetings as part of PARCS CHSS scoping in this Health Board region

Face to Face Meetings with:

- X 1 Health Care Professional, multiple meetings & correspondence
- X 1 exercise instructor
- X 1 leisure services lead, meetings & correspondence

References

ISD statistics provided by ISD

1. Source: 2012 mid-year population estimates (National Records of Scotland (NRS)) (<http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html>)
2. Source: 2011/12 version of the Urban Rural Classification (Scottish Government) and the 2012 mid-year population estimates (National Records of Scotland).
3. Urban areas are settlements of over 3,000 people. Rural areas are settlements of fewer than 3,000 people. More details can be found here: <http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification>

4. Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp>
5. Source: SMR01 (ISD), extracted February 2014. Number of patients discharged from hospital during calendar year 2012.
6. Source: Cardiac Rehabilitation in Scotland (2011/12) publication. The full publication and data tables can be found here: <https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf>

Statistics from other sources (as not collected by ISD)

7. Health Improvement Scotland Costing Report – Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) http://www.healthcareimprovementscotland.org/our_work/longterm_conditions/copd_implementation/implementing_copd_standards.aspx
8. These figures were based on responses to the PARCS survey (CHSS scoping) from services providers (this could include leisure, third sector, private). The year (i.e. 2012 -2013) from some providers was not completed. The figures are therefore intended to give a snapshot estimate of numbers in services. Also in some regions more than one provider was identified but only one or some of the providers responded. In some regions attendance fluctuated in numbers particularly in third sector groups, so figures were based on averages or the range if given. The figure provided is not a definitive figure but intended to give a best estimate based on the information available and only represents service providers and initiatives that the PARCS scoping was able to identify within the time limited constraints of the project and the data available.
9. **Register of Exercise Professionals (REPs)** is an independent, public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REP's provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards. **DEFINITION OF REPS LEVEL 3:** The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions this includes Respiratory Conditions: Asthma and Chronic obstructive pulmonary disease (COPD). Musculoskeletal Conditions, Cardiovascular Conditions, Hypertension, Hypercholesterolaemia, Psychological/Mental Health Conditions, Metabolic/Immunological Conditions e.g. Diabetes Type 1 and Type 2 and obesity. **DEFINITION OF REPS LEVEL 4:** The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the affects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease. <http://www.exerciseregister.org/resources/exercise-referral>

HIGHLAND

Service Users „I have to take a bus to meetings and there is no bus home until 2 hours after the meeting. Sometimes I can now get a lift home. I would rather go to an exercise group where I live..“ „have opened my eyes to what exercise can do to improve my health and wellbeing. The worst thing that ever happened to me was the bypass operation which has turned out to be the best thing that has happened to me. The help and encouragement I get from Bravehearts has been my lifesaver“.

Health Care Professionals (HCP) „Maintenance classes definitely need to be set up by councils /NHS.“ „There are no exercise maintenance facilities for stroke patients in my area....and is something my area is in dire need of“

GPs „it (exercise maintenance) would be more useful than most of the medical interventions we spend a lot of time and money on“ „My patients have no access to such services therefore do not get benefits of exercise programmes....“

Service Provider „We are working towards implementing more opportunities for exercise maintenance in Highland...It is challenging to sustain activities if there is no long term funding commitment in place“

BOARD PROFILE

Total Board Population (1)	319,810
Urban/ Rural (2,3)	159,119 / 160,691 (50% / 50%)

PREVELANCE & STRUCTURED CLINICAL REHABILITATION

Condition	CHD	COPD	Stroke
Prevalence (4)	14,886	5,723	7,622
Hospital Discharges (5) (number of patients)	1,485	557	566
Cardiac Rehabilitation (6) (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	400 (45.4%)		
Pulmonary Rehabilitation (7) (estimated total number of patients per year)		386	
Stroke Rehabilitation (total number of patients per year)			Not collected by ISD

AVAILABILITY OF MAINTENANCE OF EXERCISE

Known numbers participating in community based maintenance exercise/physical activity (snapshot/estimated per annum) (8)	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults/ Older Adults Activities
Leisure services provided (attendances)		40*				40**

CHSS affiliated groups (attendees, 2014)		126	60-70			
Total Known (attendances/attendees)		126	60-70			40

*Highlife Highland, Sept 2012-August 2013 approximate figures for cardiac, older adults currently being established. Figure is for numbers going through the service per year, the assumption was made this was attendances unless otherwise indicated.

** Tain Royal Academy Community Complex -Ross-shire, other regions a service is being established, therefore no data. Figure for numbers going through the service per year, the assumption was made this was attendances unless otherwise indicated.

SERVICE DELIVERY

Aspects of Delivery	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults	Other: Third Sector/ Charity Affiliated
Type of Delivery (Generic/LTC or Condition Specific *)	Some regions	Yes	Some regions	No	Some regions	Some regions	Charity affiliated group some regions
Established Pathways to Exercise Maintenance	Some regions	Some regions	Some regions	One region	Some regions	Some regions	Charity affiliated Some regions
Earliest year a Scheme Commenced	2011	2006 or earlier	2006 or earlier		2006 or earlier	2006 or earlier	Charity affiliated 2006 or earlier
Service Co-ordinator	Some regions	Yes	Some regions	No	Some regions	Some regions	Charity affiliated group some regions

*Yes/No here indicates stakeholder responses to the question what types of follow on maintenance class are available in your region generic long term conditions class, a cardiac specific class, a respiratory specific class etc (details of data sources and synthesis in the reference section below)

REFERRAL

Single Point of Referral for all Long Term Conditions to Exercise Maintenance	No. Some regions have a service co-ordinator
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DATA COLLECTION

Data Collector / Data Collected	Not collected	Leisure services	Commissioned by Third Sector/ Other	NHS – HCP	Other
Follow up data		Some regions		Some regions	
Cost effectiveness		Some regions		No	
Person centred data					

FUNDING

Funders	Local Authority	Leisure Services	Short Term Government Grant	Short Term NHS - Charitable	Established NHS	Third Sector/ Charity
Funding partners for service delivery	One region	Some regions	Some regions	One region	Two regions	
Funding for initial instructor/service provider training		Some regions			Some regions	Some regions

GOVERNANCE

Collaborative working group(s) for governance of exercise maintenance	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
	Some regions	Some regions	Some regions	Some regions	Some regions	Some regions

INSTRUCTORS WITH SPECIALIST TRAINING

Different regions have variation in numbers trained, overall total of known instructors shown

REPS Level 4 (9)	REPS Level 3 (9)	BACPR	Otago	PSI	Exercise After Stroke	Wright Foundation	Seated Exercise	NHS In-house	Data Sources
1	2	1-2 (i)	4			1			HCP, Leisure services, MCN

(i) The range in total numbers indicated represents the range of responses given, i.e. lowest number response to highest number response.

This number potentially indicates numbers known by the different data sources documented above or the variation in numbers of instructors in different geographical locations within the Health Board.

KEY CONTEXTUAL OVERVIEW - 4 Community Health Partnership Regions

Cardiac Rehabilitation is delivered at Inverness Raigmore hospital for twelve weeks. Exit strategy includes information given about local exercise; walking and support groups, available in some locations. In other locations phase four (maintenance) is delivered within Leisure (e.g. Argyll & Bute).

Pulmonary Rehabilitation (PR) is delivered at Inverness, Raigmore Hospital and Wick community hospital. PR classes run across NHS Highland with rolling classes in Nairn, Inverness, Wick and Fort William. Remote linkage via videoconferencing equipment for PR is currently being tested. Exit strategy in some locations is referral to Third Sector groups and Paths for All walking groups, available in some locations.

Stroke Rehabilitation is delivered in hospital based and community settings.

Long Term Condition Exercise Maintenance

Leisure services are working towards implementing more opportunities for exercise maintenance in Highland. Third Sector provision, (CHSS affiliated) groups in one region offering support and social activities. Local initiatives in some regions e.g. Lorn Healthy Options, a community enterprise scheme aimed at providing guided exercise opportunities for anyone either with a

chronic health condition or at risk of developing a chronic health problem. This service can be either class based or one on one instruction.

Cardiac Exercise Maintenance

Combination of Third Sector, peer led groups and some regions have localised Leisure service provision e.g. Argyll and Bute and Lochaber Leisure where NHS staff are working towards setting up post clinical exercise maintenance classes for cardiac patients. No local provision is available in some regions e.g. Dingwall, Inverness can be the nearest service provision (often too far to travel for most). Third Sector (CHSS affiliated) groups, in four regions, four exercising (two Physiotherapist led, one instructor led and one peer led) and one support (social and education) group.

Pulmonary Exercise Maintenance

Third Sector (CHSS affiliated) groups, available in four regions, three exercising (two Physiotherapist led and one peer led) and one support group.

Stroke Exercise Maintenance

There is limited service provision for long term stroke maintenance across the Highlands. There is no formal exercise after stroke programmes at present however there is liaison between Physiotherapists and Leisure services. Individualised/tailored programmes can be arranged at Leisure centres throughout the area. They cover the key elements of the Postural Stability Instructor (PSI) programme and the exercise after stroke programme. There are also plans to support a Physiotherapist to complete the exercise after stroke course at Queen Margaret University. Further, there are a number of other groups via the Third sector which can support post stroke e.g. outdoor gym at Nairn

KEY SUCCESSES

- **Community based rehabilitation** (e.g. PR)
- **Service Provision, positive impact** in localised regions with a service provision
- **Third sector (CHSS) key service provider** (although fragility in sustainability without wider partnership support, i.e. members of the public often reluctant to take on responsibilities of organisation and delivery of a group, without adequate professional support)
- **Pathway, referral**, signposting to Third Sector provision by HCP
- **Delivery of exercise to nursing/care homes** in some regions e.g. Tain, pilot in East Ross, working to upscale this to other sites in Highlands, delivering Otago classes in the community leisure facilities as well as in 3 care homes.
- **Partnership/collaborative working towards service provision**, in some regions e.g. within Highlife Highland (Leisure) to promote long term management of Chronic Heart Disease, access to the leisure centre in Fort William is free of charge for 3 months post completion of formal rehabilitation process.

KEY CHALLENGES

- **Equity of service provision across the Health Board**
- **Service provision/delivery - critical mass needed** to provide a class & timings of classes to suit working and non working retired populations
- **Access, local service provision**
- **Access, lack of transport** large distance between patients and Leisure facilities e.g. Mid and East Rosshire, Sutherland.
- **Knowledge of service**, lack of knowledge of services from all possible referrers
- **Provision of tailored exercise**
- **Resources, funding sustainability and staffing**
- **Autonomy of peer led groups**, allow groups to be peer led whilst providing some structure

Data Sources/References

The HCP, service providers/leisure services and GP survey was online in „survey monkey“ format. For HCP the dissemination process for completion was for HCP via professional networks: SNNF, SSAHP forum, SPRAG, SRNF, CRIGS, CSP Scotland website/online forum, MCN Managers, HI, CHP, NMAHP leads for cascading and internally for stroke nurses in CHSS. Leisure services/service providers, via PAHA, HI, Physical Activity leads and via identification of leisure services providers from online searches along with cross checking with a previous stroke audit and gained knowledge from the PARCS scoping to that point. The GP survey was via a CHSS list of GPs who had previous contact with CHSS and then targeted identification of practices/practice managers in regions with a no/low responses rate, by sending the link to the survey via post or email. Some questionnaires were completed in paper format during face to face meetings as part of PARCS project and then inputted manually into the survey monkey format (with permission). For service users the surveys were posted out to all CHSS group leads to circulate via their respective groups. All data was protected in line with CHSS data protection and confidentiality policies and followed the ethical standards of the charity in line with charity business/service development.

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The data represented in key contextual overview and quotes sections (above the tables) is a data synthesis from the PARCS surveys (as detailed above and including service users), meetings detailed below and other data sources e.g. reports, audits/evaluations, online resources (e.g. websites etc), identified as part of the PARCS (CHSS) scoping. Where information was missing e.g. nil responses the information was based on information available from other e.g. online resources. The accuracy of such information may not always be correct; the sense check detailed below was to enable a mechanism whereby any errors to be identified and corrected.

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PARCS surveys responses in this Health Board region (or hits on web based surveys, and stakeholders represented)

- MCN, n= 1 (Respiratory)
- Health Care Professionals, n= 18
- GPs, n= 13
- Services providers, Leisure services, n= 3
- Service Users, n= 20

Meetings as part of PARCS CHSS scoping in this Health Board region

Face to Face Meeting with: CHSS community support workers

References

ISD statistics provided by ISD

1. Source: 2012 mid-year population estimates (National Records of Scotland (NRS)) (<http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html>)
2. Source: 2011/12 version of the Urban Rural Classification (Scottish Government) and the 2012 mid-year population estimates (National Records of Scotland).
3. Urban areas are settlements of over 3,000 people. Rural areas are settlements of fewer than 3,000 people. More details can be found here: <http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification>
4. Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp>
5. Source: SMR01 (ISD), extracted February 2014. Number of patients discharged from hospital during calendar year 2012.
6. Source: Cardiac Rehabilitation in Scotland (2011/12) publication. The full publication and data tables can be found here: <https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf>

Statistics from other sources (as not collected by ISD)

7. Health Improvement Scotland Costing Report – Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10)
http://www.healthcareimprovementscotland.org/our_work/longterm_conditions/copd_implementation/implementing_copd_standards.aspx
8. These figures were based on responses to the PARCS survey (CHSS scoping) from services providers (this could include leisure, third sector, private). The year (i.e. 2012 -2013) from some providers was not completed. The figures are therefore intended to give a snapshot estimate of numbers in services. Also in some regions more than one provider was identified but only one or some of the providers responded. In some regions attendance fluctuated in numbers particularly in third sector groups, so figures were based on averages or the range if given. The figure provided is not a definitive figure but intended to give a best estimate based on the information available and only represents service providers and initiatives that the PARCS scoping was able to identify within the time limited constraints of the project and the data available.
9. **Register of Exercise Professionals (REPs)** is an independent, public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REPs provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards. **DEFINITION OF REPS LEVEL 3:** The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions this includes Respiratory Conditions: Asthma and Chronic obstructive pulmonary disease (COPD). Musculoskeletal Conditions, Cardiovascular Conditions, Hypertension, Hypercholesterolaemia, Psychological/Mental Health Conditions, Metabolic/Immunological Conditions e.g. Diabetes Type 1 and Type 2 and obesity. **DEFINITION OF REPS LEVEL 4:** The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the effects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease. <http://www.exerciseregister.org/resources/exercise-referral>

LANARKSHIRE

Service Users „aware of partnership between NHS Lanarkshire and South Lanarkshire Leisure... It is vital that funding remains in place to continue this service” „follow-on classes the best thing that could have happened to me... learning a lot.. sharing experiences with other people.”

GP „positive impact on patients and enables them to self manage and become more independent, it also continues to maintain a level of fitness and stamina.”

Service Provider North Lanarkshire „We have worked hard with our partners from NHS Lanarkshire to extend the range of referral points to ensure maximum uptake to the services...reaching as many individuals... via non-medical referral routes (i.e. Social Work). Access to the sessions is only limited by the number of appropriate qualified staff we have available to teach but also more significantly - the cost of paying instructors....Classes to encourage social interaction and peer support within the sessions....Main challenges are financial/manpower- a bigger team of people dealing with referrals would allow for more classes to be established catering for demand but would also allow for more in depth analysis of the success of the programmes ...We are unable to track those who drop out of activity or who have completed their programmes and are now back into mainstream activity.”

BOARD PROFILE

Total Board Population ⁽¹⁾	575,577
Urban/ Rural ^(2,3)	514,157 / 61,420 (89% / 11%)

PREVELANCE & STRUCTURED CLINICAL REHABILITATION

Condition	CHD	COPD	Stroke
Prevalence ⁽⁴⁾	27,292	13,844	12,197
Hospital Discharges ⁽⁵⁾ (number of patients)	2,576	1,563	916
Cardiac Rehabilitation ⁽⁶⁾ (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	641 (49.8%)		N
Pulmonary Rehabilitation ⁽⁷⁾ (estimated total number of patients per year)		953	
Stroke Rehabilitation (total patients per year)			Not collected by ISD

AVAILABILITY OF EXERCISE MAINTENANCE (EM)

Known numbers participating in community based maintenance exercise/physical activity (snapshot/estimated per annum) ⁽⁸⁾	Long Term Conditions	Cardiac	Respiratory	Stroke Within LTC	Exercise Referral Generic	Exercise Referral Older Adults/ Older Adults Activities
Leisure services provided (new referrals) (2 out of 2 known providers)	1,566 Total (657 i) +909 ii)	417 Total (159 i) + 258 ii)	134 Total (86 i) +48 ii)	89 Total (18 i) + 71 ii)	3043 Total (2079 i) 964 ii)	

Leisure services provided (attendances per annum) (2 out of 2 known providers)	19,894 (Total) (5673 i) + 14,221 ii))	3305 i) (1 out of 2 known providers)	412 i) (1 out of 2 known providers)			
Leisure services (attendances since 2009 –present)	31,205 iii)					
CHSS affiliated groups (attendees)		50				

i) North Lanarkshire Leisure, 2013 data. LTC attendances (includes back, strength and balance), attendances n= 5673. Stroke attendances, unable to breakdown to stroke conditions independently. Exercise referral generic figure includes older adults" activities.

ii) South Lanarkshire Leisure, 2013 data- Active Health , generic exercise referral figures are composed of 2 other referral and 2 social prescribing partnership referral paths iii) South Lanarkshire figure 31,205 attendances from 2009 to present (2014)

SERVICE DELIVERY OF EM

Aspects of Delivery	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults	Other: Third Sector/ Charity Affiliated
Type of Delivery (Generic or Condition Specific)	Yes	Yes for LTC	Yes for LTC	Yes for LTC	Yes	Yes	Some regions
Established Pathways to Exercise Maintenance	Yes	Some regions	Some regions	Some regions	Yes	Yes	Some regions
Earliest year a Scheme Commenced	2006 or earlier				2006 or earlier	2006 or earlier	2012
Service Co-ordinator	Yes	Yes for LTC	Yes for LTC	Yes for LTC	Yes	Yes	Some regions

*Yes/No here indicates stakeholder responses to the question what types of follow on maintenance class are available in your region generic long term conditions class, a cardiac specific class, a respiratory specific class etc (details of data sources and synthesis in the reference section below)

REFERRAL TO EM

Single Point of Referral for all Long Term Conditions to Exercise Maintenance	No. There is a single point of contact/referral and a service co-ordinator for each CHP region i.e. North and South Lanarkshire
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DATA COLLECTION FOR EM

Data Collector / Data Collected	Not collected	Leisure services	Commissioned by Third Sector/ Other	NHS – HCP	Other
Follow up data		Yes (1 out of 2 regions)		Yes	
Cost effectiveness		No		No	
Person centred data		Yes		No	

FUNDING FOR EM

Funders	Local Authority	Leisure Services	Short Term Government Grant	Short Term NHS - Charitable	Established NHS	Third Sector/ Charity
Funding partners for service delivery	One region	Yes	One region	Yes	Yes	
Funding for initial instructor/service provider training		Yes	One region	Yes	One region	

GOVERNANCE of EM

Collaborative working group(s) for governance of exercise maintenance	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
		Yes	Yes	Yes	Yes	Yes

INSTRUCTORS WITH SPECIALIST TRAINING

Different regions have variation in numbers trained, overall total of known instructors shown

REPS Level 4 (9)	REPS Level 3 (9)	BACPR	Otago (Falls)	Postural Stability Instructor Falls	Exercise After Stroke	Wright Foundation	Seated Exercise	NHS In-house	Data Sources
25	48	21		19	1	12		30	Leisure services – North & South , HCPs, MCN

KEY CONTEXTUAL OVERVIEW - 2 CHP Regions

Cardiac Rehabilitation is delivered in hospital and community based settings. The exit strategy is referral to the exercise referral scheme Active Health.

Pulmonary Rehabilitation is delivered in hospital and community based settings. The exit strategy is referral to the exercise referral scheme Active Health and other menu based options including self management/support groups.

Stroke Rehabilitation is delivered in hospital and community based settings. The exit strategy is referral to the exercise referral scheme Active Health.

Long term conditions exercise (LTC) maintenance is delivered pan Lanarkshire by North and South Lanarkshire Leisure in partnership with NHS Lanarkshire, within an exercise referral scheme, Active Health. Active Health provides a range of supported programmes to enable physical activity, this incorporates LTC. It is accessed by Health Care Professional (HCP) referral, mainly specialist nurses and Physiotherapists, with one region including GP Referral. Classes are function based generic classes. Active Health offers a free access to 10 weeks of structured exercise, after which there is an offer of maintenance or mainstream physical activity opportunities.

Cardiac exercise maintenance is delivered within Active Health pan Lanarkshire. There are Third sector (CHSS affiliated) support groups that have link with Leisure service exercise provision in some regions. CHSS also provide training for a „buddying” scheme for peer support to a local hospital. In one other region there is a support, social and exercise groups with other active options (woodworking group and bowling section).

Pulmonary exercise maintenance is delivered within Active Health pan Lanarkshire. There is also the option of direct referral for milder COPD patients to Leisure services as well as those referred by Health Care Professionals (HCP) post Pulmonary Rehabilitation.

Stroke Exercise Maintenance is delivered within Active Health pan Lanarkshire.

KEY SUCCESSES

- **Service delivery, pan Lanarkshire generic LTC classes** (function based)
- **Collaborative/partnership working**, for service delivery and governance with multi agency steering Groups for Active Health for North and South Lanarkshire
- **HCP involvement in service design & delivery** (Allied Health Professionals from all specialist areas, cardiac, pulmonary, falls, vascular, stroke, diabetes, musculoskeletal)
- **Pathway, effective referral** by HCP to services
- **Specialist instructor training**, from HCP specialists to the leisure centre staff, with annual updates and continuous professional development provided by NHS HCPs to specialist instructors
- **Positive impact of service**, feedback from Health Board classes is very positive regarding delivery, waiting times and patients” motivation to continue once static program has been completed
- **Data collection**, by Leisure services over ten week programme
- **Good attendance & adherence**, highest attendance at longest established classes
- **Social & peer support important** to foster as part of exercise classes
- **Regional single point of referral & service co-ordinator**

KEY CHALLENGES

- **Waiting time**, waiting lists in some regions
- **Resources, funding & staff** to deliver/develop services
- **Data collection**, funding & staffing for more in depth & longer period of data collection
- **Follow up/safety nets** needed at each potential transition stage

Data Sources/References

The HCP, service providers/leisure services and GP survey was online in „survey monkey“ format. For HCP the dissemination process for completion was for HCP via professional networks: SNNF, SSAHP forum, SPRAG, SRNF, CRIGS, CSP Scotland website/online forum, MCN Managers, HI, CHP, NMAHP leads for cascading and internally for stroke nurses in CHSS. Leisure services/service providers, via PAHA, HI, Physical Activity leads and via identification of leisure services providers from online searches along with cross checking with a previous stroke audit and gained knowledge from the PARCS scoping to that point. The GP survey was via a CHSS list of GPs who had previous contact with CHSS and then targeted identification of practices/practice managers in regions with a no/low responses rate, by sending the link to the survey via post or email. Some questionnaires were completed in paper format during face to face meetings as part of PARCS project and then inputted manually into the survey monkey format (with permission). For service users the surveys were posted out to all CHSS group leads to circulate via their respective groups. All data was protected in line with CHSS data protection and confidentiality policies and followed the ethical standards of the charity in line with charity business/service development.

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PARCS surveys responses in this Health Board region (or hits on web based surveys, and stakeholders represented)

- MCN , n=1
- Health Care Professionals , n=16
- GP s, n=4
- Services Providers, (Leisure) , n=2
- Service Users, n= 6

Meetings as part of PARCS CHSS scoping in this Health Board region

Face to Face Meetings with:

- X 1 leisure services coordinator
- X 1 exercise instructor
- X1 focus group with heart support group exercising in Leisure services provided classes n= 17
- Third sector (CHSS) community support worker

References

ISD statistics provided by ISD

1. Source: 2012 mid-year population estimates (National Records of Scotland (NRS)) (<http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html>)
2. Source: 2011/12 version of the Urban Rural Classification (Scottish Government) and the 2012 mid-year population estimates (National Records of Scotland).
3. Urban areas are settlements of over 3,000 people. Rural areas are settlements of fewer than 3,000 people. More details can be found here: <http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification>
4. Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp>
5. Source: SMR01 (ISD), extracted February 2014. Number of patients discharged from hospital during calendar year 2012.
6. Source: Cardiac Rehabilitation in Scotland (2011/12) publication. The full publication and data tables can be found here: <https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf>

Statistics from other sources (as not collected by ISD)

7. Health Improvement Scotland Costing Report – Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10)
http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/copd_implementation/implementing_copd_standards.aspx
8. These figures were based on responses to the PARCS survey (CHSS scoping) from services providers (this could include leisure, third sector, private). The year (i.e. 2012 -2013) from some providers was not completed. The figures are therefore intended to give a snapshot estimate of numbers in services. Also in some regions more than one provider was identified but only one or some of the providers responded. In some regions attendance fluctuated in numbers particularly in third sector groups, so figures were based on averages or the range if given. The figure provided is not a definitive figure but intended to give a best estimate based on the information available and only represents service providers and initiatives that the PARCS scoping was able to identify within the time limited constraints of the project and the data available.
9. **Register of Exercise Professionals (REPs)** is an independent, public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REP's provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards. **DEFINITION OF REPS LEVEL 3:** The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions this includes Respiratory Conditions: Asthma and Chronic obstructive pulmonary disease (COPD). Musculoskeletal Conditions, Cardiovascular Conditions, Hypertension, Hypercholesterolaemia, Psychological/Mental Health Conditions, Metabolic/Immunological Conditions e.g. Diabetes Type 1 and Type 2 and obesity. **DEFINITION OF REPS LEVEL 4:** The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the affects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease. <http://www.exerciseregister.org/resources/exercise-referral>

LOTHIAN

Service Users „The class has made me do exercise I would otherwise not have done. „I found it improved my ability ...and made me independent.“ „I believe that patients are not made aware enough about what exercise groups ...are available. Likewise more could be done to inform patients about support groups which are relevant to them. I have personally found both of the above to be very beneficial“

Health Care Professionals *HCP Cardiac* „Good service provided, patients have choice of onward referral... menu-based approach, refer to long term conditions route. Walking groups (Paths for All) sports centre, swimming...self-management group....“ *HCP Stroke* ‘The multi-agency steering group... continues to meet ...to steer the ongoing exercise after stroke service delivery... to ensure best transitions into mainstream exercise for stroke survivors in a way that extends the therapeutic nature of their rehabilitation“

GP „partnership working allows our patients to continue in a safe and comfortable environment, that suits their needs. A variety of options are available for the continuation of exercise, so they can pick whichever option suits their needs best“

BOARD PROFILE

Total Board Population ⁽¹⁾	843,720
Urban/ Rural ^(2,3)	776,239 / 67,481 (92% / 8%)

PREVELANCE & STRUCTURED CLINICAL REHABILITATION

Condition	CHD	COPD	Stroke
Prevalence ⁽⁴⁾	29,400	14,317	15,907
Hospital Discharges ⁽⁵⁾ (number of patients)	2,652	1,663	1,254
Cardiac Rehabilitation ⁽⁶⁾ (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	1,245 (70.6%)		
Pulmonary Rehabilitation ⁽⁷⁾ (estimated total patients per year)		988	
Stroke Rehabilitation (number of patients per year)			Not collected by ISD

AVAILABILITY OF MAINTENANCE OF EXERCISE

Known numbers participating in community based maintenance exercise/physical activity (snapshot/estimated per annum) ⁽⁸⁾	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults/ Older Adults Activities
Leisure services provided (New referrals)	Largely delivered within exercise referral	n= 59 ⁱ⁾ (1 out of 5 known providers)			3,057 Total (2,594 ^{iv)} + 463 ^{v))} (2 out 5 known providers)	4,652 ^{vi)} (1 out of 5 known providers)

Leisure services provided (attendances)			147 i) (1 out 5 known providers)		2,594 iv) 337 iii) (2 out 5 known providers)	
Pilot of exercise after stroke (estimated per annum, by 1 out of 5 known providers, ii)				30-40 ii) (estimated per annum, by 1 out of 5 known provider s)		
CHSS affiliated groups (attendees)		413				

i) West Lothian Xcite –Cardiac- new referral figures – for 2013/2014-, Respiratory figures numbers through service for April 2012/13. ii) Exercise after Stroke – Evaluation of a 16 week service (May 2009) – Edinburgh Leisure iii) East Lothian- numbers per annum through the service , iv) West Lothian – figures for April 2012/13, numbers thorough service v) Mid Lothian - this figure is based on total cumulative referrals since start of scheme (n= 1850) from Sept 2009 to August 2013, total = 1850 ÷4 (years of scheme) = 462.5, to give an estimate of average numbers of referrals per annum, vi) Edinburgh Leisure –Social Impact evaluation of certain projects using social return on investment (January 2012) Baker Tily, Older adults in ageing well activities annually, n= 2114 age 50-59 and over 60's n=2538, total = 4652. NB -Numbers going through the service per year, the assumption was made this was attendances unless otherwise indicated.

SERVICE DELIVERY OF EM

Aspects of Delivery	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults	Other: Third Sector/ Charity Affiliated
Type of Delivery (Generic/LTC or Condition Specific *)	Yes	Some regions	Yes	Yes	Yes	Yes	Some regions
Established Pathways to Exercise Maintenance	Some regions	Some regions	Some regions	Yes	Some regions	Some regions	Charity affiliated – some regions
Earliest year a Scheme Commenced	2006 or earlier	2006 or earlier	2008	2008	2006 or earlier	2009	2006 or earlier
Service Co-ordinator	Yes	Yes	Yes	Yes	Yes	Yes	Yes

*Yes/No here indicates stakeholder responses to the question what types of follow on maintenance class are available in your region generic long term conditions class, a cardiac specific class, a respiratory specific class etc (details of data sources and synthesis in the reference section below)

REFERRAL TO EM

Single Point of Referral for all Long Term Conditions to Exercise Maintenance	No. There are regional referral points for each CHP/ Local Authority area, East, West, Mid and City of Edinburgh Leisure and also for the Charitable/private provider (Thistle Foundation). All regions have a service co-ordinator. There is a single point of access to referral forms/procedures via the MCN website for stroke.
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DATA COLLECTION FOR EM

Data Collector	Not collected	Leisure services	Commissioned by academic institution	NHS – HCP	Other
Data Collected					
Follow up data		Some regions		Some regions	
Cost effectiveness		Some regions		Some regions	
Person centred data		Some regions		Some regions	

FUNDING FOR EM

Funders	Local Authority	Leisure Services	Short Term Government Grant	Short Term NHS	Established NHS	Third Sector/ Charity
Funding partners for service delivery (2 out of 5 known providers responded)	One region	One region	One region	Two regions	One region	One region
Funding for initial instructor/service provider training (1 out of 5 providers knew source)		One region		One region		

GOVERNANCE OF EM

Collaborative working group(s) for governance of exercise maintenance	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
Yes (this may indicate that some regions have none)		Yes		Yes	Yes	Yes

INSTRUCTORS WITH SPECIALIST TRAINING

Different regions have variation in numbers trained, overall total of known instructors shown

REPS Level 4 (11)	REPS Level 3 (11)	BACPR	Otago (falls)	Postural Stability Instructor (falls)	Exercise After Stroke	Wright Foundation	Seated Exercise	NHS In-house	Data Sources
7		6			15	3	6		HCP, Leisure services, (3 out of 5 known providers). For stroke - total is from Pan Lothian Stroke Working Group meetings

KEY CONTEXTUAL OVERVIEW – 4 Community Health Partnership regions

Cardiac Rehabilitation is delivered in hospital and community based venues pan Lothian. The exit strategy is tailored to individual need to include referral or signposting to Leisure or other menu based options e.g. support groups and walking groups

Pulmonary Rehabilitation (PR) is delivered in community based venues pan Lothian. The exit strategy is tailored to individual need to include referral or signposting to Leisure or other menu based options e.g. support groups and walking groups. There is also a pathway to psychological services as appropriate in some regions

Stroke Rehabilitation is delivered in hospital and community based venues pan Lothian.

Long Term Conditions (LTC) Exercise Maintenance is delivered by Leisure services and the Third Sector. There are five different providers: Edinburgh Leisure, East Lothian - Enjoy and East Lothian Council, Mid Lothian Council, West Lothian- Xcite (Leisure) and the Thistle Foundation (Third Sector) along with other Third Sector (CHSS affiliated) groups, in some regions linking with Leisure. All Leisure providers offer an exercise referral scheme with either an integrated or additional LTC or condition specific provision (cardiac, respiratory, stroke). There are also in some regions older adults/ageing well programmes. The Thistle Foundation offers a range of services to support those with LTC; exercise is one component of this. There is one Third Sector (CHSS affiliated) LTC exercise group (cardiac, respiratory and stroke) in Leith led by a specialist instructor.

Cardiac Exercise Maintenance is delivered within the respective regional programmes (as detailed within LTC above). There are also Third Sector (CHSS affiliated) groups in three regions: Edinburgh, West and East Lothian (at various location within East Lothian) all exercising, all are specialist instructor led, one is a cardiac and pulmonary group (this is a partnership group with other stakeholders).

Respiratory Exercise maintenance is delivered within the respective regional programmes as detailed above (as detailed within LTC above). There are also Third Sector (CHSS affiliated) groups in three locations, two exercising both specialist instructor led, one is a partnership

cardiac and pulmonary group with a GP chair, and one support and education group with members from across Scotland.

Stroke Exercise Maintenance is delivered pan Lothian via a partnership between NHS, all regional Leisure service providers, and with the Third Sector including the Thistle Foundation and CHSS. There is a multi agency steering group sitting under the umbrella of the Stroke Managed Clinical Network (MCN) which has overseen provision of training for fourteen exercise after stroke instructors. Service provision is intended; pan Lothian within both Leisure and the Third Sector within condition specific and generic LTC delivery. There is a single point of access for referral forms via the MCN website.

KEY SUCCESSES

- **Service provision for exercise maintenance pan Lothian**
- **Partnership/collaborative working**
- **Equitable pan Lothian stroke service provision**, all regions have specialist instructors trained
- **Peer visits and Leisure services visits to rehabilitation** (e.g. PR) from local exercise and support groups to encourage participation in maintenance in some locations
- **Pathway, effective referral and signposting to services** post clinical rehabilitation
- **HCP involvement in service design and delivery**
- **Provision of tailored exercise**
- **Menu based options valued**

KEY CHALLENGES

- **Equity of service provision pan Lothian for all LTC** (excluding stroke)
- **Knowledge of services** 'knowing everything that is there is difficult due to changes in services'
- **Data collection, staff and resources for long term follow up** and ability to link to frequency of admissions
- **Pathway, differing referral structures** and processes pan Lothian
- **Access transport and local access** for all

Data Sources/References

The HCP, service providers/leisure services and GP survey was online in „survey monkey“ format. For HCP the dissemination process for completion was for HCP via professional networks: SNNF, SSAHP forum, SPRAG, SRNF, CRIGS, CSP Scotland website/online forum, MCN Managers, HI, CHP, NMAHP leads for cascading and internally for stroke nurses in CHSS. Leisure services/service providers, via PAHA, HI, Physical Activity leads and via identification of leisure services providers from online searches along with cross checking with a previous stroke audit and gained knowledge from the PARCS scoping to that point. The GP survey was via a CHSS list of GPs who had previous contact with CHSS and then targeted identification of practices/practice managers in regions with a no/low responses rate, by sending the link to the survey via post or email. Some questionnaires were completed in paper format during face to face meetings as part of PARCS project and then inputted manually into the survey monkey format (with permission). For service users the surveys were posted out to all CHSS group leads to circulate via their respective groups. All data was protected in line with CHSS data protection and confidentiality policies and followed the ethical standards of the charity in line with charity business/service development.

All data incorporated within the CHSS PARCS scoping was collected for the period November 2012 – January 2014. The PARCS surveys were completed between August 2013 and January 2014.

The data represented in the tables above is compiled from a synthesis of data from PARC surveys - MCN, Health Care Professionals, and service provider (leisure services, third sector, and private provider) responses. The data synthesis process that was used for each question/table response was in relation to the number of definitive responses to that question (i.e. yes and no answers only, unsure responses were not included in the tally). For Yes or No responses, if all stakeholders reported Yes the table was populated with a Yes and the same process was used for No. If there was a mixed response from the different stakeholders, if the total responses for that question were high (>20) the majority response was used. If the total responses were low (below 20) if 2 or more stakeholders responded negatively (No) or positively (Yes) the answer was populated as „some regions“. If the responses for that question were high (>20) and the results were mixed i.e. a high number of yes and a high number of no, the answer was populated as some regions. If there was only a single response either yes or no the respective response was used and populated, or populated as 'one region' (as appropriate). If no responses, the section was left blank.

The data represented in key contextual overview and quotes sections (above the tables) is a data synthesis from the PARCS surveys (as detailed above and including service users), meetings detailed below and other data sources e.g. reports, audits/evaluations, online resources (e.g. websites etc), identified as part of the PARCS (CHSS) scoping. Where information was missing e.g. nil responses the information was based on information available from other e.g. online resources. The accuracy of such information may not always be correct; the sense check detailed below was to enable a mechanism whereby any errors to be identified and corrected.

The overview profile shown above (tables and key contextual data) was circulated prior to final production to the respective Health Board MCN Managers for sense checking (checking that the information had no obvious errors). A 2 week deadline was given (due to the time limited nature of the project). A nil response within a 2 week period would lead to the assumption that the data was acceptable and required no corrections.

PARCS surveys responses in this Health Board region (or hits on web based surveys, and stakeholders represented)

- MCN, n=1
- Health Care Professionals, n= 31
- GPs, n= 20
- Services Providers, (Leisure) n= 3

Meetings as part of PARCS CHSS scoping in this Health Board region

Face to Face Meetings with:

- X 4, Health Care Professionals
- X2, Service providers (leisure)
- X 4, Pan Lothian, Exercise after Stroke Group, including 4 leisure services providers, 1 Third Sector provider (Thistle Foundation) and Third sector (CHSS) supporting training of staff via Stroke Education Facilitator.

References

ISD statistics provided by ISD

1. Source: 2012 mid-year population estimates (National Records of Scotland (NRS)) (<http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html>)
2. Source: 2011/12 version of the Urban Rural Classification (Scottish Government) and the 2012 mid-year population estimates (National Records of Scotland).
3. Urban areas are settlements of over 3,000 people. Rural areas are settlements of fewer than 3,000 people. More details can be found here: <http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification>
4. Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp>
5. Source: SMR01 (ISD), extracted February 2014. Number of patients discharged from hospital during calendar year 2012.
6. Source: Cardiac Rehabilitation in Scotland (2011/12) publication. The full publication and data tables can be found here: <https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf>

Statistics from other sources (as not collected by ISD)

7. Health Improvement Scotland Costing Report – Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) http://www.healthcareimprovementscotland.org/our_work/longterm_conditions/copd_implementation/implementing_copd_standards.aspx
8. These figures were based on responses to the PARCS survey (CHSS scoping) from services providers (this could include leisure, third sector, private). The year (i.e. 2012 -2013) from some providers was not completed. The figures are therefore intended to give a snapshot/estimate of numbers in services. Also in some regions more than one provider was identified but only one or some of the providers responded. In some regions attendance fluctuated in numbers particularly in third sector groups, so figures were based on averages or the range if given. The figure provided is not a definitive figure but intended to give a best estimate based on the information available and only represents service providers and initiatives that the PARCS scoping was able to identify within the time limited constraints of the project and the data available.
9. Exercise after Stroke – Evaluation of a 16 week service (May 2009) – Edinburgh Leisure, (anticipated numbers for exercise after stroke service)
10. Edinburgh Leisure – Social Impact evaluation of certain projects using social return on investment (January 2012) Baker Tilly. Data relates to older adults in ageing well activities based on figures for age 50-59, n= 2,114 annually over 60s n= 2,538 annually, therefore total n = 4,652.
11. **Register of Exercise Professionals (REPs)** is an independent, public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REPs provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards. **DEFINITION OF REPS LEVEL 3:** The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions this includes Respiratory Conditions: Asthma and Chronic obstructive pulmonary disease (COPD). Musculoskeletal Conditions, Cardiovascular Conditions, Hypertension, Hypercholesterolaemia, Psychological/Mental Health Conditions, Metabolic/Immunological Conditions e.g. Diabetes Type 1 and Type 2 and obesity. **DEFINITION OF REPS LEVEL 4:** The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the affects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease. <http://www.exerciseregister.org/resources/exercise-referral>

ORKNEY

Cardiac Service User „depends on your route, if you're admitted to Balfour your experience will be positive and if you're not (via Aberdeen) it won't"

Health Care Professional – „Running at capacity...unable to develop any new services ...would love to run group (exercise) sessions in the community"

Service Provider – „Would like business plan for exercise referral, would be keen to undertake training" (for specialist instructors) ... "High dropout rate among the post-rehab patients, but no way for the exercise instructors to continue to support them as „no expertise"

BOARD PROFILE

Total Board Population ⁽¹⁾	21,530
Urban/ Rural ^(2,3)	6,976 / 14,554 (32% / 68%)

PREVELANCE & STRUCTURED CLINICAL REHABILITATION

Condition	CHD	COPD	Stroke
Prevalence ⁽⁴⁾	845	333	364
Hospital Discharges ⁽⁵⁾ (number of patients)	122	30	50
Cardiac Rehabilitation ⁽⁶⁾ (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	Not published	N/A	N/A
Pulmonary Rehabilitation ⁽⁷⁾ (estimated total patients per year)		17	
Stroke Rehabilitation (estimated total patients per year)			Not collected by ISD

AVAILABILITY OF EXERCISE MAINTENANCE (EM)

Known numbers participating in community based maintenance exercise/physical activity (snapshot/estimated per annum) ⁽⁸⁾	Long term conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults/ Older Adults Activities
Leisure services provided						
In CHSS affiliated groups (attendees)		43				
Total known (attendees)		43				

SERVICE DELIVERY OF EM

Aspects of Delivery	Long term conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults	Other: Third Sector/ Charity Affiliated
Type of Delivery (Generic/LTC or Condition Specific *)	Yes	No	No	No	No	Yes	
Established Pathways to exercise maintenance	No	Yes	No	No	No	No	
Earliest year a Scheme commenced					2006 or earlier	2006 or earlier	
Service Co-ordinator	No	Yes	Yes	No	No	No	

*Yes/No here indicates stakeholder responses to the question what types of follow on maintenance class are available in your region generic long term conditions class, a cardiac specific class, a respiratory specific class etc (details of data sources and synthesis in the reference section below)

REFERRAL TO EM

Single Point of Referral for all Long Term Conditions to Exercise Maintenance	No
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DATA COLLECTION FOR EM

Data Collector / Data Collected	Not collected	Leisure services	Commissioned by academic institution	NHS – HCP	Other
Follow up data		No		No	
Cost effectiveness		No		No	
Person centred data		No		No	

FUNDING FOR EM

Funders	Local Authority	Leisure Services	Short Term Government Grant	Short Term NHS - Charitable	Established NHS	Third Sector/ Charity
Funding partners for service delivery	Yes	Yes				
Funding for initial instructor/service provider training	Yes	Yes				

GOVERNANCE OF EM

Collaborative working group(s) for governance of exercise maintenance	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
		Yes	Yes - MCN	No	No	

INSTRUCTORS WITH SPECIALIST TRAINING

Different regions have variation in numbers trained, overall total of known instructors shown

REPS Level 4 (9)	REPS Level 3 (9)	BACPR	Otago	PSI	Exercise After Stroke	Wright Foundation	Seated Exercise	NHS In-house	Data Sources
	3					1			Leisure services

KEY CONTEXTUAL OVERVIEW - 1 Community Health Partnership Region

Cardiac Rehabilitation is delivered as a twelve week programme. Exit strategy is referral to Leisure centre on individual basis or other menu based options, e.g. walking group, Tai Chi classes, use of Heart Manual and BHF DVD for people from outer isles and those unable to attend.

Pulmonary Rehabilitation is delivered at Balfour hospital as a ten week programme. Exit Strategy is referral to the over 50's exercise class (mild COPD only) at the Leisure Centre or referral to Leisure centre on individual basis. Service users from Outer Isles can be referred on to the local Healthy Living Centres; Doonby, Stronsay.

Stroke Rehabilitation is delivered at Balfour hospital with some capacity to offer one to one support through outpatient physiotherapy.

Long Term Conditions Exercise Maintenance Over fifties group currently available at Pickaquoy leisure centre, (unsuitable for many with long term conditions). Other options: bowls, swimming, yoga. Service users from Outer Isles can attend local Healthy Living Centres; Dounby, Stronsay etc. Previously there was a GP exercise referral scheme which was well attended, this was a short-term funding stream and the funding is no longer available and thus the service is now not available.

Cardiac Exercise Maintenance Leisure services provide over fifties class or an option to attend the Leisure centre on an individual basis, with other menu based options as detailed above. One Third Sector (CHSS affiliated), social and educational support group, that signpost to exercise options. This includes bowling, swimming and yoga. This group also fund fifty percent of the cost of twice weekly attendance at Leisure centre sessions, post clinical rehabilitation, for twelve weeks, which includes a free induction. The uptake of this is only by 2-3 members per year.

Respiratory Exercise Maintenance Leisure services provided over 50s exercise class (mild COPD only) at the Leisure Centre, or attend leisure centre on individual basis.

Stroke Exercise Maintenance No specific support in community, but some people can attend Leisure centres.

KEY SUCCESSES

- **Collaborative Working, need for service development**, all key stakeholders: healthcare professionals, Leisure services and Third Sector support identify the need for further options for exercise maintenance services that meet service user needs. Long term Conditions MCN are coordinating a joint approach across the spectrum of LTCs
- **Third Sector support**

KEY CHALLENGES

- **Exercise maintenance service provision development.** All stakeholders would like a collaborative approach and resources to achieve more options for service provision
- **Pathway, referral - access to support** and onward referral is dependent on hospital of treatment referring to appropriate clinical staff in Orkney.
- **Resources, funding and staff time** for service development/delivery
- **Specialist instructor training,** need identified for more specialist training, need resources to deliver
- **Tailored exercise with appropriate exercise intensity options**
- **Adherence/follow on-after clinical rehab,** uptake low
- **Data collection,** would be ideal to collect in relation to attendance and adherence post clinical rehabilitation, resources (additional admin support) to enable data collection would be an ideal service development
- **Access, transport,** poor transport links to the leisure centre, buses based around working hours so only each way morning and night

Data Sources/References

The HCP, service providers/leisure services and GP survey was online in „survey monkey“ format. For HCP the dissemination process for completion was for HCP via professional networks: SNNF, SSAHP forum, SPRAG, SRNF, CRIGS, CSP Scotland website/online forum, MCN Managers, HI, CHP, NMAHP leads for cascading and internally for stroke nurses in CHSS. Leisure services/service providers, via PAHA, HI, Physical Activity leads and via identification of leisure services providers from online searches along with cross checking with a previous stroke audit and gained knowledge from the PARCS scoping to that point. The GP survey was via a CHSS list of GPs who had previous contact with CHSS and then targeted identification of practices/practice managers in regions with a no/low responses rate, by sending the link to the survey via post or email. Some questionnaires were completed in paper format during face to face meetings as part of PARCS project and then inputted manually into the survey monkey format (with permission). For service users the surveys were posted out to all CHSS group leads to circulate via their respective groups. All data was protected in line with CHSS data protection and confidentiality policies and followed the ethical standards of the charity in line with charity business/service development.

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The data represented in key contextual overview and quotes sections (above the tables) is a data synthesis from the PARCS surveys (as detailed above and including service users), meetings detailed below and other data sources e.g. reports, audits/evaluations, online resources (e.g. websites etc), identified as part of the PARCS (CHSS) scoping. Where information was missing e.g. nil responses the information was based on information available from other e.g. online resources. The accuracy of such information may not always be correct; the sense check detailed below was to enable a mechanism whereby any errors to be identified and corrected.

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PARCS surveys responses in this Health Board region (or hits on web based surveys, and stakeholders represented)

- MCN, n= 0
- Health Care Professionals responses, n=2
- GPs, n=2
- Services providers (Leisure) n=2

Meetings as part of PARCS CHSS scoping in this Health Board region

Face to Face Meetings with:

- X 1 CHSS affiliated Heart support group representing 67 members (exercising and none exercising members)
- X 2 Health Care Professionals
- X 1 exercise Instructor

References

ISD statistics provided by ISD

1. Source: 2012 mid-year population estimates (National Records of Scotland (NRS) (<http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html>)
2. Source: 2011/12 version of the Urban Rural Classification (Scottish Government) and the 2012 mid-year population estimates (National Records of Scotland).
3. Urban areas are settlements of over 3,000 people. Rural areas are settlements of fewer than 3,000 people. More details can be found here: <http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification>
4. Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp>
5. Source: SMR01 (ISD), extracted February 2014. Number of patients discharged from hospital during calendar year 2012.
6. Source: Cardiac Rehabilitation in Scotland (2011/12) publication. The full publication and data tables can be found here: <https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf>

Statistics from other sources (as not collected by ISD)

7. Health Improvement Scotland Costing Report – Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) http://www.healthcareimprovementscotland.org/our_work/longterm_conditions/copd_implementation/implementing_copd_standards.aspx
8. These figures were based on responses to the PARCS survey (CHSS scoping) from services providers (this could include leisure, third sector, private). The year (i.e. 2012 -2013) from some providers was not completed. The figures are therefore intended to give a snapshot estimate of numbers in services. Also in some regions more than one provider was identified but only one or some of the providers responded. In some regions attendance fluctuated in numbers particularly in third sector groups, so figures were based on averages or the range if given. The figure provided is not a definitive figure but intended to give a best estimate based on the information available and only represents service providers and initiatives that the PARCS scoping was able to identify within the time limited constraints of the project and the data available.
9. **Register of Exercise Professionals (REPs)** is an independent, public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REP's provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards. **DEFINITION OF REPS LEVEL 3:** The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions this includes Respiratory Conditions: Asthma and Chronic obstructive pulmonary disease (COPD). Musculoskeletal Conditions, Cardiovascular Conditions, Hypertension, Hypercholesterolaemia, Psychological/Mental Health Conditions, Metabolic/Immunological Conditions e.g. Diabetes Type 1 and Type 2 and obesity. **DEFINITION OF REPS LEVEL 4:** The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the affects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease. <http://www.exerciseregister.org/resources/exercise-referral>

SHETLAND

MCN „The Cardiac Nurse Specialist plays a pivotal role in liaising with all members of the Multi-disciplinary team across both primary and secondary care in ensuring a person centred approach is achieved. We have two patient representatives on our local CHD MCN who are actively involved in service review and redesign”

Service Provider „...very keen that we support the local hospital to continue on from medical treatment to lifelong management of exercise. This is delivered through exercise specific classes and a good working relationship with medical staff to find out level of conditions and find the correct pathway to take the customer out of the hospital and into a leisure environment... Usage continues to grow due to the excellent relationship between NHS Shetland and Shetland Recreational Trust. The customers are probably our 'most grateful' for the services we provide as it not only improves their physical abilities but opens a pathway for social interaction. This is essential for good quality of life - they have the challenges, we don't!“ ‘There is a severe lack of funding through the NHS for continuous improvement health specific exercise classes”

BOARD PROFILE

Total Board Population ⁽¹⁾	23,210
Urban/ Rural ^(2,3)	7,341/15,869 (32%/68%)

PREVELANCE & STRUCTURED CLINICAL REHABILITATION

Condition	CHD	COPD	Stroke
Prevalence ⁽⁴⁾	813	240	369
Hospital Discharges ⁽⁵⁾ (number of patients)	85	24	27
Cardiac Rehabilitation (CR) ⁽⁶⁾ (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients) *Data not published by ISD - Approx 40 infarcts per year, 25% will be temporary residents, + 4 CABG + 20 PCI's + 2 AVR (around 50% will attend CR Phase III class) - Data from NHS Shetland 2014	20* (attendances at Phase 3)		
Pulmonary Rehabilitation ⁽⁷⁾ (estimated total number of patients per year)		15	
Stroke Rehabilitation (estimated patients per year)			Not collected by ISD

AVAILABILITY OF EXERCISE MAINTENANCE (EM)

Known numbers participating in community based exercise/physical activity (snapshot/estimated per annum) ⁽⁸⁾	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults/ Older Adults Activities
Leisure services provided (attendances)		245*		195*		784*
CHSS affiliated groups (attendeess)						
Total Known (Attendances)		245		195		784

* Attendances per annum - Shetland Recreational Trust

SERVICE DELIVERY OF EM

Aspects of Delivery	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults	Other: Third Sector Charity Affiliated
Type of Delivery (Generic/LTC or Condition Specific *)	Yes	Yes		Yes	No	No	No
Established Pathways to Exercise Maintenance	Yes	Yes	No	Yes	Yes	Yes	Some regions
Earliest year a Scheme Commenced	2012	2008			2008	2010	
Service Co-ordinator	Yes	Yes		Yes	Yes	Yes	No

*Yes/No here indicates stakeholder responses to the question what types of follow on maintenance class are available in your region generic long term conditions class, a cardiac specific class, a respiratory specific class etc (details of data sources and synthesis in the reference section below)

REFERRAL TO EM

Single Point of Referral for all Long Term Conditions to Exercise Maintenance	No. There is a nominated person who co-ordinates exercise maintenance for people with long term neurological conditions and another person who co-ordinates exercise maintenance for cardiac conditions
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DATA COLLECTION FOR EM

Data Collector	Not collected	Leisure services	Commissioned by academic institution	NHS – HCP	Other
Data Collected					
Follow up data				Yes	
Cost effectiveness				Yes	
Person centred data				Yes	

FUNDING FOR EM

Funders	Local Authority	Leisure Services	Short Term Government Grant	Short Term NHS - Charitable	Established NHS	Third Sector/ Charity
Funding partners for service delivery		Yes		Yes	Yes	Yes
Funding for initial instructor/service provider training	Yes	Yes	Yes	Yes		

GOVERNANCE OF EM

Collaborative working group(s) for governance of exercise maintenance	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
	Some regions	Some regions	Some regions	No	Some regions	No

INSTRUCTORS WITH SPECIALIST TRAINING

Different regions have variation in numbers trained, overall total of known instructors shown

REPS Level 4 (9)	REPS Level 3 (9)	BACPR	Otago (falls)	Postural Stability Instructor (falls)	Exercise After Stroke	Wright Foundation	Seated Exercise	NHS In-house	Data Sources
1-2 (i)	3	1-2 (i)	0	1	2 (ii)	0	1	1-2 (i)	MCN, Leisure services, HCP

(i) The range in total numbers indicated represents the range of responses given, i.e. lowest number response to highest number response.

This number potentially indicates numbers known by the different data sources documented above or the variation in numbers of instructors

in different geographical locations within the Health Board

(ii) Training completed – Neurological 4 Exercise Rehabilitation at Oxford Brooks University

KEY CONTEXTUAL OVERVIEW - 1 Community Health Partnership region

Cardiac Rehabilitation is delivered as part of a pathway which includes early assessment of the individual, always seen with 7 days of discharge from hospital when the patient is reviewed weekly until the start of the Phase III class (week 6) delivered by either the Cardiac Nurse Service or link Community Nurses (Heart Manual Facilitator). (Phase II is delivered either in OPD or Patient's Home by CNS or Community Nurse). Exit strategy from clinical rehabilitation is referral to Leisure services based long term conditions (LTC) exercise maintenance.

Pulmonary Rehabilitation People can self refer to physiotherapy for pulmonary rehabilitation.

Stroke Rehabilitation is delivered in hospital and community based settings. People can self refer to physiotherapy or for rehabilitation following stroke, or a diagnosis of any long term neurological condition. The exit strategy is patients are invited to participate in a three month, hospital based, Physiotherapy-led exercise after stroke class. This is followed by referral to leisure centre based maintenance exercise classes for stroke.

Long Term Conditions Exercise Maintenance is delivered within Leisure services and entered via HCP referral. This is delivered as condition specific exercise classes in cardiac and neurological conditions only. On discharge from Phase III Cardiac Rehab Programme the patients are encouraged to attend the Phase IV class based at the Clickimin Leisure centre. If this is declined, we arranged a 1:1 meeting with Phase IV BACPR trained Fitness instructor, who will devise a personalised programme/Gym based programme for the patient to be delivered in their local leisure centre.

Cardiac Exercise Maintenance is delivered within Leisure services and entered via HCP referral. This is delivered as condition specific exercise classes in cardiac and neurological conditions only. On discharge from Phase III Cardiac Rehab Programme the pts are encouraged

to attend the Phase IV class based at the Clickimin Leisure centre. If this is declined, we arranged a 1:1 meeting with Phase 4 BACPR trained Fitness instructor, who will devise a personalised programme/Gym based programme for the pt to be delivered in their local leisure centre.

Respiratory Exercise Maintenance is not available

Stroke Exercise Maintenance

Following completion of hospital based, physiotherapy-led exercise after stroke class patients are referred to a Leisure industry based exercise after stroke class led by REP's level 4 exercise instructors (9) who have undertaken postgraduate training in stroke. This class runs weekly, and is not time limited. There are close links between Physiotherapy and our Leisure industry, after stroke exercise providers.

KEY SUCCESSES

- **Partnership working** between NHS and Leisure
- **Service provision**, sustainable model for ongoing maintenance exercise
- **HCP involvement in service design and delivery**
- **Supervised tailored exercise provided**
- **Usage and adherence**, good
- **Benefits of service provision for service users**
- **Partnership/collaborative working**, NHS Shetland and Shetland Recreational Trust (SRT) and third sector (assisting with transport)
- **Pathway, effective referral**, as is communication between Leisure and NHS

KEY CHALLENGES

- **Access**, rurality, local access and access for those housebound
- **Resources**, funding and staffing

Data Sources/References

The HCP, service providers/leisure services and GP survey was online in „survey monkey“ format. For HCP the dissemination process for completion was for HCP via professional networks: SNNF, SSAHP forum, SPRAG, SRNF, CRIGS, CSP Scotland website/online forum, MCN Managers, HI, CHP, NMAHP leads for cascading and internally for stroke nurses in CHSS. Leisure services/service providers, via PAHA, HI, Physical Activity leads and via identification of leisure services providers from online searches along with cross checking with a previous stroke audit and gained knowledge from the PARCS scoping to that point. The GP survey was via a CHSS list of GPs who had previous contact with CHSS and then targeted identification of practices/practice managers in regions with a no/low responses rate, by sending the link to the survey via post or email. Some questionnaires were completed in paper format during face to face meetings as part of PARCS project and then inputted manually into the survey monkey format (with permission). For service users the surveys were posted out to all CHSS group leads to circulate via their respective groups. All data was protected in line with CHSS data protection and confidentiality policies and followed the ethical standards of the charity in line with charity business/service development.

All data incorporated within the CHSS PARCS scoping was collected for the period November 2012 – January 2014. The PARCS surveys were completed between August 2013 and January 2014.

The data represented in the tables above is compiled from a synthesis of data from PARC surveys - MCN, Health Care Professionals, and service provider (leisure services, third sector, and private provider) responses. The data synthesis process that was used for each question/table response was in relation to the number of definitive responses to that question (i.e. yes and no answers only, unsure responses were not included in the tally). For Yes or No responses, if all stakeholders reported Yes the table was populated with a Yes and the same process was used for No. If there was a mixed response from the different stakeholders, if the total responses for that question were high (>20) the majority response was used. If the total responses were low (below 20) if 2 or more stakeholders responded negatively (No) or positively (Yes) the answer was populated as „some regions. If the responses for that question were high (>20) and the results were mixed i.e. a high number of yes and a high number of no, the answer was populated as some regions. If there was only a single response either yes or no the respective response was used and populated, or populated as 'one region' (as appropriate). If no responses, the section was left blank.

The data represented in key contextual overview and quotes sections (above the tables) is a data synthesis from the PARCS surveys (as detailed above and including service users), meetings detailed below and other data sources e.g. reports, audits/evaluations, online resources (e.g. websites etc), identified as part of the PARCS (CHSS) scoping. Where information was missing e.g. nil responses the information was based on information available from other e.g. online resources. The accuracy such information may not always be correct; the sense check detailed below was to enable a mechanism whereby any errors to be identified and corrected.

The overview profile shown above (tables and key contextual data) was circulated prior to final production to the respective Health Board MCN Managers for sense checking (checking that the information had no obvious errors). A 2 week deadline was given (due to the time limited nature of the project). A nil response within a 2 week period would lead to the assumption that the data was acceptable and required no corrections.

PARCS surveys responses in this Health Board region (or hits on web based surveys, and stakeholders represented)

- MCN, n=1
- Health Care Professional, n=0
- GPs, n= 6
- Service Providers (Leisure), n=1
- Service Users, n= 0

Meetings as part of PARCS CHSS scoping in this Health Board region

- Face to Face Meetings - nil

References

ISD statistics provided by ISD

1. Source: 2012 mid-year population estimates (National Records of Scotland (NRS)) (<http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html>)
2. Source: 2011/12 version of the Urban Rural Classification (Scottish Government) and the 2012 mid-year population estimates (National Records of Scotland).
3. Urban areas are settlements of over 3,000 people. Rural areas are settlements of fewer than 3,000 people. More details can be found here: <http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification>
4. Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp>
5. Source: SMR01 (ISD), extracted February 2014. Number of patients discharged from hospital during calendar year 2012.
6. Source: Cardiac Rehabilitation in Scotland (2011/12) publication. The full publication and data tables can be found here: <https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf>

Statistics from other sources (as not collected by ISD)

7. Health Improvement Scotland Costing Report – Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) http://www.healthcareimprovementscotland.org/our_work/longterm_conditions/copd_implementation/implementing_copd_standards.aspx

8. These figures were based on responses to the PARCS survey (CHSS scoping) from services providers (this could include leisure, third sector, private). The year (i.e. 2012 -2013) from some providers was not completed. The figures are therefore intended to give a snapshot estimate of numbers in services. Also in some regions more than one provider was identified but only one or some of the providers responded. In some regions attendance fluctuated in numbers particularly in third sector groups, so figures were based on averages or the range if given. The figure provided is not a definitive figure but intended to give a best estimate based on the information available and only represents service providers and initiatives that the PARCS scoping was able to identify within the time limited constraints of the project and the data available.
9. **Register of Exercise Professionals (REPs)** is an independent, public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REP's provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards. **DEFINITION OF REPS LEVEL 3:** The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions this includes Respiratory Conditions: Asthma and Chronic obstructive pulmonary disease (COPD). Musculoskeletal Conditions, Cardiovascular Conditions, Hypertension, Hypercholesterolaemia, Psychological/Mental Health Conditions, Metabolic/Immunological Conditions e.g. Diabetes Type 1 and Type 2 and obesity. **DEFINITION OF REPS LEVEL 4:** The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the affects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease. <http://www.exerciseregister.org/resources/exercise-referral>

TAYSIDE

Service Users „Gave me the confidence and encouragement to exercise in a safe environment. Having a medically qualified physiotherapist/instructor is essential... can't go on enough of the benefits of the maintenance activity groups and support groups in our region. I wouldn't have the quality of life I have without them” „Given a sense of involvement in self-management of condition, up to date information on COPD... wonderful routine... good social activity... with great emotional support... life-changing.”

Health Care Professionals (HCP) ‘The Stroke Liaison Service has worked hard to provide a stroke exercise group. After this was established a further maintenance class was set up through volunteers who had attended the original class following stroke. They are now Chest, Heart & Stroke Scotland (CHSS) affiliated and work closely with the Leisure Centre instructors who deliver the class.” „Exercise shows benefit! Reduced admissions seen...”

GPs ‘I find our local exercise on referral has a very positive impact on management of many individual patients in my practice” „I have a limited ability for exercise on prescription but not for this group of patients... All evidence supports exercise as being beneficial so would be good to have better service provision”

BOARD PROFILE

Total Board Population ⁽¹⁾	411,750
Urban/ Rural ^(2,3)	305,211 / 106,539 (74% / 26%)

PREVELANCE & STRUCTURED CLINICAL REHABILITATION

Condition	CHD	COPD	Stroke
Prevalence ⁽⁴⁾	18,486	9,927	10,155
Hospital Discharges ⁽⁵⁾ (number of patients)	1,637	797	784
Cardiac Rehabilitation ⁽⁶⁾ (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	623 (72.4%)		
Pulmonary Rehabilitation ⁽⁷⁾ (estimated total number of patients per year)			620
Stroke Rehabilitation (number of patients per year)			Not collected by ISD

AVAILABILITY OF MAINTENANCE OF EXERCISE

Known numbers participating in community based maintenance exercise/physical activity (snapshot/estimated per annum) ⁽⁸⁾	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults/ Older Adults Activities
Leisure services provided (new referrals) (one provider in Perth, Angus figures are documented below as delivered as a partnership provision, including Leisure and Third Sector, CHSS/Angus Cardiac and LTC groups)	96 i) (one provider)	41 ii)	8 ii) (one provider, mild COPD)	17 ii) (one provider, neurological)	294 ii)	

Leisure Services provided (attendances)	Included within 11,311 for exercise referral iii)				11,311 ⁱⁱⁱ) (one provider)	2424 ^v) 4080 walking ^{vi}) (one provider)
CHSS affiliated groups (Angus Cardiac and LTC groups) and BLF groups (attendees, 2014)	415	636	80	8-10 people (Dundee)		
NHS pilot (agreed to referral, in one region)				27 in 2009 (iv)		

i) This is known number of referrals and includes arthritis, asthma, diabetes, hypertension, COPD, MS, neurological conditions, Osteoporosis, other (not specified) pre and post surgery. This is an underrepresentation as (36%, n=106) of individuals, their condition/reason for attendance was unknown. Live Active, Perth figures, 2012-2013.

ii) Live Active, Perth figures, 2012-2013 new referrals

iii) Live Active, Perth figures, 2012-2013 attendances; this includes all health conditions and the referral general

iv) Angus Stroke Rehabilitation Classes – Pilot Project Evaluation – May 2009- November 2009- MacDonald & Mitchell (2009) Stroke Unit Physiotherapist & Stroke Liaison Team lead, Strachtho Hospital - in 6/12 pilot

v) Perth Live Active Leisure Figures - Targeted older adult community classes, 2424 attendances, (n=100 individuals approx)

vi) Perth Live Active Leisure Figures - Stride for Life walks, 95% of individuals are retirement age, 4080 attendances, (n= 300 individuals, approx)

SERVICE DELIVERY

Aspects of Delivery	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults	Other: Third Sector/ Charity Affiliated
Type of Delivery (Generic/LTC or Condition Specific *)	Yes	Yes	Some regions	Some regions	Yes	Yes	Some regions
Established Pathways to Exercise Maintenance	Yes	Yes	Yes	Some regions	Yes	Some regions	Some regions
Earliest year a Scheme Commenced	2006 or earlier	2006 or earlier	2006 or earlier	2008	2010		2012
Service Co-ordinator	Yes	Yes	Yes	Yes	Yes		Yes

*Yes/No here indicates stakeholder responses to the question what types of follow on maintenance class are available in your region generic long term conditions class, a cardiac specific class, a respiratory specific class etc (details of data sources and synthesis in the reference section below)

REFERRAL

Single Point of Referral for all Long Term Conditions to Exercise Maintenance	No. Angus has a project co-ordinator who works with Angus Cardiac Group, patients are referred to the leisure centre of their choice, and each facility has a named contact. Perth & Kinross has a Live Active Referral co-ordinator who is the single referral point Pan Perth and Kinross. Dundee has no central point of referral.
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DATA COLLECTION

Data Collector / Data Collected	Not collected	Leisure services	Commissioned by academic institution	NHS – HCP	Other
Follow up data				Some regions	
Cost effectiveness		No		Yes (one region)	
Person centred data		Yes (one region)		Some regions	

FUNDING

Funders	Local Authority	Leisure Services	Short Term Government Grant	Short Term NHS - Charitable	Established NHS	Third Sector/ Charity
Funding partners for service delivery	Yes (one region)	Yes	Yes	Yes	Yes	Yes
Funding for initial instructor/service provider training			Yes			

GOVERNANCE

Collaborative working group(s) for governance of exercise maintenance	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
		Yes	Yes	Yes	Yes	Yes (one region)

INSTRUCTORS WITH SPECIALIST TRAINING

Different regions have variation in numbers trained, overall total of known instructors shown

REPS Level 4 (10)	REPS Level 3 (10)	BACPR	Otago (falls)	Postural Stability Instructor (falls)	Exercise After Stroke	Wright Foundation	Seated Exercise	NHS In-house	Data Sources
1		7-9 (i)	2-15 (i)	2-4 (i)	2-3 *(i)	11	6-35(i)	11	Total from sources MCN (Angus), MCN Stroke, Pan Tayside response, HCP, Service Co-ordinator/ provider (one region)

(i)The range in total numbers indicated represents the range of responses given, i.e. lowest number response to highest number response.

This number potentially indicates numbers known by the different data sources documented above or the variation in numbers of instructors in different geographical locations within the Health Board.

KEY CONTEXTUAL OVERVIEW - 3 Community Health Partnership Regions

Cardiac Rehabilitation (CR) pan Tayside is tailored to individual need with the offer of appropriate menu based options, e.g. exercise, and support groups and lifestyle management.

- In **Perth & Kinross** is delivered at Perth Royal Infirmary. The exit strategy is referral to service co-ordinator (Leisure services) for Live Active, the exercise referral scheme (includes long term conditions, LTC).
- In **Angus** CR is delivered at Stracathro Hospital and Arbroath Infirmary with an exit strategy to refer to the partnership programme for LTC, Be Active ..Live Well.
- In **Dundee** is delivered at Ninewells hospital and in community based settings.

Pulmonary Rehabilitation (PR) is delivered in

- **Perth & Kinross** as a six week programme at Perth Royal Infirmary with capacity for one site linkage via Videoconferencing equipment at Pitlochry, Crieff and Aberfeldy. Patients are offered the option of community or hospital based delivery. The exit strategy is referral to the service co-ordinator (Leisure services) of Live Active, activity referral programme. Other menu based options are also offered including support groups such as BLF (Breathe Easy), walking groups, Tayside Healthcare Arts Trust projects (pan Tayside) e.g. singing for COPD.
- In **Angus** PR is offered as a roving programme across several sites. The exit strategy is referral to Live Active... Be well programme for LTC. Other menu based options include: peer/self help support Third Sector (CHSS affiliated) groups and walking groups.
- In **Dundee** PR is delivered within the Kings Cross Health and Community Care centre. Exit strategy is to encourage service users to access the maintenance classes held in either the Leisure centre or/and a local church. Drop-in sessions in the church have seen maintenance class numbers trebling.

Stroke Rehabilitation is delivered both in hospital and in the community. **Pan Tayside** the exit strategy is a core eight week exercise programme. Other menu based options include Tayside Healthcare Arts Trust projects, various arts projects for stroke survivors.

Long Term Conditions Exercise Maintenance is delivered in

- **Perth and Kinross** within the Leisure services exercise referral scheme Live Active, a twelve week programme with referral onto menu based activities.
- **Angus** by Be Active... Live Well, a programme of activities for people with a LTC, a partnership organisation between Angus Cardiac Group - CHSS affiliated, Angus Council's Leisure Services, Angus Community Health Partnership, Angus Chronic Obstructive Pulmonary Disease (COPD) Groups, Volunteer Gold and the Angus Carer's Centre in collaboration with Angus Care and Repair. The programme is not time limited. There is also delivery in care homes by trained care home staff for seated exercise.
- Other menu based options include Tayside Healthcare Arts Trust projects, various arts projects for LTC. There is also a CHSS affiliated dance group in one location.

Cardiac exercise maintenance (Phase IV – long term maintenance) is available Pan Tayside. LTC classes are available throughout Tayside and are now being joined with the Phase IV classes (as detailed above). There are three, Third Sector (CHSS affiliated groups): Angus Cardiac Group (detailed above), one Physiotherapist led exercise group in Perth and one social/support group in Dundee.

Pulmonary exercise maintenance is delivered in within regional LTC models detailed above. In **Dundee** maintenance classes held in either the Leisure centre or/and a local church. In **Angus** -Third Sector provision, four CHSS affiliated exercise groups in four

locations, three are Physiotherapist led and one is peer led. This is as well as Angus Cardiac/LTC Group (detailed above).

Stroke exercise maintenance comprises a core eight week exercise group Pan Tayside (with delivery including Stroke Liaison Nurse (s), Physiotherapist (s) and specialist instructors(s). From there, HCP referral into the below groups

- **Dundee and Angus**, to Vitalyz seated exercise for more disabled patients, and other LTC programme in Angus as appropriate. Angus patients can also self-refer to seated and circuit classes held at local Leisure facilities.
- **In Perth and Kinross** referral to Leisure services delivered maintenance class.

KEY SUCCESSES

- **Positive impact for service users**
- **Generic LTC delivery**
- **HCP involvement in service design and delivery**
- **Supervised tailored exercise led by specialist instructors**
- **Pathway, effective referral and signposting with self referral option** (in some regions) valued by service users i.e. those diagnosed and treated prior to service establishment, also allows access to suits user need/readiness
- **Menu based options**, variety of options for exercise: gym and community based, circuit , seated & walking groups, self management/support groups, arts,
- **Linkage between Leisure and Third Sector** provided groups, complement each other, i.e. Leisure based exercise class links with Third Sector support groups
- **Tailored exercise**, different intensities and levels offered
- **Adherence**, more people maintaining and numbers growing (e.g. after PR)
- **Access**, multi-located classes throughout the region
- **Partnership/collaborative working**, including LA, leisure, Third Sector , NHS, service users
- **Funding sustainability**, „able to ensure funding for exercise maintenance for people with ANY long-term condition“ (Angus)
- **Peer support/visit to rehabilitation**, beneficial
- **Volunteers** (trained), important in delivery
- **Reach**, is increased when services well established and with delivery to social services e.g. care homes

KEY CHALLENGES

- **Equity in service provision, geographical & cross population challenges & for all cardiac conditions** (e.g. angina and heart failure without CHD)
- **Pathway, effective referral for GPs**, some GPs cannot refer in some regions
- **Knowledge of services**, could still improve across all stakeholders
- **Resources, funding & staffing** ...“getting external funding (often short term)...“(Dundee) „Funding for staffing and maintaining availability“ (Perth & Kinross)
- **Instructor & volunteer training**, across all LTC (some regions)
- **Access, transport & for timings** for working and retired population
- **Data collection, transfer & sharing**, resources, staffing and funding for this
- **Partnership working**, with different priorities from partners

Data Sources/References

The HCP, service providers/leisure services and GP survey was online in „survey monkey“ format. For HCP the dissemination process for completion was for HCP via professional networks: SNNF, SSAHP forum, SPRAG, SRNF, CRIGS, CSP Scotland website/online forum, MCN Managers, HI, CHP, NMAHP leads for cascading and internally for stroke nurses in CHSS. Leisure services/service providers, via PAHA, HI, Physical Activity leads and via identification of leisure services providers from online searches along with cross checking with a previous stroke audit and gained knowledge from the PARCS scoping to that point. The GP survey was via a CHSS list of GPs who had previous contact with CHSS and then targeted identification of practices/practice managers in regions with a no/low responses rate, by sending the link to the survey via post or email. Some questionnaires were completed in paper format during face to face meetings as part of PARCS project and then inputted manually into the survey monkey format (with permission). For service users the surveys were posted out to all CHSS group leads to circulate via their respective groups. All data was protected in line with CHSS data protection and confidentiality policies and followed the ethical standards of the charity in line with charity business/service development.

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PARCS surveys responses in this Health Board region (or hits on web based surveys, and stakeholders represented)

- MCN, n= 2, Stroke (Pan Tayside), and Angus
- Health Care Professionals, n= 23
- GPs, n= 19
- Services providers, (Leisure instructor/co-ordinator), n=1
- Service users, n= 33

Meetings as part of PARCS CHSS scoping in this Health Board region

Face to Face Meetings with:

- X 3 Health Care Professionals, (multiple meeting with one)
- X 2 support/exercise (service user) groups leads (multiple meetings)
- X 1 Leisure services Health Manager

References

ISD statistics provided by ISD

1. Source: 2012 mid-year population estimates (National Records of Scotland (NRS)) (<http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html>)
2. Source: 2011/12 version of the Urban Rural Classification (Scottish Government) and the 2012 mid-year population estimates (National Records of Scotland).
3. Urban areas are settlements of over 3,000 people. Rural areas are settlements of fewer than 3,000 people. More details can be found here: <http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification>
4. Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp>
5. Source: SMR01 (ISD), extracted February 2014. Number of patients discharged from hospital during calendar year 2012.
6. Source: Cardiac Rehabilitation in Scotland (2011/12) publication. The full publication and data tables can be found here: <https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf>

Statistics from other sources (as not collected by ISD)

7. Health Improvement Scotland Costing Report – Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) http://www.healthcareimprovementscotland.org/our_work/longterm_conditions/copd_implementation/implementing_copd_standards.aspx
8. These figures were based on responses to the PARCS survey (CHSS scoping) from services providers (this could include leisure, third sector, private). The year (i.e. 2012 -2013) from some providers was not completed. The figures are therefore intended to give a snapshot/estimate of numbers in services. Also in some regions more than one provider was identified but only one or some of the providers responded. In some regions attendance fluctuated in numbers particularly in third sector groups, so figures were based on averages or the range if given. The figure provided is not a definitive figure but intended to give a best estimate based on the information available and only represents service providers and initiatives that the PARCS scoping was able to identify within the time limited constraints of the project and the data available.
9. MacDonald & Mitchell (2009) Angus Stroke Rehabilitation Classes, Pilot Project Evaluation, May 2009- November 2009. Stroke Unit Physiotherapist & Stroke Liaison Team lead, Stracathro Hospital.
10. **Register of Exercise Professionals (REPs)** is an independent, public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REP's provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards. **DEFINITION OF REPS LEVEL 3:** The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions this includes Respiratory Conditions: Asthma and Chronic obstructive pulmonary disease (COPD). Musculoskeletal Conditions, Cardiovascular Conditions, Hypertension, Hypercholesterolaemia, Psychological/Mental Health Conditions, Metabolic/Immunological Conditions e.g. Diabetes Type 1 and Type 2 and obesity. **DEFINITION OF REPS LEVEL 4:** The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the affects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease. <http://www.exerciseregister.org/resources/exercise-referral>

WESTERN ISLES

GPs „There is a small Leisure Centre locally but it is up to twenty miles from some of my patients. Hence there are issues with ease of access. Whilst absolute numbers are small it may mean that patients miss out on exercise maintenance” „The service provision at present is only for cardiac patients with specific conditions” „Many of my patients live in remote areas and are often house bound, in order for any provision of exercise maintenance to be effective it would require trained individuals to deliver it in the patient’s home environment”, „As far as I am aware, there is no stroke exercise program in our area”.

BOARD PROFILE

Total Board Population ⁽¹⁾	27,560
Urban/ Rural ^(2,3)	7,139 / 20,421 (26% / 74%)

PREVELANCE & STRUCTURED CLINICAL REHABILITATION

Condition	CHD	COPD	Stroke
Prevalence ⁽⁴⁾	1,647	484	679
Hospital Discharges ⁽⁵⁾ (number of patients)	132	57	49
Cardiac Rehabilitation ⁽⁶⁾ (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	Not published		
Pulmonary Rehabilitation ⁽⁷⁾ (estimated total patients per year)		32	
Stroke Rehabilitation (estimated total patients per year)			Not collected by ISD

AVAILABILITY OF EXERCISE MAINTENANCE (EM)

Known numbers participating in community based maintenance exercise (snapshot/estimated per annum) ⁽⁸⁾	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults/ Older Adults Activities
Leisure services provided	Not collected	Not collected	Not collected	Not collected	Not collected	Not collected
Numbers undertaking PA in affiliated CHSS groups						
Charity community group (cardiac, stroke, pulmonary specific)						
Total Known						

SERVICE DELIVERY OF EM

Aspects of Delivery	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults	Other: Third Sector/ Charity Affiliated
Type of Delivery (Generic/LTC or Condition Specific *)		Yes	Yes				
Established Pathways to Exercise Maintenance		Yes	Yes				
Earliest year a Scheme Commenced							
Service Co-ordinator							

*Yes/No here indicates stakeholder responses to the question what types of follow on maintenance class are available in your region generic long term conditions class, a cardiac specific class, a respiratory specific class etc (details of data sources and synthesis in the reference section below)

REFERRAL TO EM

Single Point of Referral for all Long Term Conditions to Exercise Maintenance	No single point of referral/contact and no service co-ordinator
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DATA COLLECTION FOR EM

Data Collector	Not collected	Leisure services	Commissioned by academic institution	NHS – HCP	Other
Data Collected					
Follow up data					
Cost effectiveness					
Person centred data					

FUNDING FOR EM

Funders	Local Authority	Leisure Services	Short Term Government Grant	Short Term NHS - Charitable	Established NHS	Third Sector/ Charity
Funding partners for service delivery	No	No	No	No	No	No
Funding for initial instructor/service provider training	No	No	No	No	No	No

GOVERNANCE OF EM

Collaborative working group(s) for governance of exercise maintenance	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
No group						

INSTRUCTORS WITH SPECIALIST TRAINING

Different regions have variation in numbers trained, overall total of known instructors shown

REPS Level 4 (9)	REPS Level 3 (9)	BACPR	Otago (falls)	Postural Stability Instructor (falls)	Exercise After Stroke	Wright Foundation	Seated Exercise	NHS In-house	Data Sources
3	1-4 (i)			Training pending (8)			3		MCN

(i)The range in total numbers indicated represents the range of responses given, i.e. lowest number response to highest number response.

This number potentially indicates numbers known by the different data sources documented above or the variation in numbers of instructors in different geographical locations within the Health Board.

KEY CONTEXTUAL OVERVIEW - 1 Community Health Partnership Region

Cardiac Rehabilitation no information provided

Pulmonary Rehabilitation is delivered in hospital and community based settings (hospital two sessions per week, community one session per week)

Stroke Rehabilitation no information provided

Long term conditions exercise maintenance No formal service available. Other options include: Paths For Health, Slainte Mhath (Leisure/Sports Centre) individual and family reduced cost membership, GP exercise referral scheme. Specialist fitness instructor training is due to take place. Self referral is available, to all the aforementioned services.

Cardiac exercise maintenance service provision changing to link with My Action - a programme that supports patients and their families at high risk of CVD (and its associated complications). This is done using a validated evidence based programme incorporating tailored physical activity, dietetic advice and specialist nursing and medical support. The ethos of the programme is based on long term self management following a period of structured rehabilitation and re-enablement.

Respiratory exercise maintenance No information provided

Stroke exercise maintenance No service available

KEY SUCCESSES

- **Older adult exercise programmes**, the Western Isles Health Promotion department provide a range of support via exercise programmes which promote health and wellbeing amongst the older population. A Health Improvement Project provides health information and links to local support groups.

KEY CHALLENGES

- **Service provision for exercise maintenance**
- **Access, local access and transport and for those housebound**, the hospital can be sixty miles away for some and the Leisure centre twenty miles
- **Access for all conditions**, cardiac specific service only at present
- **Partnership working**
- **Knowledge of services**, via Resource Development and sharing of information

Data Sources/References

The HCP, service providers/leisure services and GP survey was online in „survey monkey“ format. For HCP the dissemination process for completion was for HCP via professional networks: SNNF, SSAHP forum, SPRAG, SRNF, CRIGS, CSP Scotland website/online forum, MCN Managers, HI, CHP, NMAHP leads for cascading and internally for stroke nurses in CHSS. Leisure services/service providers, via PAHA, HI, Physical Activity leads and via identification of leisure services providers from online searches along with cross checking with a previous stroke audit and gained knowledge from the PARCS scoping to that point. The GP survey was via a CHSS list of GPs who had previous contact with CHSS and then targeted identification of practices/practice managers in regions with a no/low responses rate, by sending the link to the survey via post or email. Some questionnaires were completed in paper format during face to face meetings as part of PARCS project and then inputted manually into the survey monkey format (with permission). For service users the surveys were posted out to all CHSS group leads to circulate via their respective groups. All data was protected in line with CHSS data protection and confidentiality policies and followed the ethical standards of the charity in line with charity business/service development.

All data incorporated within the CHSS PARCS scoping was collected for the period November 2012 – January 2014. The PARCS surveys were completed between August 2013 and January 2014.

The data represented in the tables above is compiled from a synthesis of data from PARC surveys - MCN, Health Care Professionals, and service provider (leisure services, third sector, and private provider) responses. The data synthesis process that was used for each question/table response was in relation to the number of definitive responses to that question (i.e. yes and no answers only, unsure responses were not included in the tally). For Yes or No responses, if all stakeholders reported Yes the table was populated with a Yes and the same process was used for No. If there was a mixed response from the different stakeholders, if the total responses for that question were high (>20) the majority response was used. If the total responses were low (below 20) if 2 or more stakeholders responded negatively (No) or positively (Yes) the answer was populated as „some regions. If the responses for that question were high (>20) and the results were mixed i.e. a high number of yes and a high number of no, the answer was populated as some regions. If there was only a single response either yes or no the respective response was used and populated, or populated as 'one region' (as appropriate). If no responses, the section was left blank.

The data represented in key contextual overview and quotes sections (above the tables) is a data synthesis from the PARCS surveys (as detailed above and including service users), meetings detailed below and other data sources e.g. reports, audits/evaluations, online resources (e.g. websites etc), identified as part of the PARCS (CHSS) scoping. Where information was missing e.g. nil responses the information was based on information available from other e.g. online resources. The accuracy of such information may not always be correct; the sense check detailed below was to enable a mechanism whereby any errors to be identified and corrected.

The overview profile shown above (tables and key contextual data) was circulated prior to final production to the respective Health Board MCN Managers for sense checking (checking that the information had no obvious errors). A 2 week deadline was given (due to the time limited nature of the project). A nil response within a 2 week period would lead to the assumption that the data was acceptable and required no corrections.

PARCS surveys responses in this Health Board region (or hits on web based surveys, and stakeholders represented)

- MCN, n=1
- Health Care Professionals, n= 1
- GPs, n= 6
- Service Providers (Leisure), n=0
- Service Users, n=0

Meetings as part of PARCS CHSS scoping in this Health Board region

- Face to Face Meetings, nil

References

ISD statistics provided by ISD

1. Source: 2012 mid-year population estimates (National Records of Scotland (NRS)) (<http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html>)
2. Source: 2011/12 version of the Urban Rural Classification (Scottish Government) and the 2012 mid-year population estimates (National Records of Scotland).
3. Urban areas are settlements of over 3,000 people. Rural areas are settlements of under 3,000 people. More details can be found here: <http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification>
4. Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp>
5. Source: SMR01 (ISD), extracted February 2014. Number of patients discharged from hospital during calendar year 2012. Source: Cardiac Rehabilitation in Scotland (2011/12) publication. The full publication and data tables can be found here: <https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf>
6. Source: Cardiac Rehabilitation in Scotland (2011/12) publication. The full publication and data tables can be found here: <https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf>

Statistics from other sources (as not collected by ISD)

7. Health Improvement Scotland Costing Report – Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) http://www.healthcareimprovementscotland.org/our_work/longterm_conditions/copd_implementation/implementing_copd_standards.aspx
8. Health Improvement Scotland Costing Report – Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/copd_implementation/implementing_copd_standards.asp
9. **Register of Exercise Professionals (REPs)** is an independent, public register which recognises the qualifications and expertise of health-enhancing exercise instructors in the UK. REP's provides a system of regulation for instructors and trainers to ensure that they meet the health and fitness industry's agreed National Occupational Standards. **DEFINITION OF REPS LEVEL 3:** The Exercise Referral Instructor (Level 3) role includes designing, monitoring, adapting and implementing exercise programmes for individual clients with a range of medical conditions this includes Respiratory Conditions: Asthma and Chronic obstructive pulmonary disease (COPD). Musculoskeletal Conditions, Cardiovascular Conditions, Hypertension, Hypercholesterolaemia, Psychological/Mental Health Conditions, Metabolic/Immunological Conditions e.g. Diabetes Type 1 and Type 2 and obesity. **DEFINITION OF REPS LEVEL 4:** The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions. The specialist exercise instructor is able to demonstrate that they have met the Level 4 National Occupational Standards in one or more medical areas. Specialist exercise professionals are working within the healthcare sector and are also providing an interface between clinically-led exercise and community-based exercise programmes by designing, delivering, monitoring and evaluating structured, individualised physical activity programmes for clients. Additionally, they have a range of appropriate knowledge and skills that are aligned with current evidence-based, best practice guidelines regarding the affects of exercise on the specific condition/s for which they are qualified to work. Specific medical areas covered by the specialist exercise instructors include: cardiac rehabilitation, falls prevention, stroke, cancer and chronic respiratory disease. <http://www.exerciseregister.org/resources/exercise-referral>

APPENDIX 8 – Key recommendations from PARCS Advisory Sub Group: Specialist Instructor Training

16/01/2014

Attendees:

PARCS Advisory Group Members

Margaret Somerville – Director of Advice and Support, CHSS

Sarah Florida-James – PARCS Project Manager, CHSS

Richard Forsyth - Area Development Manager, BHF Scotland

Maureen Carroll – MCN, CHD Network Manager, NHS

Elaine MacKay - Team Leader Pulmonary Rehabilitation (GGC), NHS

Frederike van Wijck - Professor in Neurological Rehabilitation, Glasgow Caledonian University -

Helen Ryall - Health Improvement Programme Manager, NHS Health Scotland

Debbie Wylie - Physical and Outdoor Activities Officer, Glasgow Life/Glasgow Sport -

Non – PARCS Advisory Group (External Expertise)

Dr Susie Dinan-Young - Honorary Senior Research Fellow, University College London Medical School⁸

1) Consensus was reached for the ideal framework for transition from health to community based activity in the prevention and management of chronic conditions (see attached diagram)

Discussions around the ideal framework were based on the framework for exercise referral currently in delivery in Wales identified by BHF PARCS scoping and as part of the wider national exercise referral work (i.e. England, Wales and parts of Scotland). Susie Dinan Young and other key leads are currently involved within the UK and Canada. The ideal framework would also incorporate the Skills Active National Occupational Standards (NOS) for exercise referral (L3) and for specialist exercise referral (L4). The ideal framework was discussed in relation to the transition from health to community based physical fitness and activity, rather than solely an exercise referral context. The ideal framework in Scotland should align with the

⁸ Dr Dinan-Young kindly attended to bring her expertise in relation to her co-lead on the 2001 NHS National Quality Insurance Framework for Exercise Referral Systems (NQAF) development and on the current NQAF update: „Professional and Operational Standards for Exercise Referral in the UK“ (Royal College Of Physicians & other relevant Royal Colleges, CSP, COT, BASEM, BASES, Skills Active, REPS, UK Active etc.); currently being reviewed by DH & Public Health England. Also she is still actively engaged in Skills Active L3 ER & L4 Specialist NOS. She was on the L4 Skills Active Panel for 10 years and is still actively involved with the standards of training providers and of instructors working with patient populations.

strategic drivers of shift of care to the community and the integration of health and social care. Discussion focused on if and how the Wales framework could be modified for use across Scotland to integrate and not exclude existing varied service delivery, from all sectors, identified within the CHSS PARCS Scotland scoping. The agreed framework shows all of the different tiers with a clear distinction between tiers and the level of training within these tiers, so that the Health Board can see their own gaps.

The modification of the framework for Scotland was in relation to implementation, but not a modification where national duty of care (for patients/service users) and established professional minimum standards, qualifications and training pathways (instructors) are concerned i.e. NOS. The National Quality Assurance Framework and the new Professional and Operational Standards have both been developed in partnership with the medical defence unions i.e. MDDU of Scotland and England in relation to self-referral and screening (please refer to the last paragraph in this section).

Good practice models that demonstrate how various Health Boards are delivering this service already should be included in the report to SGHD, to give Health Boards understanding of how delivery is currently implemented.

For the exit/maintenance tier consensus was reached that this should encompass principles of self management and offer a person centred approach to delivery to include a menu based options including:

- 1 – Mainstream leisure activities
- 2 – Community activities
- 3 – Individual activities

Within the exit/maintenance tier are the different options 1-3 listed above. The issue of quality assurance and duty of care in relation to the standards of supervision and exercise delivery within these groups was raised. The framework documentation would include text that clarified to the referrer the differences in insurance and quality assurance between the qualified instructor and non-instructor led options, 1-3 above. All options 1 -3 listed above would ideally include guidance for service users with long term conditions when they are choosing a group, which may include a disclaimer. This guidance could include:

- a checklist for the person exercising which offers practical guidance when choosing a group
- appropriate details of the group e.g. whether this is peer or qualified instructor led

Signposting or referral to groups by Health Care Professionals would be dictated by the remit and delivery of exercise within these groups to align with professional standards.

Consensus was reached that the framework should offer the option of self referral; an appropriate screening process and tool would be a specific requirement for a self-referral pathway. This would ensure both the appropriate required liaison with the

individual's general practitioner and the self-referrer's safety. This screening process would be an essential gateway to the appropriate tier within this framework. The screening process is intended to be helpful (i.e. match each individual with their most appropriate physical activity) to make it enjoyable as well as safe. The internationally recommended and implemented Canadian Physiological Society's: *Physical Activity Readiness Questionnaire-Revised* (PARQ R) was identified as the current appropriate pre- physical activity screening tool for use, until the updated 2012 PARQ+ is published in 2014. BHF National Centre for Physical Activity at Loughborough University is completing its evaluation and customisation for the UK & Europe in collaboration with the Canadian Physiological Society. This updated screening tool involves an additional role by the instructor to reduce both the work for the GP and the number of inappropriate referrals.

Completion of the PARQR or PARQ +, by the self-referrer/potential service user can be undertaken within a health care or non-health care setting e.g. leisure, with initial screening within the remit of an appropriately qualified instructor. If appropriate the screening tool should then be forwarded to the GP and the self-referrer advised of this. The GP must acknowledge the appropriateness of the self-referrer to participate in the session as per the MMDU stipulation (see section 1, paragraph 2 above). The outcome of the GP review should be communicated to the self-referrer, by either the GP or the potential service provider e.g. leisure.

2) Consensus was reached in relation to the skills, knowledge and expertise needed at each tier (see attached diagram)

Level 4 –for specialist exercise delivery framework (see diagram, specialist instructor supervised exercise delivery tier)

Level 4 - The standards at level 4 have been written to outline the knowledge and skills required to work safely with patients with often chronic and complex medical conditions (<http://www.exerciseregister.org>)

Dr Susie Dinan Young expanded at the PARCS Advisory Sub Group meeting 16/01/14 that the definition on the REPS/Skills Active Website of level 4 would be better defined as:

Level 4 – Specialist Exercise Referral instructors (Skills Active & Register of Exercise Professionals, REP) category for exercise professionals within the specialist exercise delivery framework (see diagram, specialist exercise delivery tier)

Definition of Level 4 - The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions .

Specialist Exercise Delivery Tier

Ideally this could incorporate the concepts of exercise referral schemes run by L3 Exercise Referral Instructors in areas where this service exists.

At present instructor training within Level 4 has 10 different components including NOS and qualifications in:

Level 4
Cardiac Disease
Falls Prevention
Stroke
Back Pain
Mental Health
Chronic Respiratory Disease
Cancer Rehabilitation
LTNC
Long term Neurological conditions
Obesity/Diabetes
Accelerated Rehabilitation (military only)

(<http://www.exerciseregister.org/about-reps/reps-entry-qualifications>)

It is acknowledged that for stroke there is a different training programme with a different provider, content and qualification that is recognised by REPS at level 4. The CHSS PARCS Scotland scoping of the training level identified that Level 4 across Scotland is varied and there is a fragmented approach to delivery of this training.

There was discussion around the priority training areas for chronic conditions and although cardiac conditions, falls and stroke presented the greatest risk for an exercise related adverse event; these conditions may be a starting point for training delivery. The ideal training would cover all conditions (e.g. neurological/neuromuscular, metabolic, musculoskeletal etc.) to allow delivery of a generic class i.e. one that would meet the need of a range of service users with long term conditions existing from (and, whenever the need arose back to) specialist exercise pathways.

- 3) Consensus was reached that a recommendation should be a ‘generic’ specialist instructor course covering all core principles and conditions at Level 4 Specialist Exercise. A standardised national approach, for specialist instructor training across Scotland, available and delivered within Scotland, would be the ideal.**

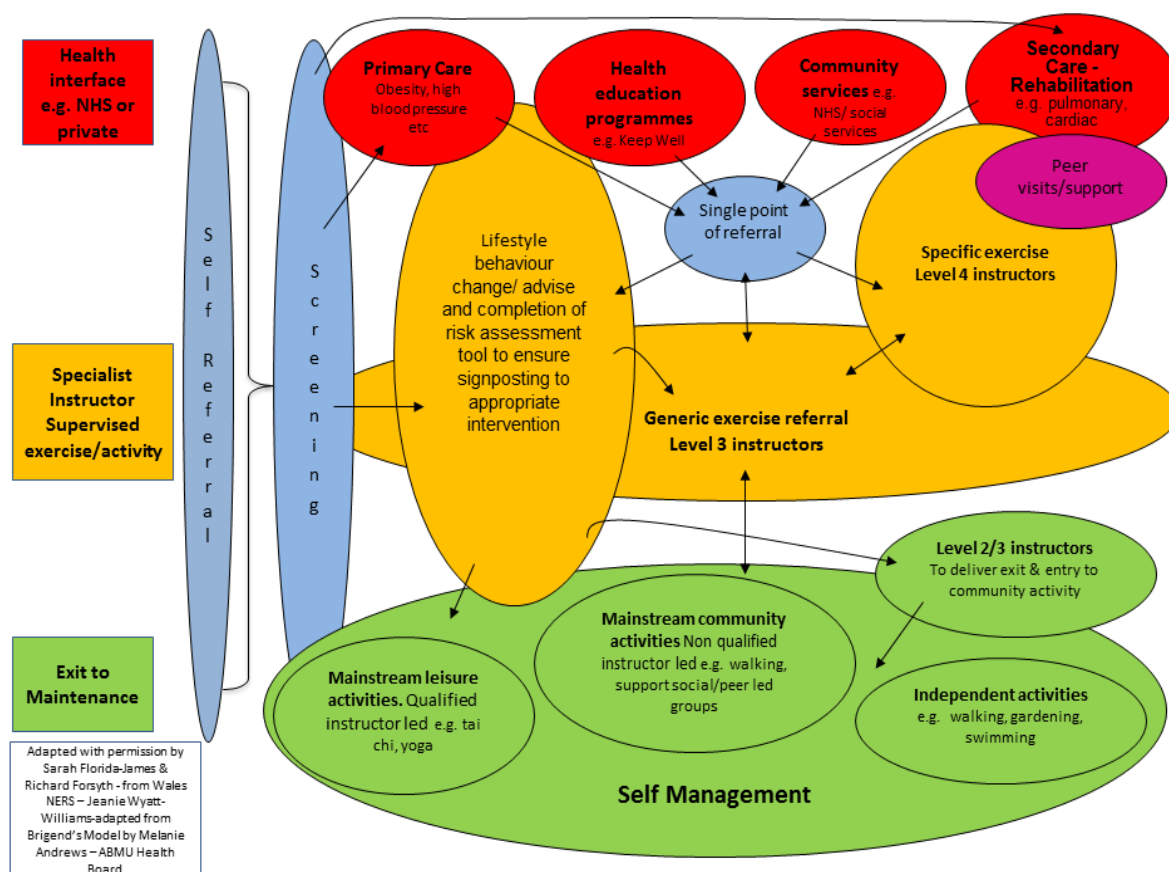
A generic modular course was identified as being available in England, at Middlesex University; this is a well-established course at undergraduate level. Several others in England are in an embryonic state. In addition, there are important relevant developments by the British Association of Sport and Exercise Sciences (BASES) not yet in the public arena (detailed in separate documentation to ensure confidentiality). Consensus was reached that Scottish academic institutions should consider developing similar generic training potentially within a professional pathway for exercise instructors which aligns with NOS.

Whilst this standardised generic training is in development, good practice models that demonstrate how various Health Boards are delivering this service should be included in the report to SGHD, to give other Health Boards an understanding of how delivery is currently implemented.

Recommendations to the SGHD:

- 1) Recommend to SGHD to use this agreed ideal framework for transition from health to community based physical activity in the prevention and management of chronic conditions (see attached framework diagram)**
- 2) Recommend that the SGHD present this framework to Health Boards in relation to the transition from health to community based physical activity in the prevention and management of chronic conditions (see attached framework diagram). This will enable Health Boards to identify where any gaps in the service in their region exist**
- 3) Recommend to SGHD a standardised national approach to specialist instructor training. It is recommended that a generic course covering all core principles, incorporating established best practice, Level 4 instructor qualifications pathways and evidence based exercise interventions for clinical conditions at Level 4 should be available and delivered within Scotland. Future work to take this forward would involve Scottish academic institutions developing and delivering this generic training for specialist instructors.**

APPENDIX 9 – PROPOSED NATIONAL FRAMEWORK FOR THE TRANSITION FROM HEALTH TO COMMUNITY BASED ACTIVITY IN THE PREVENTION AND MANAGEMENT OF CHRONIC CONDITIONS



Proposed national framework for the transition from health to community based activity in the prevention and management of chronic conditions

Basis for the framework

As part of the PARCS project the British Heart Foundation (BHF) conducted an evaluation of frameworks and systems for current service delivery for exercise referral and ongoing physical activity after formal clinical rehabilitation. This evaluation focused on those with long term conditions, primarily cardiac, respiratory and stroke. The proposed framework for Scotland is based on the framework for exercise referral currently in delivery in Wales, National Exercise referral framework. The Welsh National Exercise Referral Schemes (NERS) was identified by the PARCS project (see section D) scoping as part of the wider

national exercise referral work (i.e. England, Wales and parts of Scotland). There is also wider work in relation to exercise referral which key leads are currently concurrently working on within the UK and Canada.

The Welsh NERS scheme (see Section D) provides: a national approach to training specialist instructors (level 4 *) across a variety of conditions, including cardiac (n=137), stroke (n=40) and respiratory (n=90), a standardised single point of referral, 1 national and 22 regional co-ordinators, standardised pathways and interventions that link with rehabilitation, multifaceted model of delivery (including professional and peer support) and defined exit strategies.

Adaption of the framework for Scotland

The Wales framework was adapted for use across Scotland, to integrate and not exclude existing varied service delivery, from all sectors, identified within the CHSS PARCS Scotland scoping. This was adapted in consultation with the PARCS Advisory Sub Group and endorsed by the wider PARCS group (See Appendix 8).

The proposed framework relates to the transition from health to community based physical fitness and activity, rather than solely in an exercise referral context. The proposed framework in Scotland aligns with the strategic drivers of shift of care to the community and the integration of health and social care.

The agreed proposed framework shows all of the different tiers with a clear distinction between tiers and the level of training within these tiers, so that the Health Board can see their own gaps. The proposed framework incorporates the Skills Active National Occupational Standards (NOS) for exercise referral (L3) (1, 2) and for specialist exercise referral (L4) (1, 2). The proposed framework relates to the transition from health to community based physical fitness and activity, rather than solely an exercise referral context. The ideal framework in Scotland aligns with the strategic drivers of shift of care to the community and the integration of health and social care.

The modification of the framework for Scotland was in relation to implementation, but not a modification where national duty of care (for patients/service users) and established professional minimum standards, qualifications and training pathways (instructors) are concerned i.e. National Occupational Standards (NOS). The National Quality Assurance Framework and the new Professional and Operational Standards have both been developed in partnership with the medical defence unions i.e. MDDU of Scotland and England in relation to self-referral and screening

Good models of practice

Good practice models demonstrating how various Health Boards are delivering this service are also included in the PARCS CHSS report, to give Health Boards an understanding of how delivery is currently implemented

Skills, knowledge and expertise needed at each tier (see framework diagram)

Level 4 for specialist exercise delivery framework (see diagram, specialist instructor supervised exercise delivery tier)

Level 4 - The standards at level 4 have been written to outline the knowledge and skills required to work safely with patients with often chronic and complex medical conditions (<http://www.exerciseregister.org>)

Level 4 – Specialist Exercise Referral instructors (Skills Active & Register of Exercise Professionals, REP) category for exercise professionals within the specialist exercise delivery framework (see diagram, specialist exercise delivery tier)

Definition of Level 4 - The knowledge and skills required to work safely with patients with specific, often chronic and complex, medical conditions. To deliver exercise to pathology specific groups of people considered to be at moderate to high risk (i.e. excluding high risk who would be exercising in the medical setting) of an event when partaking in physical activity e.g. cardiac, falls, stroke, respiratory conditions .

Specialist Exercise Delivery Tier

Ideally this could incorporate the concepts of exercise referral schemes run by L3 Exercise Referral Instructors in areas where this service exists.

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Mental Health
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Cancer Rehabilitation
LTNC
Long term Neurological conditions
Obesity/Diabetes
Accelerated Rehabilitation (military only)

(<http://www.exerciseregister.org/about-reps/reps-entry-qualifications>)

It is acknowledged that for stroke there is a different training programme with a different provider, content and qualification that is recognised by REPS at level 4.

Training across Long Term Conditions (LTC)

The CHSS PARCS Scotland scoping of the training level in specialist instructors identified that Level 4 across Scotland is varied and there is a fragmented approach to delivery of this training.

The PARCS Advisory group were consulted regarding the priority training areas for chronic conditions and although cardiac conditions, falls and stroke presented the greatest risk for an exercise related adverse event; these conditions may be a starting point for training delivery. **The ideal training would cover all conditions** (e.g. neurological/neuromuscular, metabolic, musculoskeletal etc.) **to allow delivery of a generic class** i.e. one that would meet the need of a range of service users with LTC existing from (and, whenever the need arose back to) specialist exercise pathways.

Description of the Framework

The framework provides a multi intervention approach including professional and peer support.

Health Interface tier (red)

Ideally there should be multiple entry point into services

Health interface: this includes NHS services or private provider equivalent

All sectors should be addressing lifestyle factors including physical activity either as strategies for: primary prevention (screening and identification of individuals at risk) or secondary prevention (for those with established disease).

Primary Care: e.g. GPs and specialist nurses working largely in the community. In relation to LTC, the regular reviews often scheduled with primary care should be used as opportunities to discuss lifestyle issues including physical activity.

Health Education programmes: such as „Keep Well“ largely involved in primary prevention

Community services: both NHS and social services in line with health and social care integration

Secondary care: involved in the treatment and management of those with ill health including those having falls and LTC e.g. pulmonary conditions. This includes rehabilitation such as cardiac rehabilitation (CR), stroke rehabilitation and pulmonary rehabilitation (PR).

Specialist Instructor Supervised exercise/activity tier (amber)

Lifestyle behaviour change/ advice and completion of risk assessment tool to ensure signposting to appropriate intervention:

It is helpful to have discussions with service users to support behaviour change and ensure potential risks are addressed of particular importance for those with LTC considering undertaking exercise/Physical activity. This can be approached in different ways dependent

on regional infrastructure. This would ideally be started by HCPs within the health interface tier and be evident throughout the tiers. Some regions offer specific support in relation to this examples are, lifestyle advisors within primary care, and instructors within Leisure Service offering 1:1 support for behavioural change. This can range from one off support and referral/signposting or regular follow up throughout a longer period, e.g. 3-12 months.

Specialist exercise instructors level 4

Specialist instructor skills, knowledge and expertise and definitions around the different levels of instructor are detailed in the section above.

Again different approaches to delivery include, specialist/level 4 instructors working alongside HCPs to deliver rehabilitation programmes such as cardiac and pulmonary rehabilitation. Specialist/level 3 and 4 instructors delivering physical activity/exercise maintenance classes can be employed by different providers (e.g. Leisure, Third Sector, Private sector) or self employed, and in deliver classes in various community venues.

The exit to maintenance tier (green)

This tier encompasses the principles of self management and offers a person centred approach to delivery including menu based options:

1) Mainstream leisure activities

2) Community activities

3) Individual activities

1) Mainstream Leisure activities

This could incorporate a wide range of physical activities, e.g. yoga, tai chi

2) Mainstream community activities

This could incorporate a wide range of physical activities including walking, and non physical activities including social and peer support groups, cultural activities

3) Independent activities

This could incorporate a wide range of physical activities including walking, gardening, and swimming.

Quality assurance and duty of care within this tier

It is important to clarify those referring into these options the differences in insurance and quality assurance and personal responsibility between the qualified instructor and non-instructor led options, in relation to the standards of supervision and exercise delivery.

Qualified instructor lead options

The qualified instructor lead options would be delivered by instructors with the specialist skills knowledge and expertise detailed in the section above.

This could include:

Mainstream L2/3 instructors or continuing at specialist L4 instructor dependant on the assessed need of the individual and the service offered in the regions, e.g. some regions offer a specialist L4 instructor non time limited.

Non-qualified instructor led

This could include a variety of peer, volunteer, carer, led activity.

Peers/Volunteers could have often undergone training to deliver an activity e.g. Path for All Walk leader training, completed a specific course e.g. seated exercise to deliver the respective activity; this is not always the case.

Guidance for service users

All options 1-3 listed above would ideally include guidance for service users with LTC when they are choosing a group, which may include a disclaimer. This guidance could include:

- a checklist for the person exercising which offers practical guidance when choosing a group
- appropriate details of the group e.g. whether this is peer or qualified instructor led

Pathways within the framework

It is intended that there is fluidity and flexibility within the individual's pathway to respond to service user need, e.g. in cases of change in condition, represented by the double headed arrows. The pathway is also intended to facilitate ongoing communication between all stakeholders.

Rehabilitation integration

Rehabilitation integration was evidenced by PARCS BHF and CHSS as important to the pathway, in achieving a seamless transition and increasing likelihood of attendance to exercise maintenance. Strategies around this include PR and CR in community based venues, offering Pr and CR in the same venue as exercise maintenance, the exercise maintenance specialist instructor attending clinical rehabilitation sessions and promoting exit strategy, exercise maintenance session taking place one hour preceding /following clinical rehabilitation.

Referral and signposting

Signposting or referral to groups by Health Care Professionals would be dictated by the remit and delivery of exercise within these groups to align with professional standards.

Self-referral, screening and screening tool

The framework offers the option of self-referral; an appropriate screening process and tool would be a specific requirement for a self-referral pathway. This would ensure both the appropriate required liaison with the individual's general practitioner and the self-referrer's safety. This screening process would be an essential gateway to the appropriate tier within

this framework. The screening process is intended to be helpful (i.e. match each individual with their most appropriate physical activity) to make it enjoyable as well as safe. The internationally recommended and implemented Canadian Physiological Society's: *Physical Activity Readiness Questionnaire-Revised* (PARQ R) was identified as the current appropriate pre- physical activity screening tool for use, until the updated 2012 PARQ+ is published in 2014. BHF National Centre for Physical Activity at Loughborough University is completing its evaluation and customisation for the UK & Europe in collaboration with the Canadian Physiological Society. This updated screening tool involves an additional role by the instructor to reduce both the work for the GP and the number of inappropriate referrals.

Completion of the PARQR or PARQ +, by the self-referrer/potential service user can be undertaken within a health care or non-health care setting e.g. leisure, with initial screening within the remit of an appropriately qualified instructor. If appropriate the screening tool should then be forwarded to the GP and the self-referrer advised of this. The GP must acknowledge the appropriateness of the self-referrer to participate in the session as per the MMDU stipulation (see section 1, paragraph 2 above). The outcome of the GP review should be communicated to the self-referrer, by either the GP or the potential service provider e.g. leisure.

Single point of referral

Having multiple referral points (people, providers and location), with differing referral procedures, often combined with various pathways for specific conditions can be barriers from a referrer perspective. Examples of this are multiple referral forms for different providers in geographical regions, so the referrer needs the appropriate referral form but send it to the right person, assuming they are, aware the service exists and who the referral contact is. This often leads to no referral occurring. Having a single referral point/service co-ordinator appears effective in addressing lack of knowledge of services from the referrer perspective, simplifies the referral process and leads to a more effective pathway. Having a single pathway for all LTC is also helpful.

Often it may be challenging, or not feasible to have a single point of referral reasons for this includes: large geographical regions, different service structures, differing referral pathways and procedures, differing service provider's agencies and roles. Solutions evidenced in this PARCS scoping include: having a regional point of referral and having a single point of access, e.g. the MCN website. Another emerging solution explored as part of the project was the SCI Gateway. SCI Gateway is designed as a national portal for clinical communications between and within Healthcare organisations and has been developed by National Information Systems Group (NISG) as a cornerstone product of the eHealth Strategy in Scotland. Meetings as part of this project suggested the SCI may be expanded to other include social care and other agencies.

Peer support and visits

Ideally peer support would be offered across all tiers from health interface to exit and maintenance, good practice examples are reported in the CHSS PARCS scoping. A key transition area is from clinical rehabilitation to maintenance e.g. cardiac rehabilitation (CR) and pulmonary rehabilitation (PR). Visits by peers to clinical rehabilitation, often within the

References

- <http://nos.ukces.org.uk/Pages/results.aspx?u=http%3A%2F%2Fnos%2Eukces%2Eorg%2Euk&k=exercise%20referral#Default=%7B%22k%22%3A%22exercise%20referral%22%2C%22r%22%3A%5B%7B%22n%22%3A%22RefinableString00%22%2C%22t%22%3A%5B%22%5C%22%2C%7%82%22%3A%22and%22%2C%22k%22%3A%22false%22%2C%22m%22%3A%22null%7D%5D%7Dhttp://www.exerciseregister.org/resources/exercise-referral>

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APPENDIX 10 –SERVICE USERS ADVISORY GROUP MINUTES

26th February 2014

Present:

CHSS

PARCS Project Manager (CHSS, chair)

Respiratory Co-ordinator (CHSS)

Community Support Workers x2 (CHSS)

Administrative Assistant (CHSS, minutes)

Total Service Users n= 8

Cardiac conditions representatives n= 3

Pulmonary conditions representatives n= 4 (COPD & bronchiectasis)

Stroke conditions representatives n= 1

Leith Exercise Group, Lothian

Breathbusters action for Bronchiectasis, Lothian

Fife Respiratory MCN sub-group, Fife

Inverclyde Globetrotters, Greater Glasgow & Clyde

Healthy Hearts at Westwood, Lothian

Eyemouth and District Rehab Group, Borders (x 2 representatives)

Angus Cardiac Group, Tayside

Sarah Florida-James welcomed people to the meeting. Round table introductions were made.

1) General overview and update of PARCS Project to Date

Sarah Florida-James ran through a PowerPoint presentation about the aims of the PARCS project. She explained the remit of the three charities. The context of the project is the very low percentage of people achieving physical activity targets (2.5 hours a week).

Explained what data / models have been looked at. Also person-centred data (questionnaires, focus groups etc...)

Scoping to date:

- MCN (Managed Clinical Network) survey, 11 out of 14 Health Boards have returned
- Health Care Professional survey 274 returns
- GP survey 146 returns
- Leisure Service survey 40 returns
- Service Users questionnaire 221

One message that seems to be coming through all these surveys is that there are multiple benefits of being part of a group. Cardiac services are best developed whilst Stroke services are least developed.

2) Review of findings PARCS service user/CHSS affiliated groups questionnaires

Sarah Florida-James distributed collated results from the Service Users questionnaire. There was discussion to reach a consensus about the 3 key graphs and 3 key messages.

The group was amazed at the amount of physical activity completed each week (p3). 76% meeting target of 2.5 or more hours a week. This is very high compared to national average. This reflects that those who completed the questionnaire are service users, which evidences the value of groups. It is therefore important to consider people, who fall out of the loop.

Since people may not be able to exercise straight away, messages need to be repeated. P14 shows that Health Care Professional involvement, who can give the message more than once, is very important.

Social side very important, this is backed up by questionnaire results. People come as much for social aspect as for exercise. Worth considering the politics of presenting this since Scottish Government are unlikely to change policy / provide funding for social reasons. However this is about emotional well-being and effective self-management. People are also then able to contribute back to the community as volunteers.

Very great variation in pathways, would love consistency of approach, especially at discharge. Quick discharges mean that physiotherapists and nurses have no time to discuss follow-on exercise. Therefore need to cater for everyone, even if you are in and out in the same day, e.g. letter from Tayside Health Board does not put across a strong message of the need to exercise.

Pie-charts on p9 and p12 give a very strong message about benefit of both exercise and support groups.

Surprised by the graph on p10 that 82% felt it was an easy transition (but these are all people who have made the transition). Especially true of stroke, that there is a gap between hospital and community.

Graphs on p5 and p6 are trying to prove that people in groups have less hospital admissions to make the economic case. Sarah Florida-James explained that there was more work to do on this once details of national averages had been provided.

Discussion about whether peer support/buddying can help people make the transition to groups. Felt that people are far less likely to take the message of the need to exercise if the message is given just from peers. Could incorporate in rehab programmes (but some rehab

programmes are so stretched that there is no time to do this). Cost of exercise may put people off, need practical information e.g. about Edinburgh Leisure Care. The variation in cost is also an issue as it is hugely inequitable. Also need dedicated groups / times for specialized exercise so that people don't feel intimidated by others who are able to exercise more.

Knowledge of GPs and other Health Care Professionals also very important otherwise they can't refer. Q7 graph shows the need for Health Care Professionals to know what is happening, this begins to make the case for a single point of reference.

Consensus reached that the key messages to highlight from service users are:

1. Amounts of physical activity achieved by people in groups
2. Benefits of groups – both exercise and support
3. Economic benefits – in terms of hospital admissions

APPENDIX 11 – SUMMARY OF PERSON CENTRED/QUALITATIVE DATA FROM MEETINGS AND EXTRAPOLATION OF EXISTING DATA

Work strands in relation to Person Centred Arm of PARCS	Objective for PARCS Project	Work Completed To Date 02/05/2013	Emerging Themes From Person Centred Data only
Blue - work strands			<p>Blue – Themes</p> <p>Green – themes in different geographical locations</p>
<p>1) Person centred pathway for LTC for</p> <p>i) new health event</p> <p>ii) existing long term condition</p> <p>from all entry points to an exit point of community maintenance</p>	<p>i) Develop 2 recognised pathways for LTC for advisory group to get endorsement for from NAC's for HCP and to develop as information source for patients</p> <p>ii) Identify on a regional basis where drop outs/ or gaps are along the pathway</p>	<ul style="list-style-type: none"> ○ X 1 focus group n= 8 (From differing geographical regions with respiratory and heart conditions) ○ Development of 2 LTC pathways ○ Piloting & subsequent amendment of pathways of these pathways with n = 15 (average age 65 - Asthma, Bronchiectasis , ILD, COPD (Fife) 	<ul style="list-style-type: none"> ○ Date of diagnosis, condition and region are important factors as to if you reach exercise maintenance in the community ○ General consensus from focus group 6/8 did not reach exercise maintenance activities ○ Transition from health care services to community maintenance main transition barrier in pathway ○ Transition to exercise maintenance more difficult for those with respiratory conditions with a less defined pathway and episodic nature of symptoms and care
<p>2) Person centred questionnaire s in relation LTC exercise maintenance</p>	<p>To gather data to establish baseline on current service provision in 12 geographical regions from a patient/service user perspective</p>	<ul style="list-style-type: none"> ○ Questionnaire developed and piloted x 2 phases initial piloting focus groups n=8 from differing geographical regions with respiratory and heart conditions 	

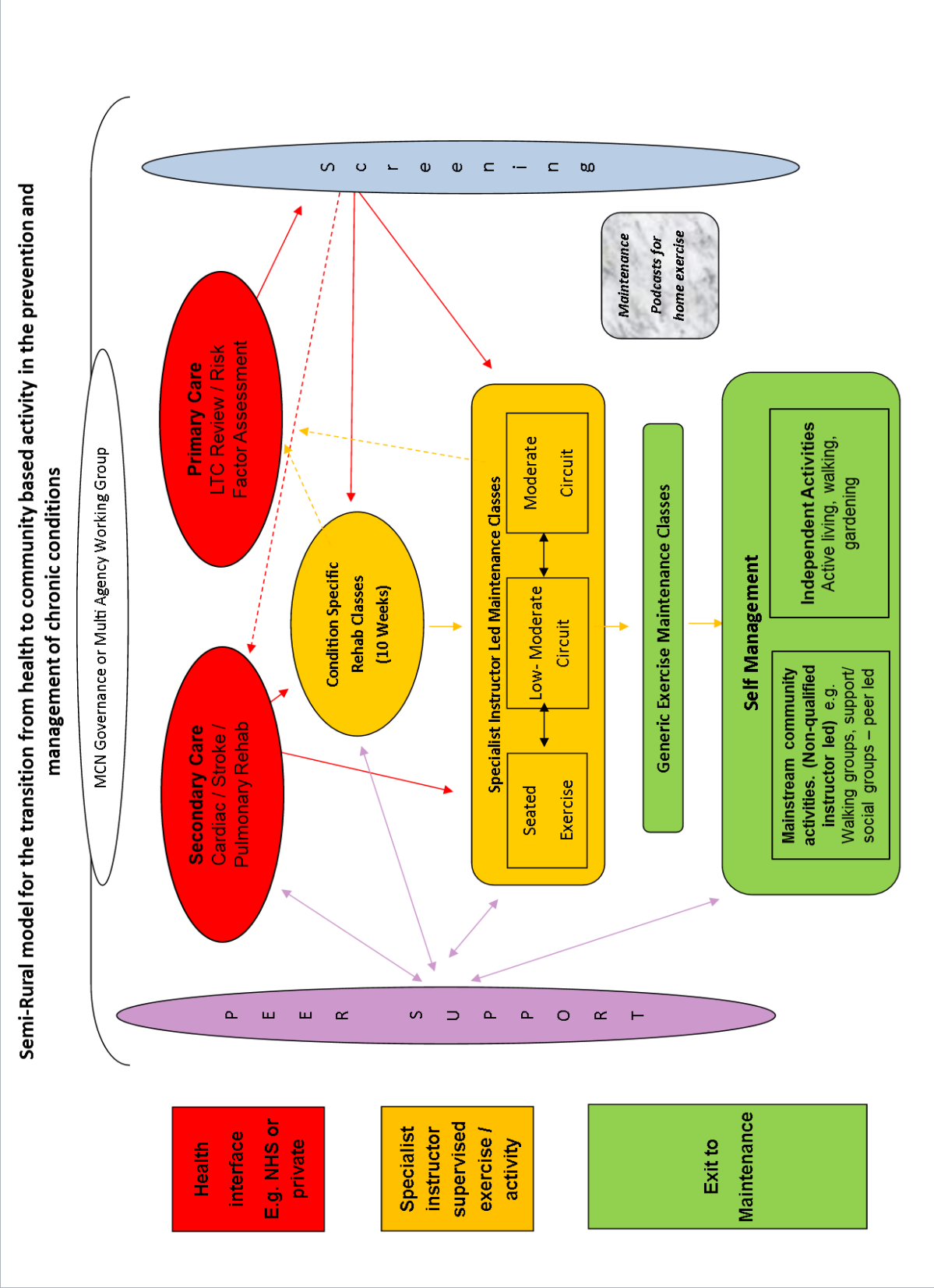
<p>3) Extrapolation of existing patient/ person centred data</p>	<p>To gather data to establish baseline on current service provision in 12 geographical regions from a patient/service user perspective</p>	<p>Key Person Centred Data extrapolated in relation to 3 conditions</p> <p>Extrapolation of patient centred data in existence in 7 health board areas</p> <ul style="list-style-type: none"> Service evaluation by leisure service of exercise maintenance classes for LTC – South Lanarkshire - n=362 with LTC, focus group with LTC n= 20 (South Lanarkshire) Service evaluation n= 402 people with LTC in exercise maintenance classes, questionnaire for LTC n=36 (Tayside) n =(30) telephone interviews with Exercise referral participants as part of Live Active (Glasgow) – not specifically LTC 	<p>In geographical regions where there is a regional collaboratively delivered service (NHS, L.A, Leisure services, user groups) specifically for exercise maintenance for LTC (2 – regions) positive patient feedback</p> <p>Benefits – improved functional ability, liked exercising with people with different conditions</p> <p>Psychological - improved confidence, improved ability to cope</p> <p>Behavioural – enabled better self management of condition</p> <p>NHS Service Usage – reduced GP visits</p> <p>Infrastructure – local access to classes/services</p> <p>In geographical areas where the service is integrated as part of the exercise referral scheme model (2 urban regions) focus groups were held for all patients for exercise referral, so data for LTC difficult to extrapolate</p> <p>Benefits – social aspects, improved relationships with others, support of professionals helpful</p> <p>In geographical areas where there is a cardiac pathway to exercise maintenance (Grampian) delivered by patient led regional group (Grampian Cardiac Rehabilitation Association) with links with NHS, LA and</p>
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		<ul style="list-style-type: none"> ○ n= 319 current cardiac exercise maintenance group members, n=68 ex cardiac exercise maintenance members (Grampian) ○ n= 107 Questionnaire on completion of <i>Pulmonary Rehabilitation evaluation (Borders)</i> ○ Stroke Specific Exercise after stroke pilot n= 27 (Tayside) ○ Lothian Service Evaluation pilot of exercise after stroke n= 14 	<p>leisure services positive feedback from cardiac service users Barriers – <i>knowledge of classes for users and HCP</i> Benefits - <i>supervised tailored exercise, social aspects important</i></p> <p><i>follow up important, encouraged other physical activity in current and ex members</i></p> <p>NHS Service Usage – <i>reduced GP visits</i></p> <p>In geographical regions where there is minimal/nil regional service (small independent patient groups in certain regions and condition specific , mainly pulmonary) (Borders)</p> <p>Barriers - <i>wanting to join an exercise group consisting of previous pulmonary rehabilitation members, what happens next ?, wanting to set up a group</i></p> <p>Stroke specific exercise maintenance services x2 regions – Data from piloting only</p> <p>Barriers - <i>location or transport issues, want long term service, chance to attend more often</i></p> <p>Benefits - <i>social interaction important, less anxious and depressed (Angus n=13)</i></p> <p>Positives <i>89% keen to be referred for exercise after stroke (Lothian n=14)</i></p>
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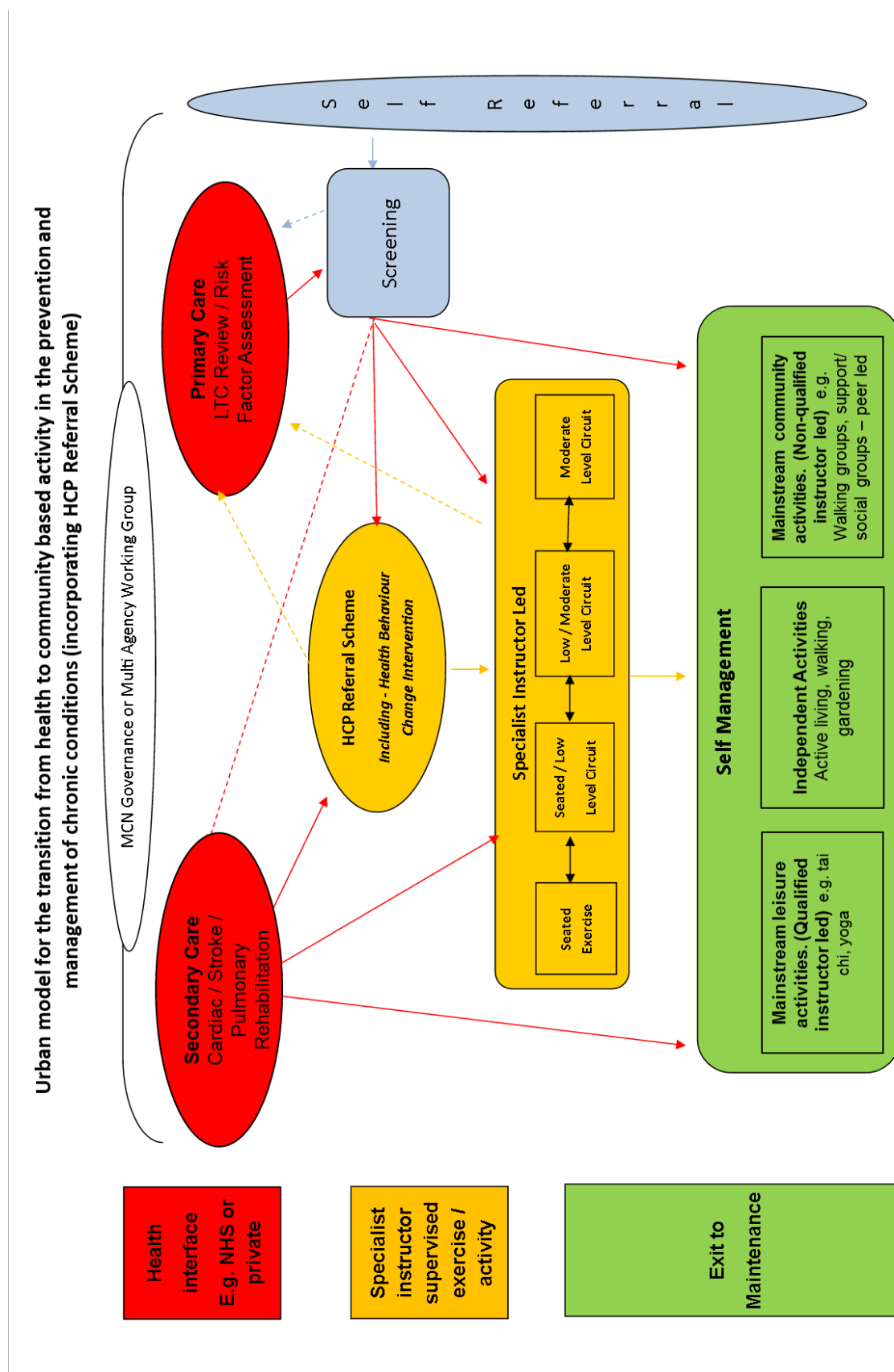
<p>4) Patient Focus Groups conducted by PARCS Project Manager</p>	<p>To gather data to establish baseline on current service provision in 12 geographical regions from a patient/service user perspective</p>	<ul style="list-style-type: none"> ○ X 2 focus groups for those <i>leaving CR</i> n=9 <i>region and PR</i> n= 2 h (n=11) (Borders) ○ X 1 focus group n= 17 with <i>Cardiac Support Group</i> attending leisure services exercise maintenance classes (Lanarkshire) 	<p>In geographical regions where there is minimal service provision small independent patient groups in certain regions and condition specific, mainly pulmonary) (Borders)</p> <p>Barriers <i>Physical -identifying suitable exercise groups, appropriate exercise intensity groups need tailored exercise as per specialist rehab</i></p> <p>Systemic <i>setting up a group</i></p> <p>Social <i>not wanting to go to gym alone with a condition</i></p> <p>Infrastructure <i>Transport, location, can only travel as far as oxygen will allow</i></p> <p>In geographical regions where there is a service specifically for exercise maintenance for LTC</p> <p>Barriers – <i>knowledge of groups from HCP, correct levels of exercise intensity, fear of exercise, hardest step through front door</i> Physical <i>improved confidence to exercise, supervised tailored exercise,</i> Psychological - <i>improved confidence, averted onset of depression</i> Social - <i>social support, not isolation & community involvement</i></p> <p>Positives – <i>seamless transition from NHS to community</i></p>
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5) Recommendations – patient steering to validate all themes and Project Manager recommendations from work strands 1)-3)	Make recommendations from PARCS project findings to SGHD		

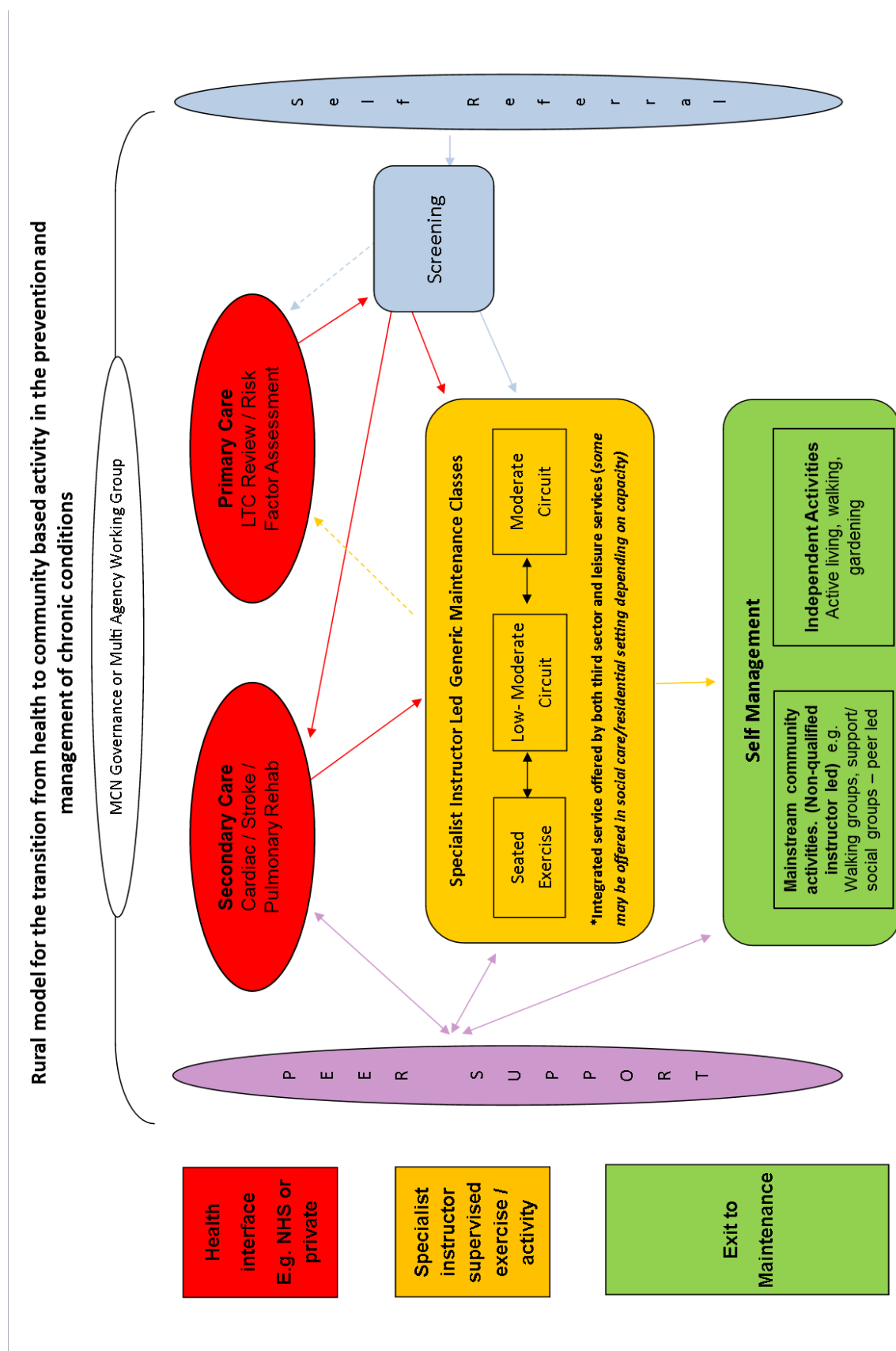
SEMI RURAL DIAGRAMATIC REPRESENTATION OF GOOD PRACTICE



URBAN DIAGRAMATIC REPRESENTATION OF GOOD MODEL PRACTICE



RURAL DIAGRAMATIC REPRESENTATION OF GOOD MODEL PRACTICE



APPENDIX 13 – TABLE SUMMARY OF CRITICAL SUCCESS FACTORS

Critical Success Factors in the transition from health to community based activity for long term conditions

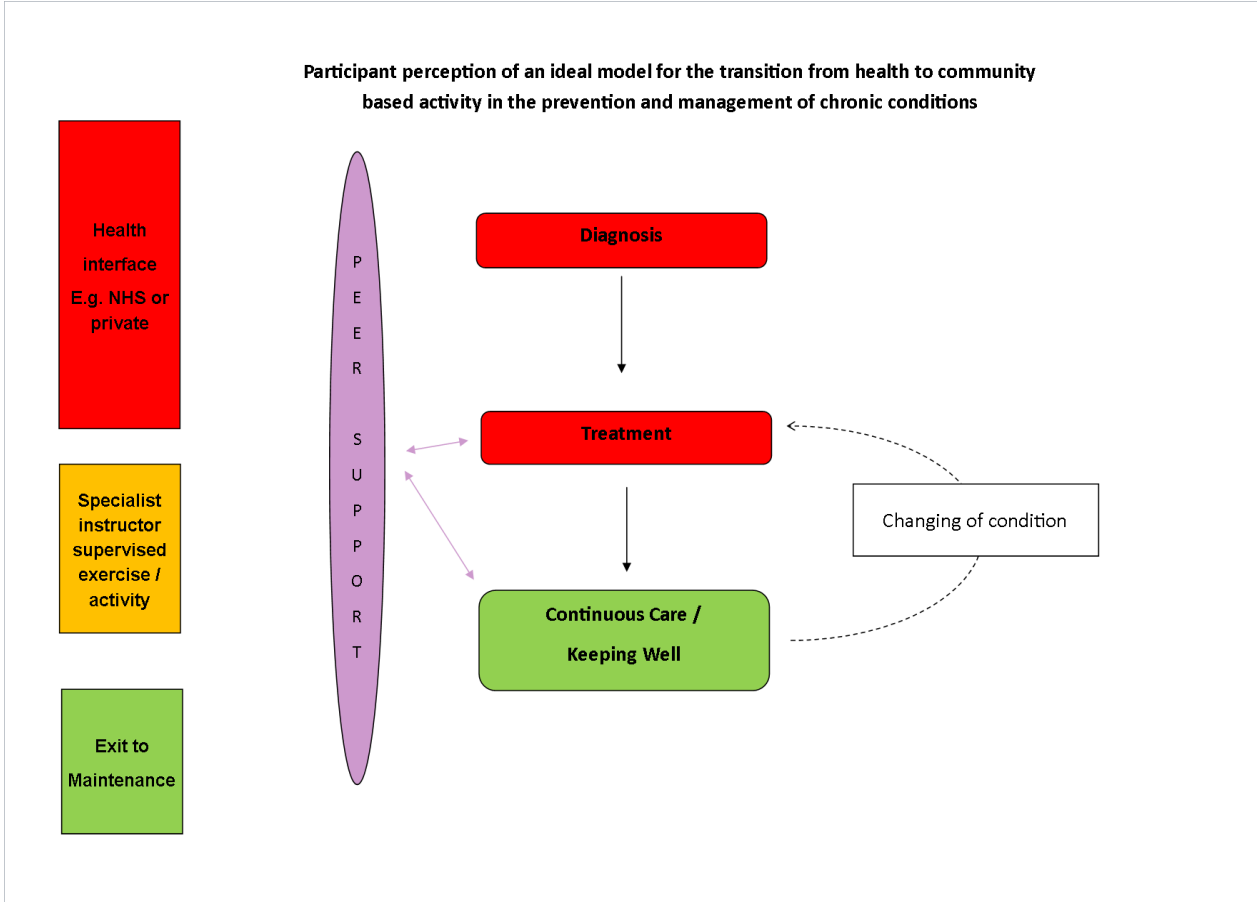
DRIVER /GOVERNANCE

MCN Collaborative working group e.g. MCNs/ Physical Activity Group

APPROACH TO DELIVERY Collaborative with Key Stakeholders	RESOURCES / FUNDING <ul style="list-style-type: none"> • Joint / Collaborative • NHS / Local Authority / Voluntary Sector 	SYSTEMS IN LINE WITH NHS QUALITY STRATEGY
<p><u>NHS</u> E.g.</p> <ul style="list-style-type: none"> • MCN group • MCN Managers • AHP/Clinical lead(s) • Health Improvement Lead <p><u>LOCAL AUTHORITY / LEISURE SERVICES</u></p> <ul style="list-style-type: none"> • Service Co-coordinator <p><u>THIRD SECTOR</u></p> <ul style="list-style-type: none"> • Third Sector Support e.g., Support Group (peer support) Patient Representative. <p><u>ACADEMIC INSITUCTIONS</u></p> <ul style="list-style-type: none"> • E.g. to lead /support research, innovations <p><u>PRIMARY CARE REP</u></p>	<p><u>JOINT FUNDING</u></p> <ul style="list-style-type: none"> • NHS • Local Authority • Leisure Services • Voluntary / 3rd Sector <p><u>TRAINING FOR INSTRUCTORS</u></p> <ul style="list-style-type: none"> • Funding for this- often collaborative e.g. NHS, Leisure Services, Third sector, and Local Authority • HCP work support of this <p><u>SPACE/VENUE</u></p> <ul style="list-style-type: none"> • for exercise/support group e.g. clinical rehabilitation delivered in leisure facility <p><u>USE OF</u></p>	<p><u>SAFE</u></p> <ul style="list-style-type: none"> • <u>Governance</u> – via steering group e.g. MCN or physical activity group • <u>Standardised Referral Process and Pathways</u>, • <u>Screening</u> for „safe to exercise“ / red flags • <u>Instructor Trained</u> – at appropriate levels • <u>HCP↔Instructor Working Relationship</u>; dialogue • <u>Content and delivery of classes</u> – appropriate and tailored <p><u>PERSON CENTRED</u></p> <ul style="list-style-type: none"> • <u>Peer Support</u> ideally for whole pathway NHS to community <p><u>EFFECTIVE</u></p> <ul style="list-style-type: none"> • <u>Data collection/ Audit of Service</u> – ideally standardized • <u>Default Referral</u> from condition specific mainstream rehabilitation

<ul style="list-style-type: none"> • e.g. GP, specialist/community nurse 	<p><u>VOLUNTEERS/PEERS</u></p> <ul style="list-style-type: none"> • Often supported by third sector training, e.g. going to clinical rehabilitation to support and encourage others 	<ul style="list-style-type: none"> • <u>Integrated Rehabilitation</u>, NHS rehabilitation e.g. PR and CR delivered in community venue with peer visit to support maintenance • <u>Education/Behavioural change component/ support e.g.</u> within rehabilitation or in community, peer and support , • <u>‘Safety net’ within system</u> e.g. at follow up review in primary care for those diagnosed before services were in place and to meet service user meet in readiness to engage <p><u>TIMELY</u></p> <ul style="list-style-type: none"> • <u>Default Referral</u> – to community maintenance exercise group <p><u>EQUITABLE</u></p> <ul style="list-style-type: none"> • Make services accessible to all, perform assessment of this • Consider innovations and technologies for hard to reach groups
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APPENDIX 14 – PERSON-CENTRED PATHWAY



APPENDIX 15 – ABBREVIATION OF TERMS

AHP: Allied Health Professional

ACSM: American College of Sports Medicine

BHF: British Heart Foundation

BLF: British Lung Foundation

BACPR: British Association for Cardiovascular Prevention and Rehabilitation

CRIGS: Cardiac Rehabilitation Interest Group Scotland

CVD: cardiovascular disease

CSP: Chartered Society of Physiotherapy

CHSS: Chest, Heart & Stroke Scotland

CHP: Community Health Partnership

CHD: coronary heart disease

GP: General Practitioner

GHA: Glasgow Housing Association

GGC: Greater Glasgow and Clyde

HI: Health Improvement

HF: heart failure

IDM: integrated disease management

IHD: ischemic heart disease

LA: Local Authority

NERS: National Exercise Referral Scheme

NISG: National Information Systems Group

NHS: National Health Service

NICE: National Institute of Clinical Excellence

MDDU: Medical and Dental Defence Union

NMAHP: Nursing Midwifery and Allied Health Professional

PAHA: Physical Activity Health Alliance

RCT: randomised controlled trial

SSAHP: Scottish Stroke Allied Health Professional forum

SGHD: Scottish Government Health Department

SIGN: Scottish Intercollegiate Guidelines Network

SPRAG: Scottish Respiratory Action Group

WHO: World Health Organisation



PARCS PROJECT - QUALITATIVE EVALUATION REPORT

August 2014

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Topic guide for interviews with Non-Engagers	

GLOSSARY OF TERMS

The following terms have been used throughout the report. We provide definitions below:

Term	Definition
Exercise maintenance	Sustained community based physical activity, (therapeutic) exercise and physical fitness training for people with long term conditions, undertaken after formal clinical rehabilitation is complete ¹ .
Exercise referral scheme	Exercise referral schemes (ERS) aim to identify inactive adults in the primary-care setting. The GP or health-care professional refers the patient to a third-party service, with this service taking responsibility for prescribing and monitoring an exercise programme that is tailored to the individual needs of the patient ² .
Journey	The stages a patient proceeds through and their experiences from symptoms/diagnosis to exercise maintenance, the healthcare professionals they encounter at each stage, the care and treatment they receive, the information they are provided and the decisions they make about their next steps
Healthcare professional (HCP)	Any clinical professionals involved in a patient's diagnosis, treatment and care, including: doctors in hospital and community settings (eg consultants and general practitioners (GPs)), nurses in hospital and community settings (including specialist nurses), allied health professionals (AHPs) in hospital and the community,
Live Active	A twelve month health behaviour change initiative specifically targeting physical inactivity. Participants are referred by their Allied Health Professional (AHP) and receive an evidence based one-to-one consultation, providing them with the knowledge, skills and confidence required to lead an independent active lifestyle. Service operates throughout NHS Greater Glasgow and Clyde region.
Long term condition	Long term conditions, or chronic diseases as they tended to be referred to, are conditions that last a year or longer, impact on a person's life, and may require ongoing care and support. The definition does not relate to any one condition, care group or age category, so it covers children as well as older people and mental as well as physical health issues. Common long term conditions include epilepsy, diabetes, some mental health problems, heart

¹ In some areas, exercise maintenance can be accessed without having attended formal rehabilitation

² Definition taken from: Pavey TG, Anokye N, Taylor AH, Trueman P, Moxham T, Fox KR, et al. The clinical effectiveness and cost-effectiveness of exercise referral schemes: a systematic review and economic evaluation. *Health Technol Assess* 2011;15(44).

	disease, chronic pain, arthritis, inflammatory bowel disease, asthma and chronic obstructive pulmonary disease (COPD) ³ .
Non-engager	A person with a cardiac, respiratory or stroke condition who is not currently engaged with organised exercise maintenance services
Pathway	The agreed (locally or nationally) stages to be followed in the care and treatment of patients who have a cardiac, respiratory or stroke condition.
Physical Activity	Any bodily movement produced by skeletal muscles that requires energy expenditure ⁴ .
Rehabilitation (Cardiac)	<p>The coordinated sum of activities required to influence favourably the underlying cause of cardiovascular disease, as well as to provide the best possible physical, mental and social conditions, so that the patients may, by their own efforts, preserve or resume optimal functioning in their community and through improved health behaviour, slow or reverse progression of disease</p> <p>In meeting these defined goals, all cardiac rehabilitation programmes should aim to offer a service that takes a multidisciplinary biopsychosocial approach in order to best influence uptake, adherence and long-term healthier living⁵.</p>
Rehabilitation (Pulmonary)	Pulmonary rehabilitation can be defined as an interdisciplinary programme of care for patients with chronic respiratory impairment that is individually tailored and designed to optimise each patient's physical and social performance and autonomy. Programmes comprise individualised exercise programmes and education ⁶ .
Rehabilitation (Stroke)	<p>Stroke rehabilitation is a multidimensional process, which is designed to facilitate restoration of, or adaptation to the loss of, physiological or psychological function when reversal of the underlying pathological process is incomplete. Rehabilitation aims to enhance functional activities and participation in society and thus improve quality of life.</p> <p>Key aspects of rehabilitation care include multidisciplinary assessment, identification of functional difficulties and their measurement, treatment planning through goal setting, delivery of interventions which may either</p>

³ Definition taken from Improving the Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan
(Scottish Government, 2009)

⁴ As defined by the World Health Organization

⁵ Definition taken from the British Association of Cardiovascular Prevention and Rehabilitation's Standards and Core Components 2012

⁶ Definition taken from British Thoracic Society guideline on pulmonary rehabilitation in adults 2013

	effect change or support the person in managing persisting change, and evaluation of effectiveness ⁷ .
Service User	A person with a cardiac, respiratory or stroke condition who is currently engaged with organised exercise maintenance services.
Support Group	A voluntary sector group created to support people with a specific condition; these groups may be affiliated to one of the charities involved in PARCS or not, and generally offer a range of services and support to its members which may or may not include exercise maintenance.
Vitality	The exercise maintenance programme in place across NHS Greater Glasgow and Clyde region for people with a variety of long term conditions; the programme offers four different levels of class, supporting participants to exercise at a level suitable to their functional abilities. Service users are assessed to determine the appropriate level for them.

⁷ Definition taken from NICE CG162 Stroke rehabilitation: Long-term rehabilitation after stroke

EXECUTIVE SUMMARY

During the winter of 2013-14, we carried out a qualitative evaluation with people with cardiac, respiratory and stroke conditions, about their experiences of exercise maintenance. We spoke with people who participate in exercise maintenance activities and those who do not, to find out their experiences of and attitudes towards exercise maintenance and the key factors influencing whether they participated or not.

The key findings of the evaluation were as follows.

The current pathways

Where the pathway from treatment to rehabilitation and onward into exercise maintenance is coherent and seamless, there is a much greater likelihood of sustained engagement in exercise maintenance and/or independent exercise. Some pathways would fit this description, especially those for cardiac and pulmonary patients which are becoming increasingly coherent. However the pathway for stroke patients is variable, fragmented and inconsistent.

Even the pathways which are coherent and seamless are system-centred, rather than person-centred. They require the patient to proceed through a linear process at a consistent pace. For those unable or unwilling to do so, it is difficult to remain on the pathway. Once off the pathway, it is difficult to get back onto it.

Touch points with certain healthcare professionals can have a big influence on a patient's decision to engage with physical activity. These are:

- ★ physiotherapists – during initial therapy sessions whilst still in hospital and during rehabilitation sessions in the community
- ★ clinical nurse specialists – whilst still in hospital
- ★ practice nurses – during routine appointments and chronic disease management clinics

However, negative messages about physical activity from other healthcare professionals can sometimes negate the value of these touch points. The entire multi-disciplinary team needs to promote consistent positive messages about the importance of being physically active to patients, albeit to different levels of depth.

Understanding more about why people engage or not with exercise maintenance

The report examines in detail the main factors influencing engagement with exercise maintenance. We present the highlights below.

Motivations – why do people participate in exercise maintenance?

People are motivated to exercise after diagnosis/treatment because they are convinced of the benefits (usually influenced by a healthcare professional) and want to „get back to normal“. They see exercising as a way to regain function and independence. Spouses' and partners' influence should not be underestimated either.

People are attracted to exercise maintenance services, as opposed to independent exercise, for the tailoring, supervision and perceived safety it offers, especially if they are new to exercising.

They are also drawn to the social aspects of a group class – our evaluation shows that this social aspect is incredibly important in both attracting and retaining people.

Once they are exercising the combined benefits of enjoyment, feeling the physical benefit and social support are the principal factors encouraging people to continue. In addition, class attendance becomes a habit or a routine.

Enablers – how do we make it easy for people to participate in exercise maintenance?

A variety of local, accessible and affordable services, offered at a range of times and on different days is essential. The process of referral and entry to the class is also important: people are more likely to participate if they perceive that they have been referred by a healthcare professional, and if there's been a seamless transition from treatment and/or rehabilitation into exercise maintenance. When exercise maintenance is the next obvious step, people are more likely to take it.

The qualities of the instructor also make a difference. They need to:

- ★ be friendly and approachable
- ★ take time to get to assess new joiners and advise on the right class and/or exercise modifications
- ★ make the classes a lot of fun

Barriers – what stops people participating in exercise maintenance?

Practical issues such as transport, accessibility and cost can be very powerful barriers. These are particularly challenging for people with mobility problems and people on low incomes, although they are not the only people affected. Dark nights in the winter, and general bad weather also act as barriers.

Alongside these practical barriers are the very real psychological barriers of fear and confidence: fear of being the new person in an established group, fear that exercising might be dangerous for their condition, lack of confidence that they will be able to manage the exercises.

Some people have multiple comorbidities which can deter them from taking exercise. Interestingly though, the people we met with comorbidities who did exercise reported feeling generally better after exercise – for example, less joint pain.

Why do people stop participating in exercise maintenance?

Some people stop attending exercise maintenance for a very positive reason: they decide to exercise independently, often progressing to more challenging exercise as they become fitter.

However, other less positive factors can also lead to disengagement. Habit and routine are very important motivators to continue exercise maintenance, so when these are broken for any reason they can be difficult to re-establish. The most common reasons we heard for these broken habits were illness and/or exacerbation of an existing condition. Once the routine is broken, we heard that the psychological barriers to initial participation come back into play. People lose confidence and therefore are fearful of starting again.

Improving provision to enable and maximise engagement

The findings of this evaluation provide some very helpful insights into how provision could be improved to maximise engagement.

Further development of seamless pathways

More work is required to develop a seamless pathway for all conditions, that introduces the concept of physical activity as early as possible in the patient's journey, reinforces positive messages about physical activity at all opportunities and facilitates a seamless transition between each stage of the pathway to minimise disengagement.

The stroke pathway is the one requiring most attention, but the pathways for cardiac and respiratory conditions both need further development too.

Follow-up and safety nets

Whilst the pathway for transitioning into exercise maintenance is a linear one, human beings don't always follow logical and linear paths. They will have different needs and motivations, and will be at different stages of readiness. Therefore the processes supporting the pathway need to become more person-centred:

- ★ if people are not willing or able to engage with the pathway at the first time of offering, there need to be processes to make it easy to engage at a later date
- ★ if people disengage, for reasons other than progression to independent exercise, there need to be processes for following up these people and making it easy for them to re-engage at the right time

Harness the influence of healthcare professionals

Healthcare professionals are very influential upon patients' attitudes about exercise and willingness to engage with exercise maintenance. Therefore all healthcare professionals involved in the patients' journey need to understand the benefits of physical activity, and play their part in encouraging patients and reinforcing their colleagues' positive messages about exercise maintenance.

The role of the third sector

Support groups and other voluntary organisations are in some cases already providing exercise maintenance and/or helping their members access exercise maintenance (for example through providing transport for people with mobility problems). Other groups have an appetite to do so too, but finance is a barrier. These established and trusted groups present a huge opportunity to reach more people with exercise maintenance; our findings indicate that people who would not go to a separate exercise class would participate in exercise maintenance if it was part of their support group meeting.

1 INTRODUCTION

The PARCS project – **P**erson-centred **A**ctivities for people with **R**espiratory, **C**ardiac and **S**troke conditions – is a partnership project led by Chest Heart and Stroke Scotland (CHSS), the British Lung Foundation (BLF) and the British Heart Foundation (BHF). The overall aim of the project is to promote integrated, community-based, long-term physical activity/exercise throughout Scotland for those with long term conditions (LTC) though with a focus on cardiac, respiratory and stroke conditions.

The findings from the PARCS project are intended to support the Scottish Government to deliver the best quality health care by informing the development of user centred services, with an increased focus on prevention. It is also hoped that through the PARCS project, partnership working between the statutory and voluntary sectors will develop further and enable resources to be used optimally whilst providing value for money.

By achieving those aims the project seeks to support people with long term conditions to enjoy enhanced physical and mental wellbeing. In addition, health care professionals involved in the provision of cardiac, respiratory or stroke rehabilitation will be more aware of the barriers that prevent people from taking up provision as well as gaining new knowledge and good practice relating to models of, and approaches to, service delivery

1.1 The PARCS project

There are four main components to the PARCS project:

- ★ scoping exercise of 14 health boards to identify current service provision - based on a literature review, consultations with Managed Clinical Networks (MCNs), health care professionals, and service providers. Aiming to identify current service provision across differing geographical regions and identify models of good practice relevant to the differing health, social and demographic circumstances across Scotland. CHSS led on this component of the project.
- ★ review of models of delivery outwith Scotland for service delivery and good – identifying good practice relevant to the differing health, social and demographic circumstances across the UK. BHF led on this component.
- ★ qualitative evaluation – conducting qualitative evaluation with people affected by cardiac, respiratory or stroke conditions. BLF led on this component, which was conducted by Brightpurpose Consulting.
- ★ economic evaluation – assessing the economic impact of exercise maintenance. BLF led on this component, which was undertaken by Brightpurpose Consulting.

This report presents the findings of the qualitative evaluation and the economic impact assessment.

1.1.1 Objectives of the qualitative evaluation and economic evaluation

Brightpurpose was commissioned to conduct a qualitative evaluation and economic assessment project as part of the PARCS project. This involved 4 distinct areas of work:

- ★ qualitative evaluation with people affected by cardiac, respiratory or stroke conditions that participate in exercise maintenance provision and who live in Ayrshire and Arran, Greater Glasgow and Clyde and Highland

- ★ qualitative evaluation with people affected by cardiac, respiratory or stroke conditions that do not participate in exercise maintenance provision and who live in Ayrshire and Arran, Greater Glasgow and Clyde and Highland
- ★ analysis of anonymised pulmonary rehabilitation exercise maintenance referral data from Greater Glasgow and Clyde
- ★ economic analysis to build the case for exercise maintenance

The objectives of the work were as follows:

- ★ examine the journeys of both those who do and do not participate in exercise maintenance provision, to understand the principal health care professional and service provider touchpoints (especially entry and exit points) from diagnosis to present day, the seamlessness (or otherwise) of these journeys, and the extent to which provision is person-centred
- ★ explore the different models of service provision in place in the three regions selected for the evaluation, and their impact on patients' journeys
- ★ identify key factors influencing physical activity and engagement with exercise maintenance services:
 - barriers to engagement
 - reasons for disengaging from service provision (recognising that these may be either positive or negative)
 - enablers to engagement
 - motivations to exercise and maintain fitness
- ★ identify potential lessons for improving delivery processes
 - if possible from the findings, identify an ideal pathway for people with cardiac, respiratory and stroke conditions to achieve appropriate levels of physical activity
- ★ identify potential lessons to inform primary prevention interventions
- ★ analyse the patterns of referral from pulmonary rehabilitation into exercise maintenance in NHS Greater Glasgow and Clyde
- ★ establish the economic impact of exercise maintenance
- ★ make recommendations for areas of further exploration, as a result of the evaluation findings

This report sets out the findings from the qualitative evaluation component of the PARCS project.

2 METHOD

2.1 Focus of the evaluation

The purpose of the qualitative evaluation, agreed with the leads from each of the three charities during the initiation phase, was to examine the experiences of service users and non-engagers drawn from three specific geographical regions

- ★ Glasgow and Greater Clyde
- ★ Ayrshire and Arran
- ★ Highland

These three regions were selected to represent:

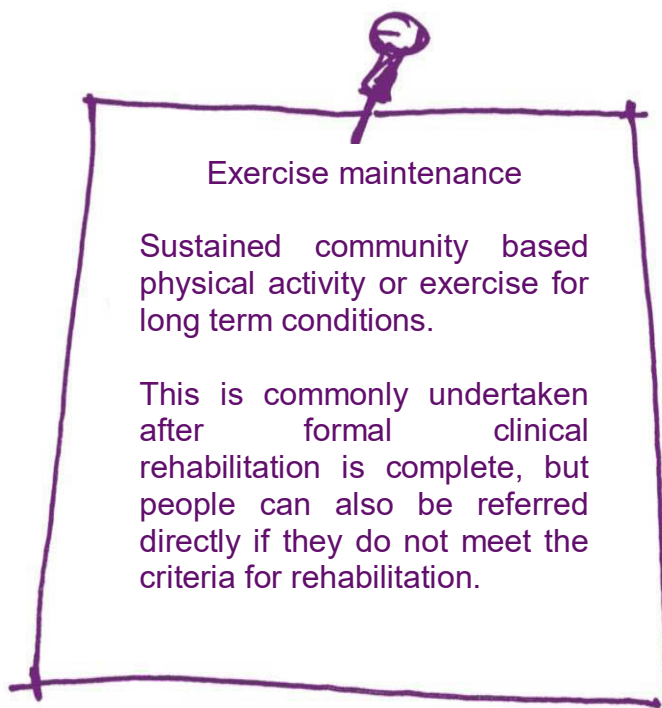
- ★ different geographical factors – specifically the comparison between metropolitan city region, mix of rural and smaller towns, and highly rural, and an examination of how services do or do not transcend local authority boundaries
- ★ different service delivery models – ranging from a comprehensive, highly developed and coordinated service to a very limited service

The lines of enquiry for the regional differences are explained in section 2.2.3.

2.2 The experiences of service users and non-engagers

We carried out semi-structured interviews with exercise maintenance service users and non-engagers:

- ★ service users – individuals participating in exercise maintenance classes or structured exercise programmes supported by a health care professional or exercise instructor to help manage specific cardiac, respiratory or stroke conditions
- ★ non-engagers – individuals who do not currently participate in structured classes of exercise maintenance, including:
 - independent (unsupported) exercisers
 - those who do not do any exercise/physical activity
 - those who have disengaged from service provision



We worked with local healthcare professionals, providers of exercise maintenance services and local support groups, to gain an understanding of the exercise maintenance activities available locally and to identify potential participants. This study was purposely constructed as a Service Evaluation and Audit, in accordance with NHS Health Research Authority's guidance and in

keeping with previous studies of this type undertaken by Brightpurpose. Participants were engaged through voluntary sector support groups, leisure services and other community groups/stakeholders.

2.2.1 Sample sizes and distribution

Our aim was to interview 16 – 22 service users and 36 – 54 non-engagers spread across the three regions and including equal proportions of people with each of the three conditions. These target numbers were based on realistic estimates of how many respondents we would be able to engage with within the timescales whilst at the same time giving us sufficient data from which to draw reliable conclusions.

Within the non-engagers it was important to identify and interview people from „hard to reach“ populations. In the context of this study „hard to reach“ included people:

- ★ from Black and Minority Ethnic (BME) communities
- ★ living in areas of deprivation
- ★ living in rural areas
- ★ experiencing multiple and complex barriers such as substance misuse and homelessness

We therefore subdivided the non-engager targets for the Ayrshire and Arran and Glasgow and Greater Clyde regions to include a proportion of respondents from these hard to reach populations.

Actual numbers achieved are shown in the tables below:

Table 1a – Number of evaluation respondents – Non engagers

Respondent groups	Total
Total non-engagers	30
Of which were from:	
hard to reach groups	9
non hard to reach groups	21

Table 1b – Number of evaluation respondents – service users

Respondent groups	Total
Service users	28

In addition we were able to facilitate two focus groups and a number of shorter informal interviews with service users which we have collated and synthesised as part of our findings.

Table 2 – Number of evaluation respondents by location and condition type

	Cardiac	Respiratory	Stroke	Total
Glasgow and Greater Clyde				
Non-engagers (general)	0	1	0	1
Non-engagers (hard to reach)	0	1	3	4
Service users	4	3	5	12
Ayrshire and Arran				
Non-engagers (general)	1	4	1	6
Non-engagers (hard to reach)	2*	3	0	5
Service users	4*	6	1	11
Highland				
Non-engagers	4	3	7	14
Service users	3	2	0**	5

*1 respondent within these categories has dual condition – cardiac and stroke

** No services for stroke

We discuss our approach to and the challenges in identifying respondents below.

2.2.2 Engaging Respondents

Respondents were identified through a number of channels. The primary routes were:

- ★ CHSS affiliated groups
- ★ BLF affiliated groups
- ★ health care professionals (physiotherapists, nurses)
- ★ leisure services staff (exercise instructors, leisure service managers)

The majority of these contacts were provided by the PARCS Project Manager or BHF and BLF project leads, so many were already aware of the project. These initial contacts were able to facilitate invitations to groups and classes that we then attended to approach potential respondents directly. In some instances, particularly in the Highlands, health care professionals were able to contact potential respondents. Despite the good range of contacts provided, and the willingness of contacts to support our activities, it was still proved extremely challenging to engage with sufficient people. Unsurprisingly, identifying non-engagers proved to be the most challenging aspect, especially in Greater Glasgow and Clyde and Ayrshire and Arran.

We therefore employed a number of routes to attempt to contact non-engagers, including contacting numerous community groups and organisations to assist, with very limited success. We also contacted health centres and hospital clinicians to explore whether they could assist us. In Highland, health centres proved a positive route, and in Ayrshire and Arran we were able to attend a cardiology clinic where the nurses spoke to patients which helped us contact a small number of non-engagers. With this type of approach healthcare professionals would make patients aware of the evaluation being conducted and what they could do to participate in the evaluation if they wanted to.

We spoke with all potential respondents either in person or via an initial telephone call to ensure they were fully informed about the purpose of the evaluation, what was required of them, how their data would be used and to address confidentiality. A written leaflet was also provided to potential respondents and those assisting with contact. Respondents could opt out at any point.

2.2.3 General lines of enquiry

The lines of enquiry for all three regions were similar but each region also had supplementary avenues for exploration identified as specific to that region.

The lines of enquiry for all three regions were:

- ★ the journey: principal health care professional contacts and service provider touch points (especially entry and exit points) and what happens at each of these
- ★ barriers to engagement
- ★ enablers to engagement
- ★ reasons for disengagement
- ★ motivations to exercise and maintain activity levels
- ★ lessons for improving delivery processes from a service user perspective

- ★ exploration of the key themes emerging from the PARCS project so far (fear factor, existence of groups, social aspects, problems at the transition points, how exercise maintenance is packaged, knowledge of what's available, etc)
- ★ lessons that might inform primary prevention interventions

The question frames were kept open to allow free responses from respondents however, we were asked to explore emerging themes from earlier evaluation. Thus topics such as the use of technology and cultural barriers to engagement were highlighted and probed with appropriate respondents. The interviews also aimed to capture specific data using standardised questions from an earlier survey carried out as part of the PARCS project to boost the quantitative dataset.

2.2.4 Geographically specific lines of enquiry

For each of the three regions additional lines of enquiry to address specific questions raised through earlier scoping work by the PARCS Project Manager were pursued.

For Greater Glasgow and Clyde

In the Greater Glasgow and Clyde region there is an established exercise referral programme and exercise maintenance classes are widely available. As a potential model of service provision the aim here was to examine if the pathway is working as well as believed and is that the same across all sections of society.

In addition there was an opportunity to carry out a specific piece of work in relation to referral from Pulmonary Rehabilitation into exercise maintenance to examine what proportion of patients are being referred and when they are not being referred what are the reasons. (See section on NHS GGC PR Referrals).

For Ayrshire and Arran

In this region exercise maintenance is delivered by different providers in each of the different Community Health Partnership (CHP) areas and the evaluation aimed to establish if this subdivision of provision affected the person-centred experience. So for example were people tied to services within their own CHP area or could they attend classes in a different CHP area if it was geographically closer or more convenient.

For Highland

In this region it appeared that there was a lack of access to exercise maintenance in some areas, particularly outwith the urban centres. The aim here therefore was to establish if this was indeed the case and what effect this had on those people living in these areas. It was also an opportunity to gauge demand for local services and what those services should look like.

2.3 Acknowledgements

We would like to thank the following organisations for their assistance in facilitating introductions to potential participants, allowing us to attend and observe exercise maintenance sessions and advising on alternative avenues for connecting with evaluation participants.

- ★ British Heart Foundation
- ★ British Lung Foundation
- ★ Chest Heart and Stroke Scotland
- ★ East Ayrshire Leisure
- ★ Glasgow City Council
- ★ Glasgow Life

- ★ Inverness Leisure
- ★ KA Leisure North Ayrshire
- ★ NHS Ayrshire and Arran
- ★ NHS Greater Glasgow and Clyde
- ★ NHS Highland
- ★ NHS Highland
- ★ Scottish Refugee Council
- ★ South Ayrshire Council Leisure Services

We are also indebted to numerous support groups, some independent and some affiliated to CHSS or BLF, who facilitated introductions to their members and allowed us to visit their groups.

3 FINDINGS – QUALITATIVE EVALUATION

This chapter details our findings from the interviews with service users and non-engagers from all three regions included in the study. We have synthesised the responses into key themes:

- ★ the journey experienced by evaluation respondents
- ★ barriers to engagement
- ★ reasons for disengagement
- ★ enablers for engagement
- ★ motivations to undertake physical activity

Throughout each section we have identified common themes whilst drawing out differences between regions and conditions. We have used case studies to help illustrate key findings and whilst these case studies represent the experiences of the respondents we have changed names and other identifiable features to protect their identity.

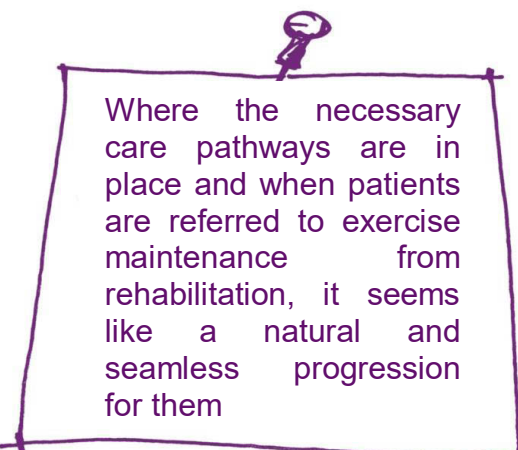
3.1 The journey

All respondents were asked to describe their journey from the point of diagnosis to the present day, to gain an understanding of how their experiences varied and also what were the common features. We found that the experiences of respondents into, through and beyond the health care system varied depending upon factors such as:

- ★ the type of condition: cardiac, respiratory or stroke
- ★ the severity of the condition
- ★ their location
- ★ when they were first diagnosed
- ★ time between symptoms/diagnosis and receiving rehabilitation

A significant determinant of the smoothness of the journey post-rehabilitation, was the type of condition people had. Those with pulmonary or cardiac conditions in general had a smoother transition from acute care into rehabilitation and then into community-based exercises maintenance provision, whilst those who had suffered strokes were far less likely to have transitioned into exercise maintenance beyond their initial physiotherapy.

3.1.1 Condition-specific issues



Where the necessary care pathways are in place and when patients are referred to exercise maintenance from rehabilitation, it seems like a natural and seamless progression for them

The experience after pulmonary and cardiac rehabilitation

In all three regions, when care pathways are fully in place the journey has the potential to run smoothly and seamlessly. The transition from rehabilitation to exercise maintenance was frequently described by service users as a natural progression, with clear signposting or (more commonly) direct referrals which provided a continuity of service provision and long term support.

Where care pathways are not complete, particularly in the rural Highlands, the journey post-rehabilitation is somewhat more haphazard; subject to the vagaries of community

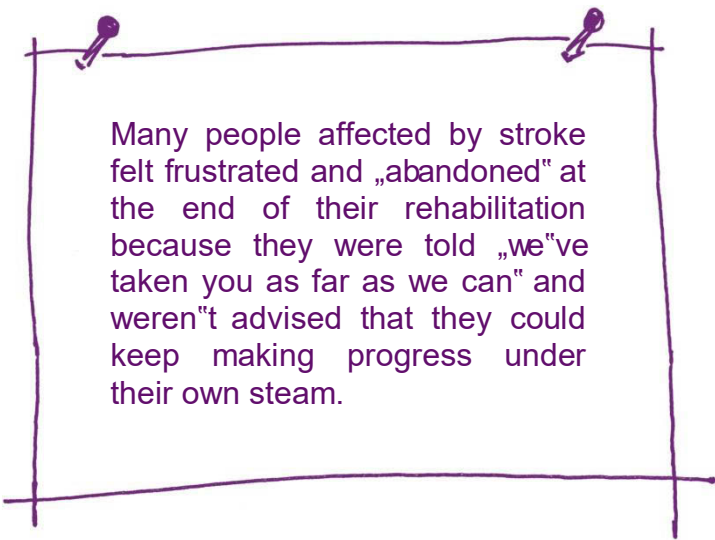
provision and available advice and guidance. Even getting to the rehabilitation stage itself can be challenging in some areas and this is explained in more detail later.

The experience after stroke rehabilitation

The experience of respondents who had suffered a stroke was more diverse, and the severity of the stroke certainly seemed to be a significant factor determining their journey and their experience of that journey. Some had been referred to exercise maintenance by their physiotherapist after rehabilitation, but not all had physiotherapy and in these cases they were usually referred on by their GP/practice nurse.

However many told us they felt that following rehabilitation and the initial period settling back into their home they felt „abandoned“. Many reported getting good rehabilitation in hospital and assistance from occupational therapists to get them back into their homes. Advice and assistance to get alterations to the home were forthcoming, as were care packages to assist with basic needs until they were able to manage themselves.

However at the end of this phase some respondents said they were being told „we’ve taken you as far as we can“, which was frequently interpreted as „this is as far as you can go in terms of your recovery“. This was compounded by a message from their physiotherapists that the majority of function would be regained during the first three months after their stroke, which was often interpreted as meaning that no more could be gained beyond that three month period. Many also hadn’t heard a message about the need to maintain the levels of function they had regained through rehabilitation and how best to do that. This is not to say that these messages hadn’t been communicated, but importantly, they hadn’t landed.

A hand-drawn purple rectangular box with two purple pushpins at the top corners. Inside the box, the following text is written in purple: "Many people affected by stroke felt frustrated and „abandoned“ at the end of their rehabilitation because they were told „we’ve taken you as far as we can“ and weren’t advised that they could keep making progress under their own steam."

Many people affected by stroke felt frustrated and „abandoned“ at the end of their rehabilitation because they were told „we’ve taken you as far as we can“ and weren’t advised that they could keep making progress under their own steam.

Resource limitations within the NHS mean that formal structured rehabilitation can only reasonably be funded for the first three months. However, it seems that even if the information was being communicated, the message was not getting through to many potential service users that there were good reasons to be active and keep themselves as fit as possible. The message respondents who had suffered a stroke received was often demotivating and, whilst it is important not to raise hope beyond realistic expectations, most people respond to having realistic goals even if those goals may take months or even years to achieve. The wife of one respondent who had suffered a severe stroke said:

“no-one would get down to the nitty gritty of what’s required which is repetitive, intensive exercise. Only one occupational therapist talked about what could be achieved and in what time”

The road to recovery tends to be slower and longer for people affected by stroke, yet the pathway seems to be the weakest and the one which people are most likely to disengage with little likelihood of return.

3.1.2 General issues (not condition-specific)

People diagnosed longer than five years ago

It appears that the pathways have only been fully established relatively recently, over the last five years or so. This is not to say that provision did not exist prior to this, but the feedback we heard from evaluation respondents suggests that the pathway, and referral mechanisms, were not fully embedded. We found that people who had been diagnosed longer than 5 years ago were much less likely to have had a smooth transition from acute care into community-based maintenance. Some did not receive rehabilitation, let alone referral to exercise maintenance. Whilst in some cases their conditions may not have rendered them appropriate for rehabilitation, this was too common a story to be explained only by that factor. This is borne out by the fact that a number had later been referred into rehabilitation and/or exercise maintenance following more recent admission or outpatient consultations. Some had also taken the initiative themselves, and asked to be referred after hearing from others about rehabilitation and/or exercise maintenance. However, feedback from evaluation respondents suggests that this later access to rehabilitation and/or exercise maintenance seemed to be inconsistent and dependent on either:

- ★ the individual being motivated to seek out support for themselves, or
- ★ the intervention of a proactive health care professional

“The GP told me I had COPD but didn’t give me information on how deal with it”

A system-centred pathway

Our findings indicate that even the well-defined and comprehensive pathways have the potential to break down, most commonly when the patient does not fit with the pathway’s timelines or processes. In these cases, people’s journeys have either been significantly delayed or not completed. In essence they have „fallen through the cracks“. The pathways appear to lack processes that act as safety nets, identifying and attempting to re-engage people who have fallen out of the standard pathway. Thus they are often lost from the pathway, unless a particularly proactive health care professional identifies what has happened (often years later) and re-engages them into the pathway, or an exacerbation of their condition leads to readmission.

It took nearly 2 years for Kathleen to be definitively diagnosed with her lung condition, by which time she was having tremendous difficulty breathing even without any exertion. Her physiotherapist advised that she'd benefit from a course of rehabilitation but Kathleen didn't feel ready. She told her physiotherapist "I'm gasping for every breath, there's no way I can do physio or exercise". So Kathleen returned home and didn't participate in rehabilitation.

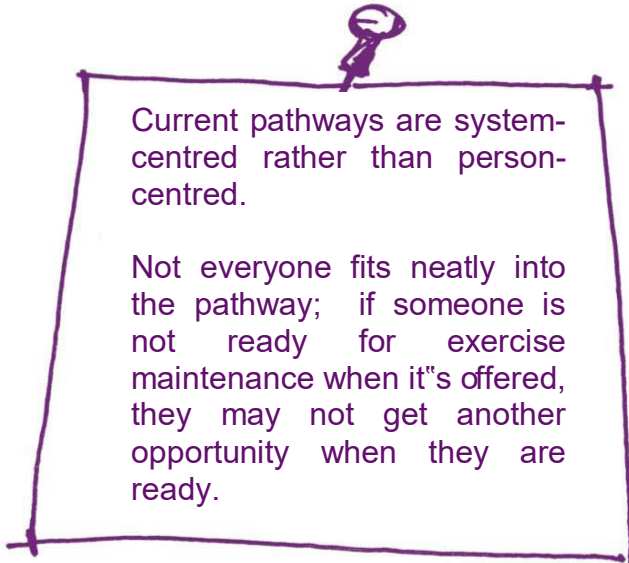
A couple of years later, at a routine check-up for her lung condition, Kathleen's Practice Nurse suggested rehabilitation again, as a way of helping Kathleen manage her condition. This time Kathleen was feeling well enough to contemplate it, and went ahead. After her rehabilitation programme, Kathleen chose to attend an exercise class run by a local community group rather than a specific exercise maintenance class. She goes regularly and also looks after her grandchildren a couple of days a week.

Key messages

- ★ timing the message to when the patient is ready to receive it is essential to successful engagement
- ★ health care professionals need to raise the issue of rehabilitation and exercise maintenance at every contact point, to catch those who have „fallen through the cracks“ due to an exacerbation or other reason(s)

Kathleen's experience is typical of many people we spoke to, who - after their diagnosis - weren't ready for rehabilitation or exercise maintenance. They had their reasons for not being ready, but were not saying never – they were saying not right now; they either lacked confidence that they could exercise at that point or had other more pressing priorities. But unless an individual in the health care system acted as a safety net to get them back into the pathway later, they would not have found their way back.

Feedback from evaluation respondents suggests that the pathways are system-centred rather than person-centred, with trigger mechanisms based on pre-set intervention points rather than patient-readiness. If a person doesn't conform to the process, their chances of a smooth transition are reduced, and getting back on the pathway is not guaranteed and can involve an element of chance.



Current pathways are system-centred rather than person-centred.

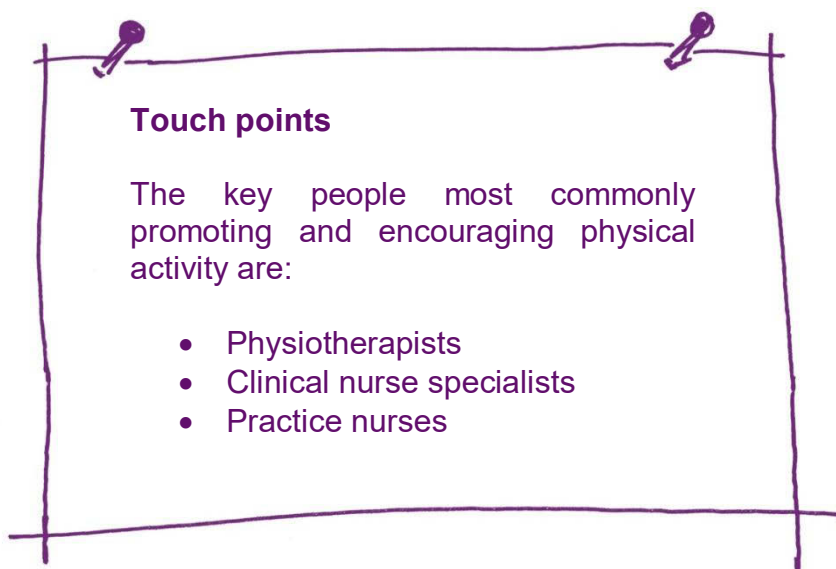
Not everyone fits neatly into the pathway; if someone is not ready for exercise maintenance when it's offered, they may not get another opportunity when they are ready.

Role of the health care professional

The role of the health care professional is fundamental to the process. For those who had fallen through the cracks and needed guiding back, a proactive health care professional was often the catalyst. This was often a practice nurse at the local GP surgery, or the health care professionals running outpatient clinics, raising the topic of becoming and keeping active – why it was important, what activity they were doing, the opportunities in the local community. However, feedback from

respondents suggested not all health care professionals actually promoted the benefits of physical activity. We also heard anecdotally from respondents that their health care professionals did not always know what was available or how to access it.

Throughout the journey we were aiming to capture the key touch points and identify the people/HCPs speaking to service users and non-engagers about the importance of physical activity. Physiotherapists were commonly cited as a key source of information and often encouragement and inspiration. Both in hospital during those initial therapy sessions to get respondents back on their feet and during rehabilitation sessions in the community, the message from physiotherapists was consistent. In hospital these messages were also often reinforced by the nurse specialist visiting on the ward. Outside hospital and back in the community, practice nurses were identified as frequently asking about levels of physical activity, encouraging respondents to do more and instigating referral to exercise maintenance classes or signposting to support groups. Practice nurses are the lynchpin for many people, particularly those that have fallen through the cracks – they are the health care professional a patient sees most often about



their condition, through regular check-ups and chronic disease management clinics.

The feedback relating to consultants and GPs was not always as favourable. Many respondents did not cite either their consultant or GP as talking to them about physical activity. Some were given very negative messages.

“What are you doing that for?”

a service users' cardiology consultant

“I wouldn't bother with that if it was me”

a service users' nephew (a GP)

Feedback from evaluation respondents suggests that the advice offered by these senior healthcare professionals can carry a significant level of influence so it is vitally important that the right messages are coming from them.

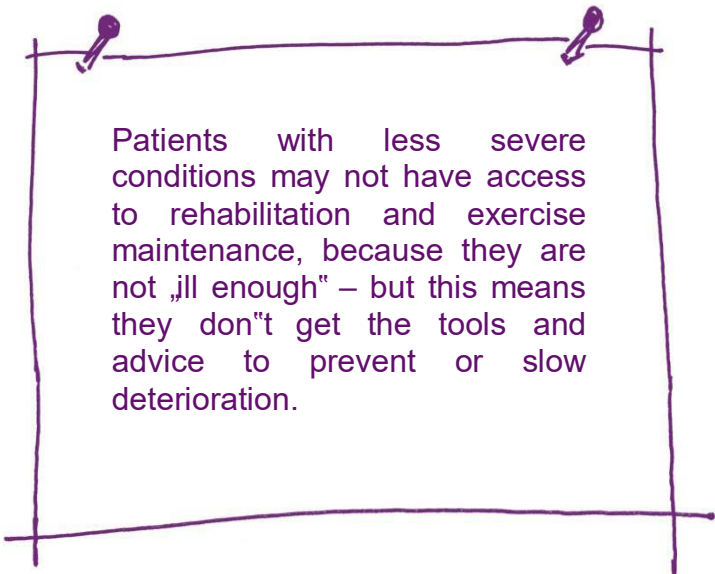
It was not all negative though, others had been referred to exercise maintenance by their GP and had been encouraged to exercise independently to help recovery, improve and maintain the fitness

levels as part of self-management of conditions and general health and wellbeing. Feedback from evaluation respondents suggests that these senior healthcare professionals can carry a significant level of influence so it's vitally important that the right messages are coming from them.

It wasn't all negative though, others had been referred to exercise maintenance by their GP and had been encouraged to exercise independently to help recovery, improve and maintain the fitness levels as part of self-management of conditions and general health and wellbeing.

Earlier intervention

Some respondents whose conditions were less severe, reported that they weren't referred for rehabilitation because they weren't considered unwell enough to need it. As the pathway into exercise maintenance is often via rehabilitation, the opportunity to encourage them to maintain an active lifestyle was often lost, even though this may have helped them maintain function or reduce the risk of a further event. In particular respondents with early onset COPD, were not deemed ill enough to require rehabilitation. This led to the perverse situation where they were not receiving the support and advice to help prevent them from becoming so ill that they did need rehabilitation. If they would benefit from some level of physical activity to maintain their current function they are often not receiving this message.



Patients with less severe conditions may not have access to rehabilitation and exercise maintenance, because they are not „ill enough“ – but this means they don't get the tools and advice to prevent or slow deterioration.

Busting the jargon

During our interviews it became apparent that the language used by respondents to describe rehabilitation and exercise maintenance is not the same as that used by health care professionals. This is an important point, as language can shape our perceptions of services, and may act as a barrier to some people choosing to access a service.

Rehabilitation was usually described as „physio“ by respondents – they described going to a structured set of physiotherapy sessions after their diagnosis or treatment. Organised exercise maintenance services (delivered by NHS, leisure services or community groups) were described as „classes“ by most respondents or occasionally as „exercise classes“.

Physical activity is not a phrase that respondents used or recognised as relating to their exercise maintenance; people tended to associate the



Respondents tended to use the following terms:

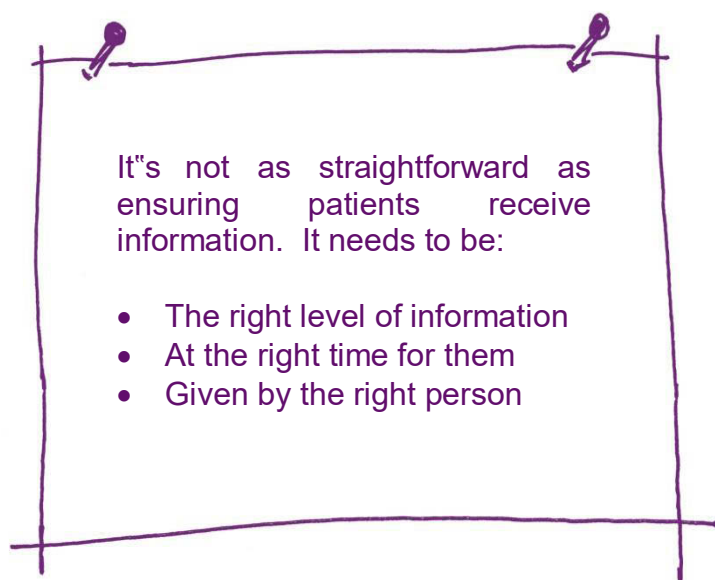
‘Physio’ – for rehabilitation
‘Keeping active’ – for physical activity
‘Classes’ - for exercise maintenance services

phrase physical activity with more formal exercise or sport. But they did respond to the term „keeping active“, and when we explained that physical activity included walking, gardening and active household chores, the level of activity reported by respondents significantly increased.

Information provision

We asked respondents to comment on the quality and quantity of written information provided about physical activity in relation to their condition. Again this varied but a number of respondents spoke about having too much information too soon. This was predominantly whilst people were still in hospital. A common theme for those in hospital was that they were just not ready to think about physical activity. They had more pressing priorities and, in some instances, had not fully accepted their situation. Few people said they had gone back to that information at a later time. One cardiac patient said:

“I got an overwhelming amount of information at the time but nothing much after that”



Once in rehabilitation, people seemed more receptive to receiving information and felt that it helped provide structure and greater understanding. Overall respondents seemed satisfied with the quality of information received at that stage in their journeys. The Heart Manual (produced by NHS Lothian) was mentioned a number of times by respondents. It was regarded as a very helpful source of information and helped to provide a structured plan for their recovery. At this phase of the journey people are starting to look forward so they appear to be in a much better position to absorb information and act on it.

3.1.3 Regional differences

In this section we draw out the findings and issues specific to each of the three regions involved in the evaluation.

Greater Glasgow and Clyde

Within Greater Glasgow and Clyde stroke survivors, particularly those with more severe restrictions to their mobility, generally do not have knowledge and awareness of what services are available and are suitable for them. That is not to say that suitable services are not available, it just isn't visible to those that could be accessing it and benefiting from them. The feedback from respondents suggests that this is an awareness issue, arising from a combination of lack of referral/signposting from a health professional and them not seeing any marketing of services.

Another factor is that they have not been proactive in trying to find out what is available, although the feedback suggests that they wouldn't really know what they were looking for.

Respondents were aware of general physical activity provision locally, but were uncertain whether it would be suitable for them. Feedback from the respondents suggests that they do not know what they would be looking for as they have never had a discussion with a health care professional about what they could or should be doing.

This is intertwined with other barriers and issues discussed in this report relating to people affected by a stroke. For some, the belief is that they have got back all of the function they are going to and are therefore not particularly inclined to be proactive in seeking the information they would need.

Beyond this, their restricted mobility means that even if provision was visible and known about, those with the most severe limitations to mobility explained that it would need to be „on their doorstep“ or would need 1-2-1 support to get to and from any provision. Respondents who had severe mobility limitations and who were participating in exercise maintenance were able to because it had been arranged to take place at a support group that they would be attending anyway. These groups tended to be supported by committed volunteers who supported group members to get to the group by providing transport and assistance.

Mary lives in the Govan area of Glasgow and is now confined to a wheelchair after gradual loss of mobility following a stroke in 2005. Prior to her stroke she lived an active life, playing lawn bowls every day of the week. Whilst in hospital after her stroke she received daily physiotherapy sessions in the gym which she really enjoyed – she was having to relearn almost everything. Prior to her being discharged her social worker was able to find alternative accommodation as Mary lived in a second floor flat. At the point of her discharge she was able to walk with the aid of a stick. Mary was provided with some exercises to do and equipment to use and told that she should try to do the exercises to maintain what mobility she had. There was no discussion about available provision that she could access that would support her to participate in exercise maintenance. She found it was difficult to do the exercises she was given by the physiotherapist without someone there to assist her and, because she lives on her own it meant she rarely did them.

Mary's mobility has gradually deteriorated and she is now confined to a wheelchair which leaves her feeling isolated. She is dependent on the free transport service and assistance provided by her local stroke support group for her to attend their sessions. Mary would participate in exercise maintenance if she knew it was going to benefit her, if the support to access it was in place and if there was something suitable for her. Mary feels that her limited mobility means that there is unlikely to be „anything that she could do“. The stroke support group that she attends would love to bring in physiotherapists to take exercise sessions as part of the group but finance prevents this from happening.

Key messages

- ★ without sustainable, appropriate exercise maintenance opportunities benefits, gained through rehabilitation can be lost
- ★ support groups want to be able to offer these opportunities but there are significant financial barriers

Ayrshire and Arran

Many respondents in Ayrshire and Arran indicated that waiting times for pulmonary rehabilitation were extremely long, with some respondents indicating that they had heard waiting times were over 40 weeks. Some respondents indicated that they were reluctant to wait for such a long period of time to access pulmonary rehabilitation and therefore opted not to go. This meant that for some non-service users there could be a loss of momentum in exercising, however, some respondents who did not access pulmonary rehabilitation took it upon themselves to exercise independently.

Many respondents also had a perception that there were too few pulmonary physiotherapists in Ayrshire and Arran and that this lack of capacity in turn led to such extended waiting times. Believing there was a lack of capacity, one patient indicated that they felt that their condition wasn't as severe as others and declined to be referred for pulmonary rehabilitation so that they weren't using up the capacity of the limited number of physiotherapists.

“There was only one physio running the classes at the time [of referral to pulmonary rehabilitation]”

A number of respondents who raised these two issues were patient representatives in groups that had members involved in the Managed Clinical Network (MCN) or other public involvement forums, and we wonder if these perceptions are a result of information heard at these meetings and relayed to other group members.

A number of respondents with different conditions indicated that they felt that not enough classes are available in Ayrshire and Arran, and particularly within their locality. Some non-service users were not aware of classes, or were only aware of one or two classes which were difficult for them to access (for a variety of reasons, most notably transport/distance). In addition, some service users indicated that the classes they attended were the only classes they were aware of which were specifically aimed at their condition (whether it be a cardiac, stroke or respiratory condition). Some service users, particularly attendees of one stroke-specific class indicated that attending classes once a week was not enough, and that they would wish to attend classes more frequently if more classes were available. This was particularly true for attendees who did not exercise independently at home.

While others indicated that one class a week was sufficient for them, for those who wished to attend classes more regularly this was not currently perceived to be an option. In addition to condition specific classes, some service user respondents in Ayrshire and Arran attended Invigorate classes (balance and tone class aimed at falls prevention) as an extra exercise class, and others have also progressed to gym-based classes or to doing independent exercise within the gym.

Despite having their classes based within a leisure centre, one support group in Ayrshire and Arran reported not being aware of other exercise maintenance classes available locally for individuals recovering from their condition. We know from anecdotal feedback and discussions with staff at the centre that other classes are available at the same venue. Therefore there appears to be a disconnect between the group and other existing local provision, which is affecting people's perceptions of available opportunity. This has possibly arisen because the group originated to fill a gap in provision, before the leisure services provider provided anything suitable. The leisure services provider now funds the instructor for the group and is also providing condition-specific training for their other instructors, and rolling this training out to other leisure services providers in Ayrshire.

From our discussions with instructors during our visits to classes in Ayrshire and Arran, there appears to be good co-ordination between the leisure services operating in each of the three CHP areas in Ayrshire and Arran. The lead staff at each centre meet regularly to keep in touch, update each other and share practice. For example, one provider is delivering stroke-specific training for instructors into the other CHP areas. Whilst the referral paperwork is slightly different in each CHP area, all three services accept referrals from all three areas, and if a service user wants to attend classes outside of their resident local authority area this is organised informally and effectively by the leisure services leads. The success of this system appears to be based on excellent relationships and good communication between the staff in the three services. This is potentially vulnerable if staff move on to different jobs and new relationships need to be forged to ensure that the service remains seamless from the service user perspective across the different CHP boundaries.

Highland

In the Highland region, where people live is a key determinant of what happens post-rehabilitation. Opportunities to engage with structured exercise maintenance classes are patchy and focussed in the more populated areas. None of the respondents in Highland outside the Inverness area were able to access exercise referral schemes.

In Lochaber there is a scheme for people completing cardiac rehabilitation which gives them free access to the leisure centre gym as a way on encouraging independent exercise. However, within the Lochaber area individual circumstances play an important part in how accessible that scheme is, as demonstrated in the case study below.

In the Inverness area, local HCPs told us that the exercise referral scheme (a scheme whereby GPs can refer patients at risk of a variety of long term health conditions to a structured, fixed-term programme of assessment and physical activity to encourage long term adoption of a healthier lifestyle) which had been delivered in partnership with the local leisure services was no longer in operation. Respondents who were engaged in structured exercise maintenance were doing so through CHSS affiliated support groups. There were both chest and heart groups in Inverness and a couple of chest groups further north, in Wick and Invergordon, all of which offered weekly exercise sessions. However, the local CHSS co-ordinator reported that there was no stroke group offering exercise maintenance.

David and Michelle are both of working age and live in the Lochaber area of the Highlands. David is in employment, whilst Michelle is in receipt of unemployment benefits. Both had heart attacks last year, in August and September respectively, and each had stents inserted at Raigmore Hospital.

David, who lives in Fort William got onto the cardiac rehabilitation programme straight away. Having completed the six week programme which he described as „brilliant“ he then moved onto exercise independently, taking advantage of the new scheme in Lochaber which offers free membership to the leisure centre following cardiac rehab. When we spoke to David it was his first day back at work, just three months after his heart attack and well before he expected he would be. He is also now regularly walking with his partner and plans to get a bike and cycle to work in the future.

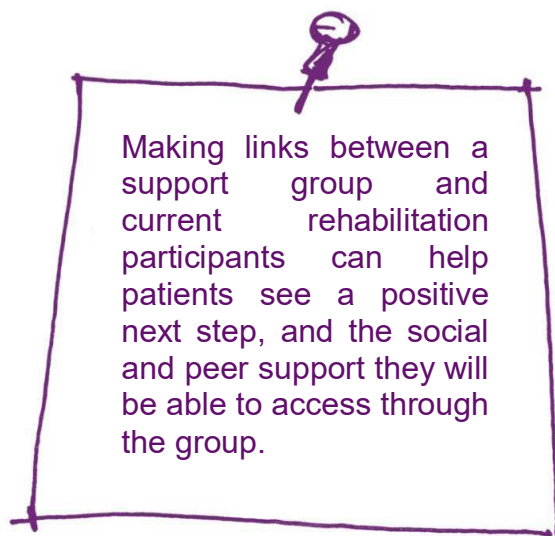
Michelle lives 43 miles from Fort William, and when we spoke to her in November she was hoping to get onto the cardiac rehabilitation programme in January. However, this is a three hour round trip and will cost £7.10 each time. Although Michelle’s physiotherapist is helping her to claim travel expenses, “even if I get expenses I still have to find the cash up front, and when you’re on benefits there just isn’t spare money”.

Michelle remains positive and is heeding the advice she has been given about diet and exercise. But there are no local exercise classes, never mind exercise maintenance. She would swim but the local pool has been closed. She has bought a 2nd hand Wii to help her exercise in the house and she takes her dog out for short walks. Even that’s difficult though because the weather is poor and Michelle can’t afford a decent weatherproof jacket.

Michelle has also applied to the local authority to be rehoused in Fort William. She is prepared to leave her home and her friends to get access to better services. That’s how important it is to her.

Key messages

- ★ people living within the same health board area may not have access to the same services; proximity to services and facilities significantly influences engagement
- ★ people on low incomes may have reduced opportunities to participate in exercise maintenance



An example of good practice we found was that members of a cardiac support group would go and speak to patients going through cardiac rehab. This approach allowed those with lived experience to paint a positive picture of the future, encourage participation in exercise and introduce them to the group. This particular practice should help address some of the barriers to engagement that we discuss in the next section. That said one of the respondents who delivered these talks did say he was surprised at the number who **didn't** come along to the group. He was unable to offer any reasons why that should be so.

3.2 Barriers to engagement with exercise maintenance

This section describes some of the barriers to both engaging with services and exercising in general that were identified by respondents. Some barriers were identified more frequently and as such, have greater bearing when it comes to recommendations. Some of the less commonly identified barriers have been included here, if only to illustrate the point that we are all different and when designing pathways and schemes, being able to eliminate as many barriers as possible should lead to greater uptake and overall success.

The table below provides a summary of the barriers and which category of respondent they relate to. Each of the barriers are then discussed in the following sections.

Table 3 – Barriers to engagement with exercise maintenance, by respondent group

Barrier	Service Users	Non-engagers who exercise independently	Non-exercisers
Transport Especially: severe stroke, rural areas and night time	X	x	x
Cost Class, equipment, instructor to come to a group	x	x	x
Weather and dark nights (big impact on independent exercisers)	x	x	
Knowledge/awareness of services		x	x
Fear and confidence (“dare I do it?”)	x but overcome by class		x
Fear of entering new social interaction	x but overcome		x
Image of group (eg group name or perceived demographic)		x	x
Not a „joiner“		x	x
Lacking motivation Message eg re stroke Lack of knowledge re benefit			x
Concern about taking another’s place – and perception that system isn’t coping		x	
Busy life		x	x
Broken routine after exacerbation, hard to get back into it			x
Other co-morbidities	x	x	x
Respiratory patients with portable O2 – it’s not that portable		x	x
Concern about activity level affecting welfare benefits			x
Perceptions of what a class might be like, eg Bootcamp		x	x

3.2.1 Transport

Being able to physically get to the exercise class venue was a significant barrier for many non-engagers and non-exercisers. Whilst wanting to take part in exercise classes the responses were often not unlike the one below from a non-exerciser in the Highlands:

“It would have to be nearby and I don’t drive. Even then the weather can put me off walking”

Transport issues were also cited by service users as a potential barrier or a barrier which had delayed engagement. For those able to drive and with access to a car it was less of a factor, though driving at night and over longer distances on rural roads did put some people off.

For many, driving was not an option either because they were no longer able to drive due to their condition or because they just didn't drive. In these situations there was often reliance on spouse, family member or friend to help with travel. For one service user it was only when her husband retired that she was able to get to the support group and take up exercise. She waited seven years.

Fellow group members and classmates do sometimes help with lifts and this is a spin off benefit from the social engagement that you get by participating in classes rather than exercising independently. However, those that rely on getting a lift from another class member usually can't attend if that person is not able to make it.

For many, public transport was their normal way of getting about and this posed several problems. Firstly, particularly in rural areas was the travel time and frequency of service. One respondent from Ayrshire & Arran indicated that they didn't attend classes because doing so would require them to wake up very early to catch the bus, they had to take 2 buses to get to the venue, and the total travel time was more than an hour. This could make travelling to facilities at worst impractical and at best really tiring. Even in urban areas the need to change buses which may involve waiting and still comparatively long journey times (when compared to travelling by car) could leave people tired. There can be other challenges with public transport for those with restricted mobility. Though low floor buses ease access for those with restricted mobility they are not always routinely used. If not in use a passenger has the option of waiting for another, in the hope it does have a low floor or not making the journey. One respondent said that if the bus did not have a low floor he would have to wait for the next one, and then maybe he wouldn't make the class in time. So was it worth it? Add to that the inclement weather and the challenge of public transport can become a tipping point to non-participation.

There are also difficulties with confidence and mobility, especially for those who have suffered a stroke, which meant public transport for many was not an option. In some areas Dial-a-Bus services and Car Plan schemes can help and provide a more bespoke service but these are patchy and some people still require assistance to get from the house to the vehicle and this is not always available through these schemes. In addition, some classes, such as the Different Strokes group in North Ayrshire, had explored the potential for accessing a bus to support people to get to classes, but hadn't been able to negotiate a bus service. As a result respondents in this group were reliant on access to a car or a lift.

The cost of transport was also highlighted. This is discussed in more detail in section 3.2.3.

3.2.2 Accessibility

Allied to the transport issue is accessibility. In the case of those using public transport the distance from their home to the bus stop or from the bus stop to the venue could be problematic. Even car drivers can face accessibility barriers in terms of available parking and proximity of parking to the venue. Relatively short distances can be problematic particularly for people with mobility problems or who are prone to breathlessness.

On the positive side we didn't hear anything with regard to the venues themselves being difficult to access, for example too many steps.

For some respondents with respiratory conditions, accessibility to venues was constrained by their need to carry portable oxygen cylinders. The problem is twofold. Firstly, there is the practicality of having to carry heavy and bulky cylinders. Secondly, the actual amount of oxygen in the cylinder - usually an hour's supply - restricts the distance that can be travelled. We understand that there is a roll-out of lighter, home fill portable oxygen cylinders underway, but certainly our respondents in this had not yet benefited from this.

3.2.3 Cost

Cost was another frequently identified barrier across both service users and non-service users. The cost of travelling to the venue particularly for those using public transport was a challenge. Even relatively short distances by public transport can be expensive. Whilst the older users may be able to use their bus passes this was not the case for younger people.

Although exercise maintenance classes are often subsidised there is still a fee to be paid by the service user and this can present a challenge, especially for those on low incomes. In addition, many of the classes have developed a social aspect, with class members going for a coffee together afterwards; again this has a cost attached.

In the support groups where an instructor is brought in to deliver exercise, this is paid for by the group. For larger, established groups this appears to be manageable. However, its sustainability is heavily reliant on the size of the group being maintained and the professional fee remaining reasonable. We spoke to two leaders of smaller groups (for different conditions), and both were concerned for the future of their groups, as they were not receiving many new referrals and the group size was shrinking; this may make the cost of a qualified instructor or physiotherapist unsustainable.

A cardiac support group based in Glasgow currently provides people with a cardiac condition the opportunity to participate in up to 2 hours of exercise maintenance once a week. The first hour is made up of gym based exercises taken by a qualified instructor whilst the second gives them access to the swimming pool which is overseen by two qualified⁸ lifeguards.

A group lead there is very concerned that the group faces closure in the very near future. Changes to local authority rules regarding the use of the swimming pool means that the group would have to pay for two local authority approved lifeguards which would roughly treble the existing costs for the group. This is because the lifeguards they use currently only charge „a token amount“, and although qualified as life guards are not local authority lifeguards so cannot be used. In addition to this, the group are not receiving enough new referrals to maintain the numbers required to cover costs.

Key message

★ increased costs and/or reduced group size can sharply reduce the financial viability of voluntary sector provision

A few people mentioned the cost of equipment to exercise at home. Whilst most home exercises provided by physiotherapists identify common household objects to use as apparatus some people, particularly those without access to classes had purchased some sort of exercise equipment such as exercise bikes and interactive games consoles. A more fundamental cost

⁸ The respondent was not able to distinguish between whether the lifeguard was qualified as a lifeguard or qualified to monitor a cardiac swimming session

barrier to exercising was being unable to afford training shoes or a weatherproof coat to allow them to walk in less clement weather.

3.2.4 Weather and dark nights

For many of the respondents walking was a major element of their exercise regime, and poor weather and dark nights deterred them from their routine because walking was less enjoyable in these circumstances. For independent exercisers this potentially eliminated their sole form of physical activity or at best reduced it. A small number said that if they couldn't walk they would do something else such as dance to music in the house. Whilst this is commendable and a positive finding that people are seeking an alternative form of exercise whether they are able to reach the same level of intensity is questionable.

The difficulty for those that do exercise mainly by walking is that it has the potential to become very much a seasonal activity. The problem then is firstly getting back into the habit once the weather improves and secondly regaining the fitness lost through a period of relative inactivity. Many respondents were also keen gardeners, but again this is largely seasonal.

3.2.5 Knowledge/awareness of services

Fundamental to participation is awareness of services. As discussed in section 3.1 people are not always being referred or signposted to relevant activities. Some of the respondents we spoke to had found out about classes by word of mouth from an existing user or through their own online search. Once they had found out about what was available they had either made contact with the organisation themselves or where necessary approached their GP for further advice or an actual referral.

Other people had stumbled across leaflets or found out about groups from a third party, in one instance their hairdresser. Even when services are not being provided by the local authorities or health sector, such as in the Highlands, many respondents felt they were not even signposted to groups or other professionals who could help them. This has led them to seek services based on their own knowledge and evaluation. However, this takes someone to already be motivated to get active and confident enough to ask the questions.

People did have different levels of expectation:

“If you want anything you have to ask, shouldn't have to.”

“People are very busy – just have to find out things for yourself”

Regardless of expectations, awareness and knowledge of services is fundamental. It does appear that some groups and organisations providing services are not always getting the message out to the right people at the right time. In other instances, group members take it upon themselves to promote the group amongst local GPs and health centres but are pessimistic about the affect this has.

3.2.6 Fear and confidence

Whilst many service users said they were not concerned about taking up exercise maintenance classes this was usually followed by a comment that they felt confident because they had been

through rehabilitation, knew what their limitations were and what they were capable of doing. They had been given coping strategies should they feel out of breath and they knew that they were being monitored by someone who knew what they were doing. As we discuss in a later section, rehabilitation seems to play a vital role in preparing patients for ongoing exercise maintenance and easing the transition into it.

Several spoke about how fearful they had been before attending rehabilitation or a supervised exercise class if they hadn't been to rehabilitation:

“I was worried sick – what if I overdid it and dropped dead in the street.”

In addition some respondents were unsure whether exercise was beneficial for their condition, or whether it was beneficial where they had a range of co-morbidities. One patient with arthritis indicated that he felt the doctor was focussed on getting him the right medications for his condition, and physical activity was not a priority at this time.

“No one has suggested I do anything physical”

Those who were exercising independently or not at all tended to report higher levels of fear and uncertainty and were generally less confident about what they could and could not do. For example a couple of respondents specifically mentioned they liked to swim but were unsure if they were „allowed“ to do that now. Certainly many would not have ventured out for a walk without the support of a spouse. One person who had had a stroke said;

“I wasn't really sure what I should or shouldn't be doing”

It wasn't always cited as a barrier, but could be inferred from responses that without rehabilitation and without appropriate supervision of classes, anxiety levels would be higher. Therefore those people who are not able to access supervised activities and particularly those who do not qualify for rehabilitation, fear may well prevent them from undertaking even moderate independent activity. One respondent who was in principle happy to exercise independently felt she needed professional input, as she put it:

“someone who knows what's best”

3.2.7 Fear of entering new social interaction

For some it wasn't the fear of physical activity acting as a barrier but the fear and trepidation of new social interaction. Meeting new people and being the „new person“ entering an established group can be a daunting task at any time in our lives. Add to that the vulnerability and lower levels of confidence brought about by their change in health status and all that goes with it, and it becomes even more challenging.

Some said that they had to make themselves go the first few times until they settled in. It wasn't that people were unfriendly just that they weren't always particularly welcoming. By this we mean they were not especially proactive with new members so the level of interaction a new member got might well be dependent on how outgoing and confident they were themselves. As one respondent put it:

“Taking the initial steps is difficult and I can see why some less confident people may not find it easy and may not come back. You need to want to do it.”

Those without access to classes, which are at least made up of people with similar conditions and shared experiences, face similar social challenges.

“I would go to the gym but they can be cliquey I enjoyed the class [rehab] because we weren't made to look silly”.

3.2.8 Image of group

People can be put off from even going once because of their preconceptions of what the group may be like. Younger people in particular perceived that groups would be full of old people, that would spend time bemoaning their situation and dwelling on negatives. The reality seems to be very different with groups in general having a very positive outlook and whilst they had shared experiences they didn't spend their time comparing symptoms.

We did hear that groups do tend to be dominated by the older generations, so younger people may not feel as comfortable there; one respondent commented on the significant male bias in the group. Another person in the Highlands but who had only relatively recently moved there felt that she didn't fit the „social scene“ so even if there were groups to go to they would not be for her.

A more extreme example, and a view expressed by only one respondent was the image that the name of a group can convey. In this instance a potential service user was put off from attending the local CHSS group because the conjured up an image of

“old men and women coughing, spluttering and moaning”.

Whilst this is likely to be a result of a difference in sense of humour, it is an interesting point to note; when people are vulnerable and lacking confidence perhaps even the slightest thing can put them off.

3.2.9 Not a 'joiner'

Some people are simply not „joiners“ – they are not attracted to group activities. A number of independent exercisers when asked would they join a class if there was one locally simply responded no they prefer to exercise alone, or with their spouse. For these people a different approach may be needed, one which offers signposting and support so that they are undertaking the right type of activities and feel confident doing so but that does not require them to exercise with others. However we did receive feedback that, in some instances, when attending their regular check with their practice nurse they did discuss the exercise that they were doing and that the nurse was happy that they were exercising appropriately.

3.2.10 Lacking motivation

We discuss in a later section what motivates people to exercise so it is relevant to mention here that a lack of motivation, whatever the cause is a significant barrier to engagement. The lack of

motivation may be underpinned by messages received from health care professionals as discussed in section 3.1. The belief that nothing can be done to improve their condition so why bother. A poor understanding of the benefits too will result in low levels of motivation.

For some they know the benefits but they just can't see a reason to try. Typically these are people who are living alone and have limited social and family interaction. One person we spoke to said she had lived her life, it had been a good one and now she was just waiting out her time.

Another responded:

“I know what I should be doing, I need to take responsibility for my own actions”

For these people finding the key which switches their behaviour may be very difficult, if not impossible, to find.

Tam had a stroke in 2001 and is affected by limited movement in his left side. Whilst in hospital he had daily physiotherapy sessions to help him regain mobility and this was followed up with weekly physiotherapy sessions for 2 months after discharge. However, at the end of his rehabilitation programme the only discussion around physical activity was the physiotherapist advising him that he should try to get out and about and keep active.

Whilst he initially had the motivation to be active, shortly after this and in a relatively short space of time Tam experienced a series of serious problems involving close family members. As a result, Tam is simply no longer interested in physical activity. As he put it, after going through what he's been through he is happy to „dodge away, living out his days“. He struggles to see any reason to make an effort to be any more active than he is already.

Key messages

- ★ motivation is essential to sustaining engagement in physical activity
- ★ once motivation lost it can be difficult to re-establish; finding a reason to carry on can be so hard

3.2.11 Concern about taking another's place – and perception that system isn't coping

In Ayrshire and Arran, some respondents reported that they hadn't engaged with pulmonary rehabilitation or exercise maintenance classes because they felt that there were others more in need of help, others who were worse off and therefore should have their place.

However this view appeared amplified because there was a perception that the system was under-resourced and wasn't really coping with demand. It is interesting that this perception of systemic failure seemed to be prevalent in a particular group in which one of the organisers was involved in a patient involvement group. There is a possibility that they were hearing things at meetings in relation to resourcing and later sharing their interpretation of that with other group members.

3.2.12 Busy life

For some, leading a busy and active life just didn't leave room for an exercise maintenance class. For those living in areas where there was just one opportunity per week this is certainly a potential barrier. One person who was a regular at a CHSS group but chose to stop going to help look after grandchildren said, that if another class was available on another day they would go.

For those where there are multiple opportunities, such as urban centres where classes are delivered in multiple locations and on different days, it should be less of a barrier. Certainly respondents in Greater Glasgow and Clyde were offered different classes and could therefore choose the one which best fitted their routine.

Some may have other priorities in their lives which push exercise to the bottom of the „to do“ list. This in some instances may reflect complex lives where health matters are pushed to the bottom of the agenda.

Kali had moved to Glasgow several years ago as a refugee. She had spent time in low grade accommodation which she believes caused her to have respiratory problems. She has seen a doctor and been diagnosed with a pulmonary condition for which she has been prescribed medication. However, there has been no discussion about exercise and in reality Kali is too busy trying to build a life for her and her young daughter to take time out to gain a full understanding of her condition and what she should be doing to help manage it. She is currently living in emergency accommodation which is not properly heated. She is working part-time whilst attending college in an effort to get qualifications for a better job and a better life. She is worried about her condition, what would happen to her daughter if she became more unwell, but she has no time to exercise.

Key message

★ people with busy lives find it difficult to make time for exercise maintenance, even when they know it's important

3.2.13 Broken routine after exacerbation

Habit, routine and structure are key factors in sustaining a healthy lifestyle. Many of the service users told us that their classes had become part of their weekly routine, and they kept coming back. But when a routine or habit is broken it can be difficult to get back into it. A number of people who had previously been service users or independent exercisers reported finding it difficult to get back into their habits of exercising, whether independently or part of exercise maintenance classes, after an exacerbation in their condition.

Bridget has had COPD for several years. She attended rehabilitation and then began attending multi-condition low intensity exercise maintenance on a weekly basis. She really enjoyed the exercise class, as she felt the benefit, liked the people she met there and the instructor made it great fun. About nine months ago Bridget got a nasty chest infection which aggravated her COPD and she was very unwell. She didn't have to be admitted, but was very limited in what she could manage for several months.

Gradually, she has got better, and taken on more activities again – she's looking after her grandchildren again, doing her housework and getting out and about. However, she hasn't gone back to her exercise class. She's lost confidence in whether she'll be able to do the exercises again, and she's daunted by the idea of going back into the group again after so long away. As she told us: "I know it's up to me and I'd feel better if I did it, but I just can't bring myself to go along"

Key message

★ a relapse or exacerbation can break the habits of exercise maintenance, and knock confidence – this can make it hard to re-engage

Bridget's story highlights just how hard it can be to get back into a routine. Taking that first step back can be almost as much of a barrier as taking the step in the first instance. There is a real risk that once that routine is broken and a person drops out of the pathway they may never get back into it.

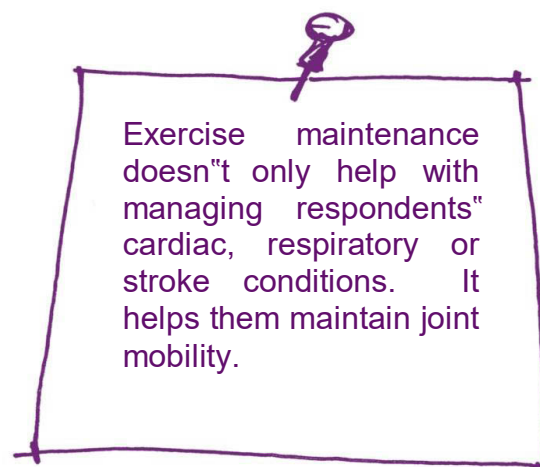
Staff delivering classes may not have the time, or be paid/tasked, to follow up on people who disengage. In some instances we heard that friends from the classes will call someone who has disengaged to see how they are and prompt them to return. This is a positive spin off from the social side of these activities. However we did hear from one group that they had made such welfare calls a couple of times only to find the individuals in question had passed away. This apparently caused some distress for both the caller and the family concerned, and the group has now stopped this type of follow up.

3.2.14 Other co-morbidities

A few of the respondents we spoke to described other health conditions that they were also affected by in addition to either a stroke, cardiac or respiratory condition. Having other co-morbidities appears to, in some circumstances, present additional challenges in relation to engaging with exercise maintenance provision. One respondent was unsure what type of activity would be suitable for his circumstances. Another was still having regular visits to his GP to find a medication regime that best suited his circumstances and until this was done he wasn't really considering participating in physical activity.

A number of respondents had joint issues, to varying degrees of severity, and these conditions made movement and thus exercise more difficult. However, we attended a low intensity multi-condition class where many attendees had joint problems as well as their principal presenting condition, and most indicated that the activity loosened them up and minimised their joint pain and stiffness on the day and for a couple of days after the class.

One respondent who had multiple conditions and as such was receiving disability living allowance was concerned that appearing to be active could have a negative impact on his benefits - that he would no longer be entitled to disability living allowance leaving him financially deprived.



3.2.15 Perceptions of what a class might be like

We have already identified how people's perceptions can become barriers in relation to the image of the group and the other people attending. Perceptions of exactly what's involved can also act as a barrier, both in terms of the perceived format and content of the class in terms of social dynamic, and the type/intensity of exercise. Feedback suggests that this is probably more relevant for those who have led less active lives prior to becoming unwell so they have limited experience of exercise classes. A perception that they will be like „boot camp" with someone ordering you about was raised by a few respondents.

“I’ve never been interested in vigorous exercise – I don’t want to go to something that’s like bootcamp. The class I go to [movement to music] might not be so intensive, but it has lovely music and I enjoy it”

“I don’t need someone barking at me, telling me to bend down, stand up”

3.2.16 Multiple barriers

Of course often there is not just one barrier to engagement but a combination of factors each additional one making it harder to reach the final destination. But when they can be overcome the results can be very rewarding.

Susan was 60 when she was diagnosed with COPD 12 years ago. She was given rehabilitation and signposted to a CHSS group offering support and exercise for people with respiratory conditions. She didn’t go, she knew she should but she couldn’t drive and public transport was unsuitable.

Seven years later she was given a second block of rehabilitation sessions and was signposted again to the group. By now her husband had retired so he could give her a lift. She decided to go because “I missed rehabilitation and I knew I should be doing something”. She was able to take her husband into the class which helped get over those first day nerves. The husband stayed and joined in. He had a heart condition and since retiring wasn’t really as active as he would like to be so he was happy to participate.

They never miss it, unless they are on holiday. They are both getting regular exercise which is helping them to manage their conditions they are now enjoying a broader social life, with new friends and regular outings. They look forward to Monday morning – not many of us can say that.

Key messages

- ★ it’s not always a single barrier that prevents engagement, and more barriers make it harder to engage
- ★ conversely, there is not just a single benefit: participation can lead to multiple benefits and varied rewards

3.3 Reasons for disengaging

A small number of respondents had been attending exercise maintenance classes or support groups but had subsequently disengaged. We discuss the reasons cited in the following sections.

3.3.1 Provision disbanded

In some instances ceasing participation was not a matter of choice but rather a decision forced upon them because the class had stopped. This appears to be a feature of schemes delivered as projects which have a finite life and if a case cannot be made to continue the scheme as part of

business as usual this inevitably results in the provision being disbanded. People may continue to exercise independently but also may not.

“I really enjoyed classes so I was disappointed when they stopped.”

3.3.2 Exacerbation of existing condition

Exacerbation of a condition can also trigger someone disengaging. In these instances the resulting break of habit can re-establish barriers. In some instances the barrier becomes insurmountable and the person just stops permanently.

3.3.3 Using time for other things

Some respondents disengage for more positive reasons either to use their time for other meaningful activities such as volunteering or helping to support the family for example helping to care for grandchildren. In some cases it may be used as a bit of an excuse and there is a risk that some alternative activities will not offer the same physical benefits.

3.3.4 Preference to start exercising independently

The most positive reason we heard for disengaging was because they had started to exercise independently, as they began feeling fitter and wanted to move beyond the level of exertion delivered in the exercise maintenance class. One respondent described the maintenance class as:

“A useful stepping stone to more challenging exercise”

Interestingly, this particular individual who now exercises for 2½ hours three times per week still attends the support group where the class is delivered. She still joins in but moderates her exercise intensity to fit with her peers, such is the social draw of these groups.

3.4 Enablers to engagement

3.4.1 Having a service to use – and knowing about it

The fundamental enabler to access exercise maintenance services is the existence of a service in the first place. Where services are not available, then people can't access them. Closely allied to this is awareness of the services that are out there. Even if they exist, if potential service users aren't aware of them, then they won't use them. We have already discussed the key role that health care professionals can play in ensuring people are aware of the services available and in motivating them to access these services. The feedback from our evaluation however did not provide any insights into whether other types of marketing of services would deliver the same impact.

3.4.2 Local accessibility

People want services to be as local and accessible as possible, especially when they have limited mobility and/or did not have access to a car or a lift. Even when transport wasn't an issue, some respondents indicated that making sure the service was local was important as it minimised the travel burdens of them.

For respondents with limited mobility, the walking distance required to access classes was often a key consideration. It is important to consider the total walking distance for people travelling to access services. Some respondents indicated that ensuring that parking was available close to the exercise maintenance class was an important consideration – as some respondents indicated they could be fatigued by even short walks which would limit their ability to participate in classes – making them unlikely to attend. In addition, walking distances to access public transport must also be taken into account as some respondents indicated that they could get to facilities using public transport, but often had to change buses and walk between bus stops and often the time and distance were prohibitive

3.4.3 Range of classes and times

To maximise uptake of classes some respondents indicated that it would be beneficial to have exercise maintenance classes available at a range of times, throughout the day and evening. This was especially noted by respondents who had work or other commitments, such as caring for grandchildren. The feedback suggests that what suits people best differs widely and depends on their own circumstances, rather than specific times of day or night being suitable for particular groups.

“I can’t go [to the exercise maintenance class] because I get my shopping on Thursdays and I need to get a lift from my friend”

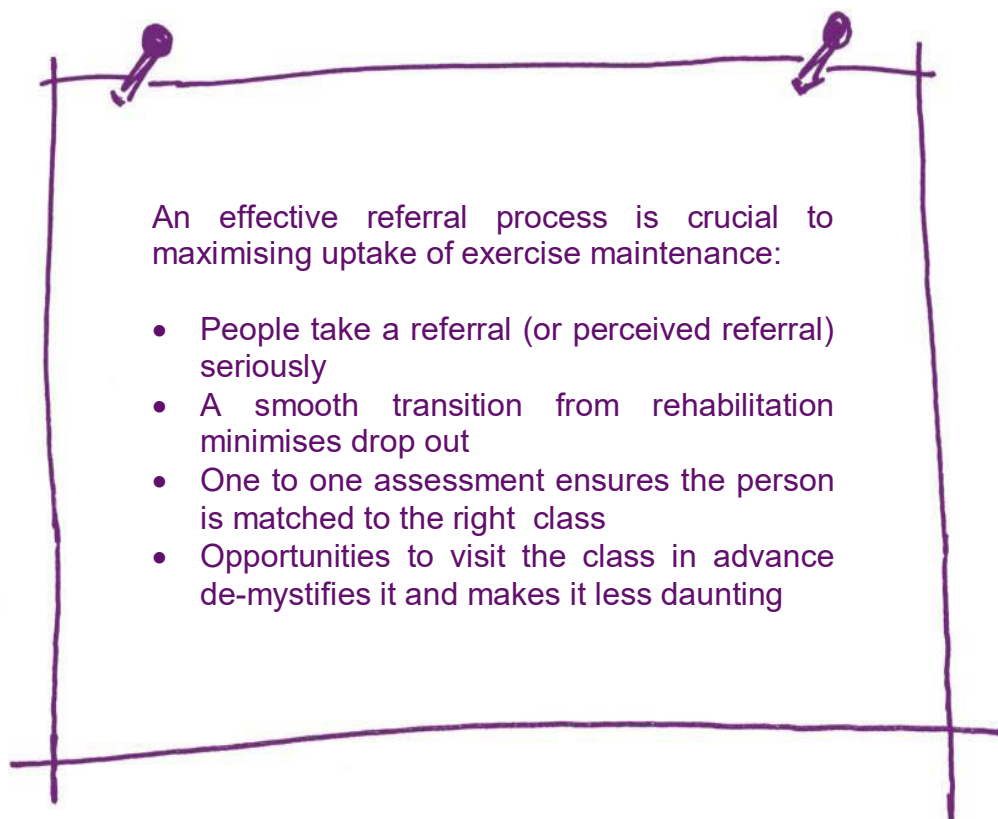
3.4.4 Perception of being referred

The vast majority of service users we interviewed perceived that they had been referred to exercise maintenance rather than signposted regardless of whether this was the case or not. They felt that their health care professional had endorsed the programme which provided reassurance that it was safe and suitable for them and their condition. Furthermore, feedback suggests that it is presented to them in a way that makes it seem like the logical next step and that it is a natural progression.

3.4.5 Referral/entry process

A smooth referral/entry process encouraged service users to attend in the first place and keep attending. This seemed to work best in the following instances:

- ★ approaching the end of a structured rehabilitation programme, the physiotherapist referred them onto a class and sometimes even took them along to see a class in action (or show them a video of a class)
- ★ when a referral into exercise maintenance led to an initial private meeting and assessment with a class instructor, to determine the right class for the person and explain to the individual what to expect
- ★ when respondents transitioned directly between rehabilitation and exercise maintenance without any break – so they didn’t break the habit of exercising, and are therefore more likely to maintain their exercise regime



3.4.6 Confidence

Many respondents required a degree of confidence to participate in exercise maintenance classes. In some instances respondents indicated that they were initially reluctant to attend classes, fearing that they would be too challenging, or that they might not enjoy the social aspect. Some service users indicated that this initial reluctance was overcome by attending their first class, where the staff and other class members were welcoming and they were able to see first-hand the range of abilities within the class. In other instances the physiotherapist making the referral had provided enough reassurance that the nature of the activity would be suitable for them.

“I was enthusiastic about attending and I had an idea of what I was going to”

3.4.7 Clear understanding of (and belief in) the benefits

Respondents were more likely to participate in exercise maintenance when the benefits to their health were clearly articulated to them, and particularly where these were validated by a health care professional. Many service users in Greater Glasgow and Clyde indicated that they had been convinced that participating in exercise maintenance would benefit the management of their condition, help them to get better quicker and remain better, and this was a key motivator to participate.

Prior to his heart attack, Brian had been a long time smoker, worked in a high pressure job and didn't have the healthiest of diets. He also did very little in the way of physical activity. Whilst in hospital the cardiac nurses really pushed the importance of physical activity as a means of helping his recovery and in helping him to remain well. This message was reinforced by the physiotherapist during his rehabilitation programme. This really hit home for Brian and he was really starting to feel the benefit of the rehabilitation programme. When his rehabilitation came to an end he jumped at the chance to be referred to an exercise maintenance class and now does more physical activity than he ever did before.

Key message

★ getting a clear and consistent message from professionals, combined with a positive experience of embarking on physical activity, can result in significant positive lifestyle changes

3.4.8 Disposable income

Access to disposable income was another key factor which enabled respondents to access exercise maintenance. Respondents indicated that there were a range of costs associated with exercise maintenance, including:

- ★ travel and transport costs (bus fares, parking, fuel costs, etc)
- ★ class fees (typically £2.50-£4.50)
- ★ equipment costs (e.g. trainers and clothing)
- ★ costs of associated social events (e.g. costs of coffee after classes)

One service user indicated that the cost of classes alone was affordable, but when they factored in costs of having coffee, and getting to and from classes, the costs mounted up. While many of the respondents considered the classes and costs to be very affordable, the extent to which classes were considered affordable varied widely depending on the amount of disposable income available. One respondent in Greater Glasgow and Clyde also indicated that another member of the family controlled the finances, meaning they did not have access to money for classes.

3.4.9 Instructor

Service users often indicated that they were motivated to engage with, and continue to participate in, exercise maintenance classes due to the personality traits displayed by their instructors. Service users indicated that it was important that staff were friendly and approachable and made the class enjoyable. In many of the classes we observed the instructors were proactive in engaging service users in the social component of the classes, whilst also doing their exercises. This often emerged as a friendly „banter“ between service users and the class instructor.

“She’s brilliant! There’s always loads of banter. She’s so approachable and fun, it hardly feels like we’re working”

Many respondents also indicated that they felt encouraged to attend exercise maintenance because the instructor pushed them to do the right level of exercise for them. It is important to note however that the level of exercise that respondents considered appropriate varied widely from individual to individual, with some respondents looking to push themselves hard, and other respondents wishing to get in some exercise without pushing too hard. It was therefore important that the instructor provides the patient with the right level of exercise for them – to ensure they are

challenged where appropriate, and not pushed too hard where this may stop them enjoying classes and ultimately stop them coming, and even exercising.

Alan had a stroke in 2002 and reported that he had received no rehabilitation or advice regarding exercise. Up until recently he did very little physical activity. However, his wife had started attending an exercise class at a local leisure facility that Alan would take her to. He would usually see her to the door and go off and do his own thing until the end of the class. After a while the instructor starting asking Alan why he dropped his wife off then left, and suggested that he should join the class as well. Alan declined the offer, but over the following weeks the instructor kept chipping away and eventually Alan agreed to start. He has now been attending the class regularly for the past 8 months and wishes he had started long before he did.

Key messages

- ★ people don't always get the message first time, or second, or third..... but sometimes persistence pays
- ★ proactive professionals get results

3.4.10 Technology

The use of technology to support exercise maintenance was identified by the PARCS Team as a potential area of interest to explore with respondents particularly in areas of poor service provision such as the rural Highlands where the sparseness of population makes providing services difficult. The respondents here gave very mixed responses to questions about how technology could be used to support them.

Some thought that exercise programmes delivered through television or via the Internet would be good and something they would try. For one respondent this was followed by the caveat that it would need to be on Freeview. So cost again is a potential barrier. The respondents who viewed this option more favourably were generally younger. Interestingly, one support group in Ayrshire and Arran had produced a DVD for people to use for home-based exercise.

A good example of where technology is being used to encourage physical activity is with a walking club in the West of Scotland. Although the group and members get together for gym based sessions they also have an online platform where group members can record the walking that they have done outside of the class using pedometers. The group set challenges such as walking the length of Route 66, with all members contributing to achieving the distance. This encourages group members to do more outside of the class than they would otherwise do.

Key message

- ★ the use of technology can extend exercise beyond the gym and open new horizons

Others were not using technology in other areas of their lives and so for them it was not something of interest.

“It may have a place, but not for me”

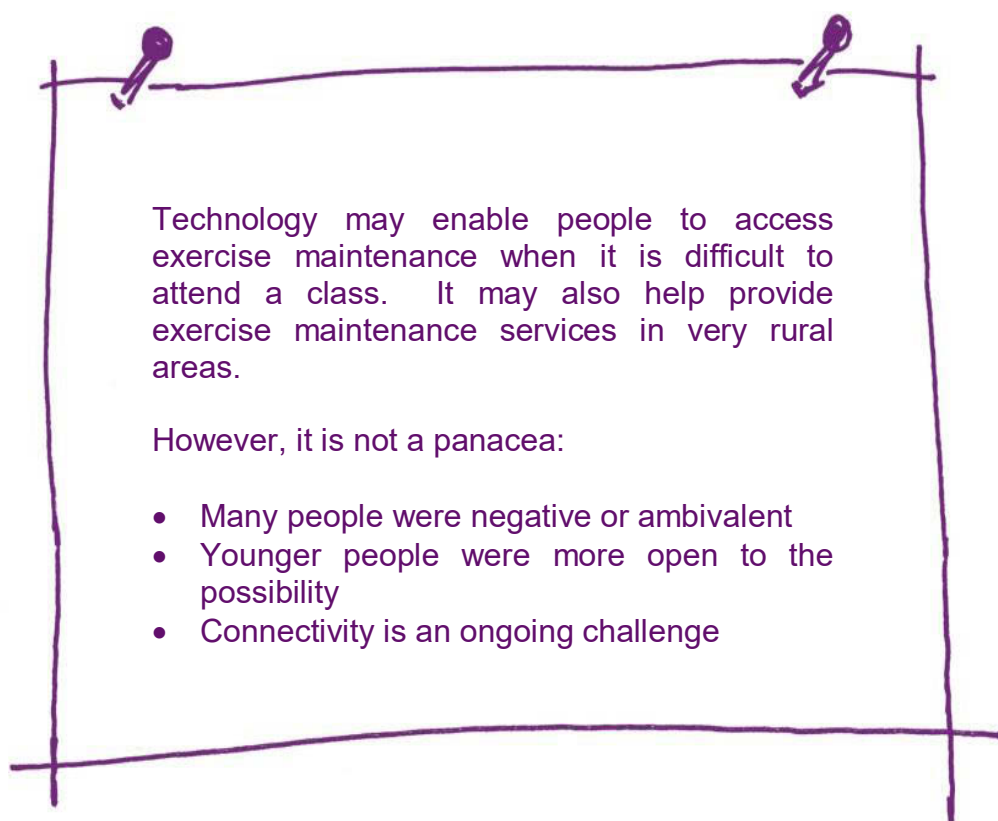
Most were fairly ambivalent, and whilst they wouldn't rule it out didn't seem wholly convinced that it would be for them.

“I have used DVDs before so I would consider something through the TV or computer”

“I wouldn’t dismiss it”

“I wouldn’t rule it out – could do things in my own time then”

Two respondents north of Inverness had participated in rehabilitation which was delivered at two sites linked by video. Neither respondent seemed to know why the sites had been joined together, and neither felt it was particularly beneficial for them personally. Both stated that having someone in the room when they are exercising was important to reassure them and keep them safe. However, it may be that the staff supporting class participants at „satellite” sites would not to have the same level of qualifications as the person delivering the class. This may ease some of the resourcing issues and extend reach. The challenge with technology, specifically in these areas, is even if the people will engage the connectivity is often poor so practically it may not be feasible.



3.5 Motivations to exercise

3.5.1 Belief in the benefits

Most respondents indicated that they were motivated to exercise because they believed that exercise was beneficial to their health. Many believed that being active was important for their

general health and wellbeing, however, the extent to which respondents understood that physical activity was beneficial for their condition varied widely depending on the information they had accessed and how proactive their health care professionals were in discussing physical activity.

“My practice nurse said to remain as active as possible and not be afraid of breathlessness at times”

“All of them [health care professionals] have made it clear that if I don’t do physical activity my condition will deteriorate”

Where respondents believed that exercise was beneficial for them this meant that they were more likely to exercise.

3.5.2 Desire to get well and ‘back to normal’

Linked to respondents’ belief that physical activity could support improvement in their health was their desire to get well again. Respondents who were extremely unwell were often motivated by the fact they didn’t wish to feel as poorly and immobile as they did, and understood that doing exercise was a way to help themselves recover in the long term. People were motivated to exercise to allow them to enjoy a range of activities which they had previously done, such as:

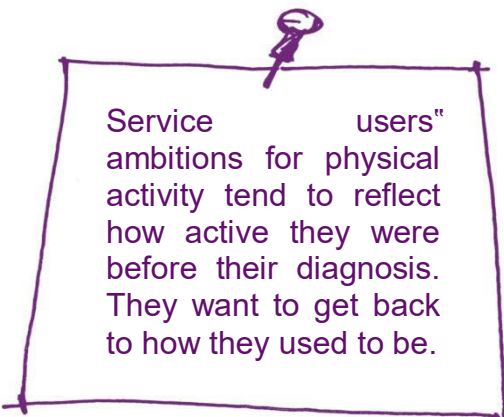
- ★ visiting friends and family
- ★ caring responsibilities
- ★ playing with, and caring for, grandchildren
- ★ walking dogs
- ★ returning to work

The feedback we received suggests that these goals were identified by the individual, rather than a structured goal setting intervention supported by a health care professional or other intermediary.

“I was determined to win back the bowls trophy I won the year before I got ill. And here it is – this year I won it”

3.5.3 Personal aspirations for activity levels

It’s important to note that in most cases the service users’ ambitions for their activity levels were a direct reflection of their pre-diagnosis activity levels. Many people who were previously very active and sporty aspired to once again participate in these sports. Conversely, those who were less active prior to diagnosis were more likely to aspire to lower activity levels or lower intensity exercise. However we did come across instances where those who were

A hand-drawn purple rectangular box with a purple paperclip icon at the top center. Inside the box, the following text is written in purple: "Service users' ambitions for physical activity tend to reflect how active they were before their diagnosis. They want to get back to how they used to be."

Service users’ ambitions for physical activity tend to reflect how active they were before their diagnosis. They want to get back to how they used to be.

relatively inactive prior to their health event were doing more now than they had ever done. In these instances the messages about the benefits (and experiencing the benefits through rehabilitation) had sunk in and prompted them to take action.

3.5.4 Influence of spouse/partner/family member

Many of the people we spoke to who were married indicated that their spouse was very influential in encouraging them to exercise, and supporting them to do so. This was observed for both service users, and non-service users, and also extended to the wider family. One person indicated that their daughter would constantly encourage them to exercise and would have been worried if they weren't exercising. Another example given was where someone's daughter actually helped them with chair based exercises when they came round to visit. In addition, some respondents indicated that their spouse didn't just encourage them, but directly enabled them to participate, for example, by driving them to the exercise maintenance classes.

“We push each other to stay active – we’d feel like we were letting the other one down if we didn’t do it”

3.6 Motivations to continue exercise

3.6.1 Enjoyment

Those attending exercise maintenance classes often indicated that they continued to attend classes because they enjoyed them.

“We have such a laugh. Even if I don’t feel in the mood when I arrive, I always feel great by the end because we have such a laugh together”

For many the classes were enjoyable because of the friendly and sociable nature of the classes rather than the physical activity components of the class. For many, this helped to mitigate against isolation and many service users indicated that they saw class members outwith classes, at less formally-organised social events.

“I’m on my own these days, and if I didn’t come here every week, I wouldn’t get out at all. I’ve got friends here and I feel better for being active. I never miss it if I can help it.”

Staff running exercise maintenance programmes were important in facilitating this friendly, sociable, and enjoyable environment, as well as developing the social dynamic of the group whilst supporting new members to join.

3.6.2 Feeling the benefit

Many service users and independent exercisers reported feeling the physical and emotional benefit of exercising, and that this kept them going. Many respondents reported that they had more energy and that by exercising they were able to increase the amount of exercise and activity that

they could do – which meant being able to do the things they enjoyed on an ongoing basis. The feedback from respondents seems to suggest that those who exercised independently were more likely to continue to exercise because they had previously led active lives or because they believed that physical activity was important for managing their condition, recovering, maintaining their health, or slowing deterioration.

For some it was just a general feeling of wellbeing:

“I get a good night’s sleep, I have a clear conscience, I’m not worried because I know I’ve done some exercise”

“I hate swimming – but I feel the benefit, know it’s doing me good, so force myself to do it”

For others there was more certainty that exercise was having a tangible effect on their condition:

“I feel better and I’m more active than before I had the heart attack”

“I would’ve had more hospital admissions if I hadn’t kept active”

Some respondents indicated that they had stopped doing their exercises on a number of occasions and that they had felt more poorly as a result – for example feeling that they had less energy, or feeling that they had aches from prolonged periods of inactivity.

In addition, respondents cited benefits to their mood and to their mental health from participating. Some respondents indicated that it was good for clearing the mind, while others indicated that it „makes you feel better – happier“. This often linked to the fun and enjoyment aspect already discussed.

“it’s not just the physical benefits, I feel better mentally as well, more upbeat, more positive”

3.6.3 Routine and habit

For some people, attendance had become a part of their routine, with some individuals having regularly attended classes for up to 10 years. They can’t think what it would be like to not do it, and emphasises the importance of sustained long term service provision.

3.6.4 Lack of time limit

Respondents in exercise maintenance classes were often motivated to continue by the knowledge that their classes were not time limited – and that their exercises could be done on an ongoing basis to continually support them to improve or manage their health.

3.6.5 Mutual support

Some respondents were inspired to participate by peers in their class, and seeing them managing their condition. They indicated that they were motivated by their peers when they saw:

- ★ improvement in the condition of their peers
- ★ that there are others with conditions more serious or debilitating than their own who are exercising and working to improve their condition

“When someone new comes along, I can say to them: look, I’ve been where you are, and I never thought I’d be able to do this, but now I can – and you can too.”

Others reported that they were motivated to continue exercise maintenance to support others, and to act as an example. In these instances they had often benefited in the same way when they had first started the class and they wanted others to receive the same welcome and support.

3.6.6 Continued progress and self-efficacy

For some individuals it was important to prove to themselves that they could do it, and that exercise could make a difference to their condition. For example, for one service user who had a stroke said it was important to show that it was possible to continue increasing their function beyond the early stages of recovery (which respondents reported that many health care professionals emphasised as the most important period for recovery).

3.7 Motivations to engage with organised classes/services

3.7.1 Safety, tailoring and supervision

One of the key reasons many service users indicated that they were motivated to participate in exercise maintenance classes was because the classes offered a safe environment in which they could exercise. Many respondents were reluctant to exercise at home, or to push themselves, due to fear of over-exerting themselves and exacerbating their condition. This fear was often mitigated in exercise maintenance classes by the presence of a trained instructor or health care professional who knew about the respondents condition and could tailor and supervise their exercise to ensure it was done at a safe and appropriate level. It is important to highlight that respondents trusted both health care professionals and instructors of classes aimed at people with long term conditions, to understand their condition and devise appropriate exercises for them.

“the exercise instructor has a good knowledge of my condition, medication and what exercises are appropriate for me”

“Classes give you a better understanding of your condition and what you can and can’t do to help”

3.7.2 Social benefits

Whilst most service users did not join classes specifically for social interaction, for some the social aspect made classes more appealing and motivated them to participate. For others, particularly those who were socially isolated, the opportunity to join a social group was both motivational and rewarding.

“I’m on my own these days, and this class is one of the few things I go out for. I wouldn’t miss it, the social bit is so important.”

One stroke support group that we visited have a qualified physiotherapist come in and run exercise sessions for the first hour, with different areas of the venue being used for different types of exercise and intensity. The second hour is „tea, cakes and games” – and if you want to attend the social aspect you need to come along for the exercise. The attraction of the social element is enough to get those that are a bit more resistant to exercise to come along and participate during the first hour. As one group member put it:

“I hate the exercise – I know it is good for me but it reminds me of all the things I can’t do anymore. I’m really here to socialise but I do the exercises as well”

3.7.3 Stepping stone to other types of exercise

Some service users were also motivated to attend structured exercise maintenance classes as a pathway to allow them to access further classes, or as a platform to support themselves to build up their fitness and be able to exercise independently. Some service users indicated that being in a class opens up doors, helping them to learn about, and progress onto other classes. One service user in Ayrshire and Arran indicated that they had graduated to a higher intensity class, however, they only became aware of this class through their initial engagement in the exercise maintenance classes. However, this was not always the case, and was dependent on the number and type of classes available in each area, as well as the health of the individual and the range of classes they might potentially move onto.

One respondent who had progressed onto independent exercise indicated that they had benefited from building a rapport with the exercise maintenance instructor, who had helped them develop a tailored plan for exercising independently. This individual was now happy to exercise independently, knowing they were doing exercises which were suitable for them, and had been approved by an instructor who understood their condition and the appropriate exercises to manage their condition.

4 CONCLUSIONS AND AREAS FOR CONSIDERATION

4.1 The journey

In this section we present our conclusions about the patient journey into exercise maintenance.

4.1.1 Touchpoints

Our findings suggest that there are specific touch points between service users and healthcare professionals that can greatly influence the decision to engage with physical activity:

- ★ Physiotherapists - in hospital during initial therapy sessions and during rehabilitation sessions in the community
- ★ Clinical nurse specialist – in hospital, on ward
- ★ Practice nurses – during routine appointments and chronic disease management clinics

Positive messaging, reassurance, inspiration and encouragement provided by healthcare professionals at these key touch points are often the catalyst for a engagement with rehabilitation and/or exercise maintenance.

However, they are not the only health professionals that have a role to play and consistent positive messaging across all roles is essential. In particular consultants, other hospital doctors and GPs can play a role in instigating the idea of physical activity as part of their recovery and ongoing management. Whilst these health professionals often can't have the same depth of discussion as those at the key touch points, they can be beginning to encourage their patients to consider physical activity. For instance, a consultant mentioning to their patient that a nurse or physiotherapist would be speaking to them about rehabilitation sessions and why rehabilitation is important, would be enough to plant the seed and place added emphasis on its importance.

4.1.2 Continuity of pathway

Our evaluation has shown that a cohesive and continuous pathway is critical in influencing and enabling people to have a sustained engagement in physical activity beyond their diagnosis and/or treatment. We heard from several respondents who had experienced a seamless transition from the point of diagnosis and/or treatment, through rehabilitation and into community exercise maintenance provision. Where this seamless pathway is in place it greatly increases the potential and likelihood for continued engagement in physical activity.

Our evaluation suggests that in recent times the cardiac and pulmonary pathways have become increasingly cohesive and largely effective in providing a continuous journey. However, the experiences of those people affected by stroke were more varied, and suggested a more fragmented and inconsistent pathway with many experiencing a successful entry into rehabilitation but little support, advice or signposting thereafter.

4.1.3 A system-centred pathway

A consistent theme from our evaluation has been that the pathways into rehabilitation and exercise maintenance are system-centred rather than person-centred; the pathway works well provided the service user is ready to proceed at the same timetable as the pathway proceeds. If a patient is unable or unwilling to proceed at that pace, this acts as a barrier to remaining on the pathway and

making a successful transition into rehabilitation and/or exercise maintenance. Once off the pathway there is no guarantee that a person will find their way back.

4.2 Regional Specific points

Our evaluation specifically aimed to investigate differences in services, from the service user perspective, in three different regions of Scotland. Our conclusions in relation to these differences are presented below.

4.2.1 Greater Glasgow and Clyde

Greater Glasgow and Clyde has an established and mature exercise referral scheme, Live Active, which Allied Health Professionals can refer in to and caters for a wide range of long term conditions. In addition, Vitality is an exercise maintenance programme in place across NHS Greater Glasgow and Clyde region and can also be accessed by people with a variety of long term conditions. However, during our evaluation we found that those with the most restricted mobility, specifically those severely affected by stroke, perceived a lack of provision available and suitable for them. This was compounded by barriers and challenges relating to transport and assistance as well as a lack of knowledge and understanding about the benefits of physical activity in relation to their condition and what exercise would be appropriate for them.

This evaluation did not involve a mapping element, but we are aware of peer mentors being available in some but not all Vitality classes. There appears to be a need to make available provision more visible and consider how the additional support needs of this client group can be provided for if it does not already exist eg greater access to buddying and practical support to get to classes.

Many support groups have access to volunteers that help their members with mobility challenges to get to and from the group. Where these groups are not in a position to provide their own exercise maintenance activities it would be worth exploring with the groups whether this can be facilitated through existing community resource/provision. As we discuss later in this section, support groups have the potential to be a key vehicle for and enabler to engaging with exercise maintenance for their group members, particularly those with the most severe barriers to engagement.

Areas for consideration:

- ★ conduct a scoping/mapping exercise to fully understand what provision is available and suitable for people affected by stroke, particularly those with severe mobility restrictions; in addition this scoping should explore the extent of potential needs for these services including additional assistance requirements of the potential service users
- ★ where gaps in terms of required service provision and additional support needs are identified during the scoping/mapping exercise referenced above, work with statutory and voluntary sector providers to explore how these gaps can be filled
- ★ explore how third sector support groups (those that do provide exercise maintenance activities for members and those who do not), and their volunteer resource, can support members to access existing exercise maintenance provision
- ★ work with HCPs to ensure the messages regarding the importance and potential benefits of physical activity participation are being delivered to those affected by Stroke

4.2.2 Ayrshire and Arran

Across Ayrshire and Arran there appeared to be good interaction amongst lead staff in leisure services, most strongly across the south and east of the region. This has enabled good practice to be shared and provision to be co-ordinated. Whilst this way of working is potentially helping to ensure that good quality and suitable provision is available, and that movement between the provision is possible, it does seem to be reliant on the long term relationships formed by the leisure services leads. Therefore it is potentially vulnerable to changes in staff.

Although our discussions with leisure services staff indicate there is good interaction and collaboration across the different leisure services providers, our meetings with support groups indicate there is a need for those providing leisure services to make local support groups, and other potential service users, more aware of the full range of provision available.

The evaluation also found that there were perceptions that capacity was lacking or stretched:

- ★ **Shortage of physiotherapists** – We heard several stories relating to the waiting times (in some instances over 40 weeks) to access pulmonary rehabilitation. As well as this creating a barrier in itself it has also contributed to the perception that there just aren't enough physiotherapists.
- ★ **Insufficient classes** – Although there were instances of service users moving across geographical boundaries in order to access provision, others indicated that they felt that not enough classes are available in Ayrshire overall, and particularly within their locality. Either greater awareness of existing provision or additional provision to meet need is required.
- ★ **Shortage of suitably qualified instructors** – There is a perception that there are not enough qualified instructors to run exercise classes for people with long term conditions. If there was sufficient provision available to meet the needs of the local population this would go a long way to removing this perception

Consequently there are people who would like to be participating in exercise maintenance but aren't, and others who would like to do more than they already are, but feel they can't.

Areas for consideration:

- ★ encourage closer interaction between third sector support and/or exercise groups and leisure services providers in Ayrshire and Arran to ensure that groups and their members are fully aware of all existing provision
- ★ ensure HCPs at the key touch points on the pathway are fully aware of all available provision and the mechanism for making referrals
- ★ review data from the PARCS CHSS scoping exercise to understand whether there is a real shortage of classes and qualified professionals to take rehabilitation and/or exercise maintenance. If gaps are identified, work with relevant partners and stakeholders from the statutory and third sector to identify how gaps will be filled.

4.2.3 Highland

Perhaps unsurprisingly the main challenge specific to the Highlands was the distinct lack of service provision outwith the main urban centres, with those living in the more rural and isolated areas facing significant barriers to access.

The challenges around transport and accessibility for regions with a high proportion of rural areas mean that there is a real need, and demand, for services to be truly local. The main challenge in addressing this need, however, is that smaller populations make it more difficult to provide a cost effective high quality provision that meet the needs of the local population and can justify the

investment. Our evaluation suggests that technology does not currently offer a suitable solution to this challenge, due to a combination of ambivalence amongst the target population and a lack of appropriate connectivity infrastructure.

Areas for consideration:

- ★ explore and identify areas outwith the main urban centres that could act as a hub for several surrounding areas with smaller populations
- ★ if any areas are identified, work with the necessary statutory and third sector organisations to explore how and what services can be delivered
- ★ when designing services for areas with smaller populations, where possible these should be suitable for a wide range of long term conditions, perhaps combined with a general exercise referral service, therefore maximising the potential pool of service users

4.3 Key factors influencing physical activity and engagement with services

The diagram below provides an overview of the key factors that our findings indicate influence initial engagement and continued participation in physical activity including:

- ★ Barriers – what gets in the way of people engaging
- ★ Reasons for disengaging - what is it that makes people stop their participation
- ★ Enablers – what is it that makes it possible for people to engage
- ★ Motivators – what makes people want to exercise generally, what makes them engage with available services and why do they continue

Figure 11 – Factors influencing engagement with exercise maintenance

Barriers	Reasons for disengaging	Enablers	Motivators to start and continue
<ul style="list-style-type: none"> • transport • accessibility • cost • weather and dark nights • lack of awareness of service • fear and confidence • fear of entering a new social interaction • image of group • not a joiner • lack of motivation • concern about taking another's place • busy life • broken routine • other co-morbidities • perceptions of exercise • compound effect of multiple barriers 	<ul style="list-style-type: none"> • broken routine • provision disbanded • exacerbation of condition • using time for other things • preference to start exercising independently 	<ul style="list-style-type: none"> • having a service available • local and accessible • range of classes and times • perception of being referred • referral/entry process • confidence • clear understanding and belief of the benefits • disposable income • instructor qualities 	<ul style="list-style-type: none"> • to exercise <ul style="list-style-type: none"> • belief in the benefits • desire to get well again and 'back to normal' • influence of spouse/partner/family • to engage with services <ul style="list-style-type: none"> • safety, tailoring and supervision • social benefits • a good place to start their exercise • to continue: <ul style="list-style-type: none"> • enjoyment • feeling the benefit • routine and habit • lack of time limit • mutual support • continue to see progress

4.4 Lessons for improving delivery processes

Whilst our evaluation only focused on the respondents' perspectives we have identified a number of lessons for improving delivery processes.

4.4.1 Suggested pathways

We were asked to consider whether our findings suggested an ideal pathway that service users should experience as they proceed from symptoms/diagnosis into exercise maintenance. Much work has already been done through the PARCS project to develop ideal pathways in detail. The figures below provide an overview of the suggested pathways generated as our interpretation of our findings. However, as already discussed, whilst these are simple and logical, the timetable for an individual's journey through the pathway will not be consistent and this is where complexities arise. If a service user is unable or unwilling to engage with the next step in the pathway at the logical time of first offering, there need to be processes in place to ensure they can re-engage easily with the pathway when the time is right.

Figure 12 – Suggested pathway – new event/diagnosis or worsening/change in condition

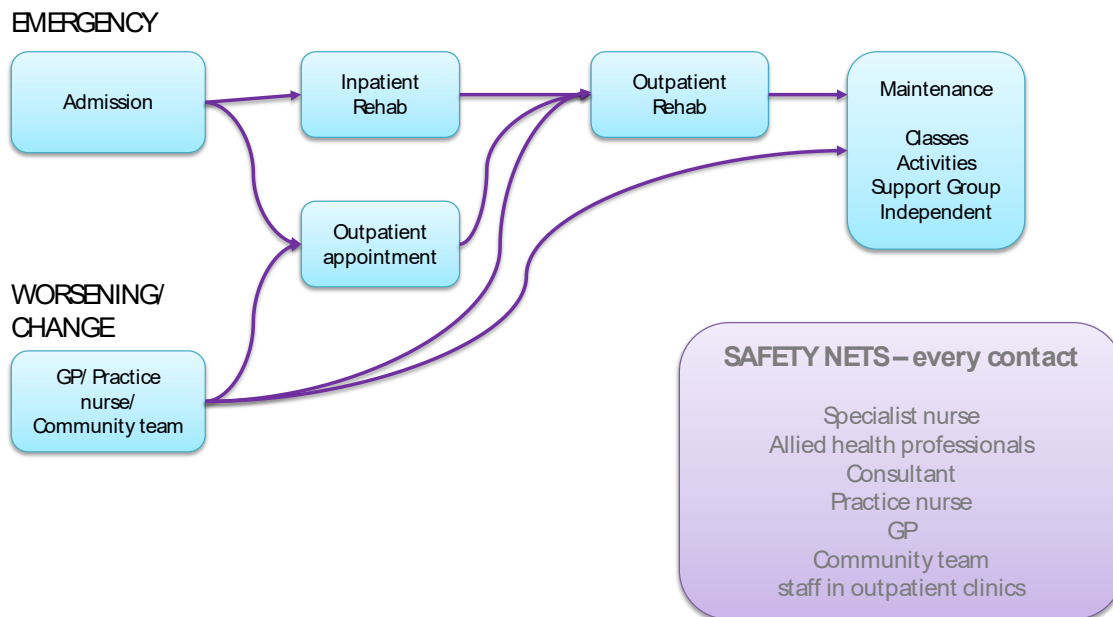
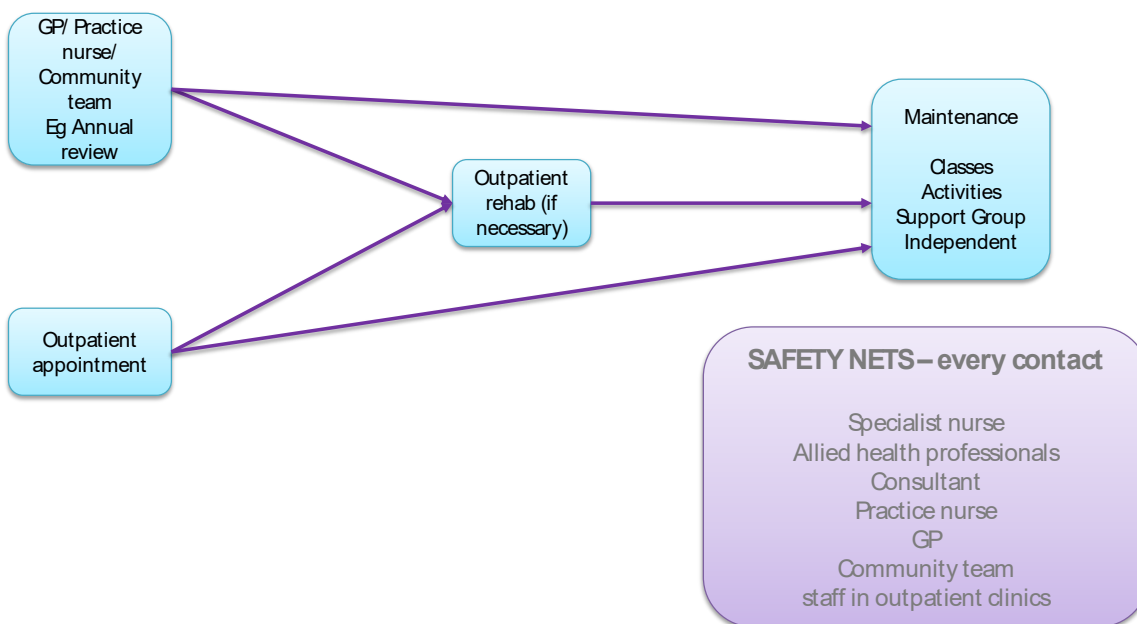


Figure 13 – Suggested pathway - existing condition but not currently involved in exercise maintenance



To maximise the effectiveness of these pathways, 4 key components must be embedded:

Figure 14 – key components affecting effectiveness of pathway

Introduce it early	Keep reinforcing	Avoid hiatus/breaks	Provide safety nets
<ul style="list-style-type: none"> HCPs need to be discussing physical activity and communicating positive messages regarding physical activity with the patient and at the earliest point. eg diagnosis or post treatment Initial message from a senior HCP (eg consultant) can carry more weight At this stage the focus is selling the benefits of physical activity 	<ul style="list-style-type: none"> Throughout the patient journey it is critical that the messages in relation to physical activity and exercise maintenance are continually reinforced Mix of health care professionals providing a consistent message - nurses, physiotherapist, doctors - at every contact 	<ul style="list-style-type: none"> Seamless transition between recovery, rehabilitation and exercise maintenance gives highest chances of continued and sustained engagement Any delays at the transition points can lead to disengagement and people leaving the pathway Vital that, when an individual is ready to make the next step on the pathway, that this is facilitated with as little break in time as possible (no break at all is the ideal) 	<ul style="list-style-type: none"> People disengaged for a variety of reasons - there needs to be safety nets in place, to ensure they are re-engaged when the time is right for them This will require a proactive approach from HCPs in the primary and secondary care settings For those that disengage from exercise maintenance a process for 'follow up' should be introduced to encourage/ease re-engagement as appropriate

Areas for consideration:

- ★ Ensure that the following 4 components are embedded in the patient pathways:
 - Introducing physical activity early – introducing the benefits and importance of physical activity in relation to the patient's condition at the earliest point
 - Reinforcing the message – consistent and positive messages delivered at key points along the patient pathway by a variety of HCPs
 - Avoiding breaks – seamless transition into and from the different stages on the pathway
 - Providing safety nets - ensure the appropriate systems and follow up is in place to act as safety nets for those that do not engage through the pathway or disengage following referral
- ★ the pathway for stroke patients appears to be in greatest need of improvement. Therefore a priority is to work with relevant HCPs to ensure that the pathway for Stroke patients is as cohesive and seamless as that of the cardiac and respiratory pathways

4.4.2 The role of the HCP

The role of the HCP is a critical one. They are in a position of key influence and are facilitators along the patient pathway. Whether it is a nurse in a GP practice, or a physiotherapist taking rehabilitation classes, they have the greatest opportunity to encourage and enable a patient's participation in physical activity.

But to do that, HCPs at the key touch points on a patient's journey (and beyond) need to understand and be convinced of the importance of physical activity, have good information about options and local provision, and provide positive and consistent information to their patients.

Areas for consideration:

- ★ ensure HCPs understand the critical nature of their role in influencing patients' propensity to engage with physical activity
- ★ ensure HCPs are equipped with the skills, knowledge and confidence to deliver the necessary messages and discuss the various options available with their patients

4.4.3 Communication

Our evaluation suggests that to maximise engagement in rehabilitation and subsequently exercise maintenance, all HCPs involved in a patient's journey need to be delivering a consistent and positive message. The vast majority of service users that we spoke to took motivation from the messages they received from HCPs about the importance and associated benefits of physical activity participation. Conversely, many of the non-service users that we spoke to reported a lack of communication, or mixed messages, in relation to physical activity. This meant that many were unaware of how physical activity could benefit them and also what was appropriate for them to be doing.

Our evaluation also shows a disconnect between the terminology used by HCPs relating to physical activity and the language used by respondents. Where HCPs refer to rehabilitation, our respondents tended to refer to this as „going to physio“. Where HCPs talk about exercise maintenance our respondents tended to refer to exercise classes. The term most open to different interpretations though was „physical activity“. This conjured up a range of different meanings to different people, with most seeing it as some form of formal, organised sports. Things like gardening and walking were often not considered as physical activity. „Being active“ seemed to be the catch all that people related to.

Whilst this may seem a relatively minor point it is important to be delivering a clear message and in terms people can understand and relate to. This can potentially reduce some of ambiguity and misconceptions that prevent people from participating

Areas for consideration:

- ★ work with HCPs that are engaging with patients at the key touch points along the pathway to ensure that the right messages are being delivered at the right time and in the right way; this should include the language and terminology being used

4.4.4 Role of third sector support groups

Many support groups are already adding to the range of services available to people with long term conditions (eg social and peer support) and there are more that, with the right support, could expand this further. During our evaluation we have visited support groups that have made arrangements to bring in qualified instructors and/or physiotherapists to deliver some form of exercise maintenance activity. This is providing a valuable service to group members, many of whom would not be able to/want to access other provision. Some of these groups see it as a constant struggle to get new members and question how often health care professionals actively refer or signpost to their groups.

More groups would like to be able to offer exercise maintenance. We visited support groups that would really like to be able to bring in qualified physiotherapists and/or instructors for their group members. The group leads are aware that their members would benefit greatly from it and currently are unable to access any other existing provision. The problem appears to be one of

finance, with groups unable to finance the additional costs associated with providing the service. This is a real missed opportunity to integrate exercise maintenance into existing activities and routines, which group members are therefore likely sustain.

Often it is these support groups that have also catered for the additional support needs of their members – for example, assistance to get out the house or transport to the venue – and therefore removed the practical barriers that would otherwise prevent their group members from participating. Other types of provider are unlikely to be able to offer this level of assistance and support, so individuals with additional support needs group would often be unable to access exercise maintenance otherwise.

Areas for consideration:

- ★ explore ways to ensure the third sector support groups offering structured exercise maintenance, overseen by a suitable person/professional, is embedded in the referral options and pathway to help ensure new people are going to the groups and they are able to retain a sufficient member base to make the groups financially viable and sustainable
- ★ assist support groups in identifying and applying for/accessing funding opportunities relating to the provision of physical activity
- ★ identify and work with existing support groups that have a desire to provide „in-house“ exercise maintenance to overcome the barriers that are currently preventing them from doing so
- ★ identify and work with existing support groups to explore how their volunteer resource can support group members to access existing provision
- ★ explore whether there is scope to achieve greater integration between third sector support groups and other service providers; eg could leisure services provide or 'loan' specialist instructors to third sector groups?

4.4.5 Service Design

The way a service is designed will have a significant impact on whether it is successful or not. An ill-designed service can unwittingly create barriers that need not be there. Our findings from service users indicate the following design issues should be considered when designing exercise maintenance services:

Continuity

Continuity of provision is critical for individual service users as well as health care professionals. Individual service users take great comfort and confidence in knowing that they do not have a defined time limit on their attendance. It is not just a 13 week programme or the provision is not going to disappear in a few months" time because it has been funded through a pot of money that is no longer available. It enables them to build a routine and develop relationships with other service users which can sustain participation. From a health care professional's perspective it is impossible for them to remain up to date with provision that is here today and gone tomorrow. There needs to be a fairly stable and visible provision that they feel confident referring into. Whilst we appreciate that short term pilot provision does have its place in terms of its value in evidencing need and impact, the finite nature of it can cause issues and prevent it from being as successful as it could be.

Accessibility

The extent to which a service is accessible by the target audience will have a huge influence on whether people will engage with it or not. Accessibility need to be considered from two different yet related aspects. The first is in terms of accessibility to the venue – is it linked by public transport, how long will the journey be from intended catchment areas, should the provision be

made available during the day or in the evening, do the buses run at the right times to get there and back, what additional support might service users need? The second aspect is access into the venue itself – is there enough car parking overall, is there enough parking near the entrance to the venue, are there hills or steps that make it more difficult to access?. In considering accessibility it is worth seeing it through the eyes of the service user. Therefore we would recommend that service users are involved in the design of services particularly in relation to assessing the accessibility of proposed provision, and that exercise maintenance services should be subject to equality impact assessment.

Integration into the referral pathway

Whilst we came across a few evaluation respondents that had been proactive in seeking out a referral to exercise maintenance provision, they were the exception rather than the rule. More often than not service users had been signposted or referred by a health care professional. This suggests that any new service being designed (or existing service being redesigned) needs to be integrated into the pathway. Essentially this means that the appropriate health care professionals need to be aware of it, be confident that it is safe and appropriate provision and understand the referral process.

Data collection

Most services currently collect very limited (if any) data about service uptake, attendance, characteristics of service users, continuity of attendance and disengagement. The lack of local data has proved an obstacle to the economic impact assessment, and we understand it has also been a challenge to the PARCS scoping exercise. Without accurate and appropriate data collection, it is impossible to assess the capacity, effectiveness and efficiency of services. It is equally challenging to plan for future services.

Areas for consideration:

- ★ ensure that these 4 design issues (ie continuity, accessibility, integration into the referral pathway and robust data collection) are considered in the design of future services and the further development of existing services
- ★ ensure that development of consistent data collection is prioritised for existing services across Scotland

4.5 Lessons to inform secondary prevention

4.5.1 Getting the timing right

The point at when someone is referred/signposted to rehabilitation or exercise maintenance does seem to have one rather striking peculiarity. Our evaluation suggests that in most instances referrals are made at the point of diagnosis or shortly after treatment. However, our evaluation revealed a number of instances where patients had been diagnosed with a condition (eg COPD) that was not considered severe enough to warrant signposting/referral to rehabilitation or exercise maintenance. This is perhaps understandable due to resource constraints, but these individuals were later referred to rehabilitation and exercise maintenance due to a deterioration in their condition. An earlier referral may have helped them manage their condition and remain at a less severe end of the spectrum for longer, therefore may have represented a saving in the longer term.

This evaluation project was not extensive enough to conclusively prove that earlier referral/signposting would deliver benefit.

Areas for consideration:

- ★ to understand the extent to which „delayed“ referral (in relation to severity of condition and rehab/exercise maintenance offered) is taking place and whether there would be health and economic benefits associated with earlier referral.
- ★ if the health and economic case is proven then the evidence should be used to influence a change in practice

APPENDIX 1

TOPIC GUIDE FOR INTERVIEWS WITH SERVICE USERS

Background details

Name:	
Age:	
Gender:	
Ethnicity	
Work status:	
Postcode:	
Region: e.g. Angus, Tayside	
Condition(s):	
Date of Diagnosis:	
Contact email/telephone:	

Health context

1 Can you tell me a little bit about your condition from when you were diagnosed?

Get the interviewee to tell their story in their own words -use pathway template

Ensure the following is also captured

- Do you still attend hospital as an outpatient – if yes who do you see (which clinics)
- How often do you visit your GP for your condition

Never		3 x per year	
Annually		4 x per year	
2 x per year		> 4 x per year	

- How many times have you been admitted to hospital over the last year, and were these related to your condition

None		Three	
One		Four	
Two		> four (how many)	

No. related to condition	
--------------------------	--

- 2 When you were being seen by health care services (NHS) for your condition, were you advised about the importance of physical activity in relation to your condition?**

Yes		No	
-----	--	----	--

- 3 Who talked to you about the importance of physical activity/exercise? (Tick all that apply)**

GP		Peer	
Hospital doctor		Support group	
physiotherapist		Charity (pls name)	
Occupational therapist		You, yourself	
Nurse		Other (pls state)	
Exercise instructor		Don't know	
Family			

- 4 What did they tell you?**

Make sure you capture who said what.

Probe if there were options, „a menu“ were they helped to navigate around the options, were they getting the same message from all, or was it mixed messages?

- 5 What did you think about that?**

Probe around quality and quantity of information, the way it was presented, was there anything to take away for reference. What information did they not get, would they like options to choose from?

- 6 What other advice were you given with about looking after yourself?**

Prompt for healthy eating, smoking cessation, weight loss etc

- 7 Have you acted on any of the advice given?**

What, why, why not?

Current situation

- 8 Can you tell me what exercise and activities you participate in on a regular basis as part of an organised group/class?**

In relation to any organised class/groups:

- Who provides it and where

Name of Group	Location

- Is it condition specific or generic?
- How long have you been attending the class?

< 6 months		6 mths – 1 yr		1- 2 yrs		2-3yrs		> 3yrs	
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- How often do you attend this class?

< 1 per month		1 per week	
1 per month		2 per week	
2 per month		> 2 per week	
Other:		State:	

- How long is the class?

9 Does the activity or group you participate in do anything other than physical activity?

10 Physical activity includes walking, active household chores, and sport and leisure activity. How much time do you spend on these activities per week and what are they?

- What else?

Exercise maintenance		Walking independently	
Walking in a group		Golf	
Gardening			
Others:			

- How much per week

None	
< 30 mins	
30 – 60 mins	
1 – 2.5 hrs	
> 2.5 hrs	

The journey

11 How was it you came to be at the class/group?

Probe for was it referral or signposting, by who and at what point in the patient journey?

- How did you find out about your exercise class suitable for your condition in your area?

Via NHS		Other	
GP		Exercise instructor	
Hospital doctor		Family	
Physiotherapist		Peer	
Occupational therapist		Support group	
Nurse		Charity (pls name)	
		You, yourself	
		Other (pls state)	
		Don't know	

- If NHS did someone formally refer you or tell you about an exercise maintenance class?

Referral	
Told	

- Where did you find out about your exercise class?

When attending cardiac rehab		When attending routine review with GP/nurse	
When attending stroke rehab		When attending consultant specialist review	
When attending pulmonary rehab		I found out myself	
never		Other pls state	

- When in relation to your diagnosis did you find out about a suitable class?

When diagnosed		1-2 years after diagnosis	
Within 6 months of diagnosis		2-3 years after diagnosis	
6-12 months after diagnosis		More than 3 years after diagnosis	

12 How did you find the process from being referred/signposted to actually getting to the class?

Probe for how information was passed, how much and quality of information; any delays in accessing services, was there any follow up.

- Was it an easy move from hospital/health to community support (including maintenance exercise activity and advice on self-management)? **Yes/No**
- If no – what were the issues/difficulties?

No advice on exercise maintenance groups		Advice and support ended after hospital care finished	
No exercise maintenance groups in area		Advice and support ended after rehabilitation finished	
Lack of advice and information about how to manage my condition in the community		Advice and support ended after I went home	
No advice about support groups		Other (please state):	

- What was good about it? What went well?

13 Were you referred/signposted to any services that you have been unable to access?

The experience

14 How did you feel about being referred to a class?

15 Did you have any concerns?

16 How did you feel when you arrived at the class for the first time?

17 How is it now?

18 Has there been anything which has made it more difficult for you to participate in the class?

If yes, how have you overcome these difficulties?

Probe – travel, accessibility, cultural factors

19 Have you seen some other people who attended disengage?

If yes, why do you think that might have happened?

Outcomes

20 What have been the benefits of being part of this exercise class?

Probe for general health and wellbeing, specific improvements such as see GP less, reduced medication, mobility, spin offs such as increased social contact

None		Helped me to remain independent	
Social support/interaction		Motivation to exercise	
Helps well being		Encouraged me to do more physical activities independently	
Feel part of community		Helped me to maintain my activity levels	
Helps understand and manage my condition(s)		Increased my activity levels since having this condition / diagnosis	
Helps mental health (better mood)		Allowed me to achieve my goals e.g. play with grandchildren	
Improved function – able to do day to day tasks more easily e.g. walking		Helps me to remain active whilst I have changes in my condition	
Helped me to remain more active		Others pls state	

21 How do you feel your condition is since joining?

Worse	
Much the same and how I manage it has remained unchanged	
Much the same but I can manage it better	
Better	
Not applicable	
Other (please state):	

22 Would you recommend the class to a family member or friend who had a similar condition?

Why do you say that?

APPENDIX 2

TOPIC GUIDE FOR INTERVIEWS WITH NON-ENGAGERS

This topic guide should be used in conjunction with the patient pathway template.

It is also important to ensure all the boxes are completed as these will supplement the PARCS questionnaires.

Background details

Name:	
Age:	
Gender:	
Ethnicity:	
Work status:	
Postcode:	
Region: e.g. Angus, Tayside	
Condition(s):	
Date of Diagnosis:	
Contact email/telephone:	

Health context

1 Can you tell me a little bit about your condition from when you were diagnosed?

Get the interviewee to tell their story in their own words -use pathway template

Ensure the following is also captured

- Do you still attend hospital as an outpatient – if yes who do you see (which clinics)
- How often do you visit your GP for your condition

Never		3 x per year	
Annually		4 x per year	
2 x per year		> 4 x per year	

- How many times have you been admitted to hospital over the last year, and were these related to your condition

None		Three	
One		Four	
Two		> four (how many)	

No. related to condition	
--------------------------	--

- 2 When you were being seen by health care services (NHS) for your condition, were you advised about the importance of physical activity in relation to your condition?**

Yes		No	
-----	--	----	--

- 3 Who talked to you about the importance of physical activity/exercise? (Tick all that apply)**

GP		Peer	
Hospital doctor		Support group	
Physiotherapist		Charity (pls name)	
Occupational therapist		You, yourself	
Nurse		Other (pls state)	
Exercise instructor		Don't know	
Family			

- 4 What did they tell you?**

Make sure you capture who said what.

Probe if there were options, „a menu“ were they helped to navigate around the options, were they getting the same message from all, or was it mixed messages?

- 5 What did you think about that?**

Probe around quality and quantity of information, the way it was presented, was there anything to take away for reference. What information did they not get, would they like options to choose from?

- 6 What other advice were you given with about looking after yourself?**

Prompt for healthy eating, smoking cessation, weight loss etc

- 7 Have you acted on any of the advice given?**

What, why, why not?

Current situation

Service available – not used (Use this section if service is within 5-6 mile radius)

- 8 What do you know about physical activity or support groups available in your area for people with your condition? Are you aware of other groups and services which exist to help you manage your condition?**
- 9 Have you ever attended? Tell me about your experience.**
- 10 If attended and dropped out - why did you stop going?
If never attended - what stopped you attending?**
Are there any cultural issues at play?
- 11 What or who would encourage you to participate (again)?**
Are there key people?
- 12 Is there anything that could be done practically that would help you to participate?**
Explore:

Attitudes to use of technology –explore attitudes to support delivered through TV, any experience of tele-health internet (eg Skype) – is the infrastructure in place to facilitate this e.g. broadband, satellite, cable

Accessibility – travel to location, time of day, venue e.g. perceived exposure to public, other users (cultural)

13 Do you do any sort of other physical activity? Tell me about it?

Define physical activity as including walking, active household chores, and sport and leisure activity. How much time do you spend on these activities per week and what are they?

Exercise maintenance		Walking independently	
Walking in a group		Golf	
Gardening			
Others:			

- How much per week

None	
< 30 mins	
30 – 60 mins	
1 – 2.5 hrs	
> 2.5 hrs	

Go to 23

No service available

14 Do you do any sort of physical activity? Yes/No If yes go to 15, if no go to 17

15 Tell me about it?

What, how much, how often, challenges, motivation?

Define physical activity as including walking, active household chores, and sport and leisure activity. How much time do you spend on these activities per week and what are they?

Exercise maintenance		Walking independently	
Walking in a group		Golf	
Gardening			
Others:			

- How much per week

None	
< 30 mins	
30 – 60 mins	
1 – 2.5 hrs	
> 2.5 hrs	

16 What have been the benefits of physical activity?

17 Would you like to do some form of physical activity /Is there any other physical activity you would like to do?

18 If there was an appropriate exercise class or activity group available in the area would you attend?

If no, why do you say that? (Go to 21)

Are there any cultural issues at play?

19 What sort of exercise class or group would you like to see in the area?

20 What else would be needed to enable you to access such a group?

Accessibility – travel to location, time of day, venue e.g. perceived exposure to public, other users (cultural)

21 What or who would encourage you to participate in physical activity?

Are there key people?

22 Is there anything that could be done practically that would help you to participate in physical activity?

Explore:

Attitudes to use of technology –explore attitudes to support delivered through TV, any experience of tele-health internet (eg Skype) – is the infrastructure in place to facilitate this eg broadband, satellite, cable

Accessibility – travel to location, time of day, venue eg. perceived exposure to public, other users (cultural)

Perceptions of exercise

23 Do you have any concerns about physical activity? What are they?

24 Do you think not taking any physical activity has had/is having a negative impact on you condition or general health and wellbeing?

With care and if appropriate rapport has been established probe re possible depression, medication

25 What do you think the benefits of participating in physical activity are?



PARCS PROJECT – THE ECONOMIC CASE FINAL REPORT

August 2014

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EXECUTIVE SUMMARY

This report examines the potential economic case for providing exercise maintenance services across Scotland. The comprehensiveness and conclusiveness of the calculations are limited by the lack of availability of data about exercise maintenance in Scotland, in particular:

- ★ participation levels
- ★ outcomes

To calculate approximate costs and benefits of exercise maintenance, we therefore made assumptions about possible uptake levels and drew inferences from a range of research evidence relating to both exercise maintenance and cardiac and pulmonary rehabilitation. There was insufficient evidence to calculate an economic case for exercise maintenance for people with stroke conditions.

Costs of delivery

The costs of delivering exercise maintenance to people with cardiac, pulmonary and stroke conditions across Scotland, based on a projected uptake of 12.45% of the eligible cohort, would be as shown in the table below:

Condition	Cost of classes with 20 participants	Cost of classes with 15 participants
Cardiac	£1,856,518	£4,367,677
Respiratory	£542,962	£1,277,382
Stroke	£545,401	£1,283,121

Potential savings for cardiac conditions

At 65% uptake, exercise maintenance could reduce avoidable readmissions by 30%. At the projected uptake levels, readmissions could be reduced by 5.75%.

The value of these readmissions would be in the range of £191,018 to £531,279, which alone is not sufficient to recover the costs of exercise maintenance.

However, there is an extensive evidence base describing the range positive outcomes of cardiac rehabilitation, together with research that shows these benefits mostly dissipate over a 6 to 12 month period without continued physical activity.

We would therefore argue that the reduced admissions, combined with the potential costs of not supporting cardiac rehabilitation completers to participate in exercise maintenance, together justify the expenditure.

Potential savings for pulmonary conditions

The evidence base is more comprehensive in relation to exercise maintenance for people with pulmonary conditions, and shows that it can lead to between 30 and 40% reduction in admissions.

Based on the projected 12.45% uptake levels, this would generate a net saving after the cost of delivery of between £369,354 and £1,652,686.

1 INTRODUCTION

Whilst there is considerable evidence of the physical and quality of life benefits of physical activity/exercise (more generally and for people with stroke, respiratory and cardiac conditions), the evidence base related directly to the economic benefits of exercise maintenance for people affected by stroke, respiratory and cardiac conditions is patchy. In order to fully quantify the benefits, further research is needed. In Scotland the lack of availability of data relating to exercise maintenance participants is a major limiting factor.

The PARCS project presented an opportunity to strengthen the evidence base, by assessing the economic impact of providing exercise maintenance services to people with cardiac, respiratory and stroke conditions across Scotland. The analysis described in this report was focused on the societal perspective in terms of NHS cost savings. Data to enable the analysis was drawn principally from secondary data sources, with bottom-up calculation of service costs. This has enabled an assessment of:

- ★ costs of service delivery – including an average unit cost at different scales of session delivery
- ★ cost-effectiveness based on savings from avoided admissions and readmissions¹

¹ In relation to respiratory and cardiac conditions respectively; lack of data prevented a similar analysis for stroke.

2 METHODOLOGY FOR ASSESSING THE ECONOMIC CASE

Whilst the evidence base relating to the economic benefits of exercise maintenance is very limited, there is considerably more evidence about the economic benefits of rehabilitation, and the durability of these benefits; some of this can be used to make reasonable assumptions about the economic benefits of exercise maintenance. We also had access to a small amount of self-reported data from service users in CHSS-affiliated community based physical activity/exercise and support groups who responded to a PARCS survey (referred to as PARCS survey in the remainder of this chapter), which further assists in assessing whether there is an economic case for exercise maintenance.

2.1 Perspective of the economic assessment

We have assessed the potential economic case from the societal perspective, in terms of cost savings to the NHS as a result of exercise maintenance. In particular this is focused on admission and readmission rates.

2.2 Evidence available

The ideal basis for assessing the economic case for exercise maintenance would be high quality academic evidence (as described below) that examines the economic benefits of exercise maintenance on the three condition groups that are included in the PARCS project. Where this is not available, the next best option is evidence for the economic benefits and durability of benefits of rehabilitation for these condition groups (as exercise maintenance might be viewed as a long term extension of those benefits – see below). Each piece of evidence used in the economic assessment is referenced as a footnote (or, occasionally where more appropriate, in the main body of the text). After the reference, the level of evidence it represents is noted in brackets, using the following rating scale:

- | | |
|-----|---|
| 1++ | High quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias |
| 1+ | Well conducted meta-analyses, systematic reviews, or RCTs with a low risk of bias |
| 1- | Meta-analyses, systematic reviews, or RCTs with a high risk of bias |
| 2++ | High quality systematic reviews of case control or cohort studies
High quality case control or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is causal |
| 2+ | Well conducted case control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal |
| 2- | Case control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal |
| 3 | Non-analytic studies eg case reports, case series |
| 4 | Expert opinion |

We considered whether evidence related to the economic benefits of generic exercise referral schemes might be a third option in the absence of directly transferable evidence bases. However these are aimed at people at risk of developing a range of conditions, rather than those who have actually been diagnosed with cardiac, respiratory and stroke conditions, therefore we concluded

that we could not confidently draw inferences from this evidence about the economic benefits of exercise maintenance for people with diagnosed conditions. The benefits could be more or they could be less, therefore it would be risky to base any assessment on this data.

The types of evidence available for this assessment were as follows:

Table 1 – Evidence available for assessment of benefits of exercise maintenance and rehabilitation

Condition group	Academic evidence on economic benefits of exercise maintenance	Academic evidence on economic benefits of rehabilitation	Academic evidence on durability of benefits of rehabilitation ²
Cardiac	No	Yes (1++)	Yes (1++)
Respiratory	Yes (2++)	Yes (1++)	Yes (1++)
Stroke	No	No	No

In addition, we had access to the PARCS survey data (n=221). This was used as supplementary data. We also had evidence of adherence and completion rates for exercise referral schemes and rehabilitation, which we used to inform assumptions about adherence rates for exercise maintenance. This was supplemented by data on cardiac rehabilitation numbers in Scotland supplied by the NHS Services Scotland Information Services Division.

Given the available evidence, we must make inferences from the pulmonary evidence-base to inform the assessment of the economic case for exercise maintenance for stroke and cardiac conditions (to a greater and lesser extent, respectively).

2.2.1 Why consider the benefits and durability of benefits of rehabilitation?

Rehabilitation (as defined in the glossary) is an intervention that combines a variety of inputs including advice on self-management, prevention and support with overcoming the psychological/emotional impacts of the condition. However, a major component of rehabilitation is supervised exercise to enable the person to regain functional capacity and develop habits that will enable them to maintain any gains achieved during the rehabilitation programme.

Rehabilitation is a fixed-term intervention, usually lasting between six and twelve weeks depending on the condition and provider. In many cases, patients are given advice on home-based exercise and/or the benefits of continuing physical activity at the end of rehabilitation. There is evidence that the quantifiable benefits (exercise capacity and amount of physical activity regularly undertaken) gained during cardiac³⁴ and pulmonary⁵⁶ rehabilitation diminish after the intensive programme ends.

² The evidence in this category is not related to the economic benefits of rehabilitation, per se. However we are making an assumption that, if exercise maintenance extends the physical benefits of rehabilitation beyond the period they would typically endure without exercise maintenance, then economic benefits of rehabilitation will also be extended.

³ Davies P, Taylor F, Beswick A, Wise F, Moxham T, Rees K, Ebrahim S. Promoting patient uptake and adherence in cardiac rehabilitation. Cochrane Database of Systematic Reviews 2010, Issue7. (1++)

⁴ Pinto B, et al. Maintenance of Exercise After Phase II Cardiac Rehabilitation: A Randomized Controlled Trial *Am J Prev Med*. 2011 September ; 41(3): 274-283. (1+)

⁵ Brooks D, Krip B, Mangovski-Alzamora S, Goldstein R. The effect of post-rehabilitation programs among individuals with COPD. *Eur Respir J*. 2002;20(1):20-29. (1++)

Based on this evidence we have concluded that exercise maintenance can extend the benefits of rehabilitation. The evidence only allows the assumption that benefits are extended by a year. Further research would be needed to demonstrate whether the benefits can be maintained beyond that period.

2.2.2 The cost benefits of exercise maintenance

The principal available evidence related to the economically quantifiable benefits of exercise maintenance is for patients with pulmonary conditions⁷. The evidence is based on a population-based sample (n=2386) tracked from 1981-3 to 2000 and 1991-4 and 2000. The study found that exercise equivalent to 2 hours cycling or walking per week or more was associated with a 30-40% reduction in COPD-related hospital admission and respiratory mortality.

2.2.3 The cost benefits of rehabilitation

A recent NHS Improvement document models potential economically quantifiable benefits of cardiac rehabilitation⁸. Based on data from across England, the modelling shows the potential for a 30% reduction in unplanned cardiac readmissions in a twelve month period, based on implementation of a 'gold standard' cardiac rehabilitation model with 65% patient uptake. It also cites other evidence, from a large scale systematic review, that a comprehensive cardiac rehabilitation service has the potential to reduce unplanned cardiac readmissions by 26% over a 5 year period⁹. The report also acknowledges a variety of other positive impacts associated with cardiac rehabilitation, cited by current English national clinical guidelines and quality standards¹⁰ including, but not limited to:

- ★ a 26% relative reduction in cardiac mortality over five years according to an analysis of more than 48 randomised trials
- ★ a reduction in cardiac-related morbidity
- ★ an improvement in functional capacity and quality of life.

The economic assessment in this evaluation does not attempt to quantify these positive outcomes economically.

⁶ Beauchamp M, Evans R, Janaudis-Ferreira T, Goldstein R, Brooks D. Systematic Review of Supervised Exercise Programs After Pulmonary Rehabilitation in Individuals With COPD. *Chest*. 2013;144(4):1124-1133 (1++)

⁷ Garcia-Aymerich J, Lange P, Benet M, Schnohr P, Anto JM. Regular physical activity reduces hospital admission and mortality in chronic obstructive pulmonary disease; a population based cohort study. *Thorax*. 2006; 61:772-778 (2++)

⁸ NHS Improvement. Making the case for cardiac rehabilitation; modelling potential impact on readmissions. 2013

⁹ Davies EJ, Moxham T, Rees K, Singh S, et al. Exercise based rehabilitation for heart failure. *Cochrane Database of Systematic Reviews*. 2010; Issue 4 (1++)

¹⁰ National Institute for Health and Care Excellence (NICE). NICE CG48, NICE CG94, NICE CG108 and NICE QS9.

There is also evidence for reduced admissions as a result of pulmonary rehabilitation for patients with COPD. One randomised control study (n=191) found a 39.8% reduction in admissions over 12 months for patients completing pulmonary rehabilitation¹¹. Another randomised control study (n=200) found no reduction in admissions, but a halving of the length of stay for patients who were admitted who had completed pulmonary rehabilitation¹².

2.2.4 Supplementary data on impact on admissions

We had access to the PARCS survey data on self-reported admissions (related to their condition) by exercise maintenance service users, and were able to compare this with national-level admissions data from ISD (2011)¹³¹⁴.

Table 2 – National data on admissions, bed days and patients derived from ISD data tables (referenced above) for calendar year 2012

Condition group	Admissions	Patients	Admitted patients as % of total prevalence		Total bed days	Mean bed days per admission	Mean admissions per patient
CHD	24897	19911	5.021%		113493	4.6	1.250
COPD	18904	12163	10.488%		144389	7.6	1.554
Stroke	7899	7607	6.530%		202767	25.7	1.038

Self-reported data on admissions from the 221 PARCS survey respondents showed average numbers of admissions per respondent as follows:

- ★ Cardiac conditions: 0.38
- ★ COPD: 0.42
- ★ Stroke: 0.76

In addition, the majority of respondents had not had an admission in the previous year (78% of respondents with cardiac conditions, 67% of respondents with respiratory conditions and 60% of respondents with stroke conditions).

This suggests a substantial reduction in admissions compared to the national data. However it is important to note that the national admissions data also includes initial acute events, whereas many of the survey respondents had been living with their condition for a number of years. Nevertheless this small scale dataset does offer positive indications of the role of exercise maintenance in reducing admissions.

¹¹ Bourbeau J, et al. Reduction of hospital utilization in patients with chronic obstructive pulmonary disease: a disease-specific self-management intervention. *Arch Intern Med*. 2003;163:585-591 (1++)

¹² Griffiths TL, et al. Results at 1 year of outpatient multidisciplinary pulmonary rehabilitation: a randomised controlled trial. *Lancet*. 2000 Jan 29;355(9201):362-8. (1++)

¹³ Cardiac and Stroke data taken from ISD Table: Number of bed days, admissions and patients for selected conditions, NHS Scotland, Calendar Year 2011.

¹⁴ COPD data taken from ISD Table: Total and average number of admissions and bed days for COPD, NHS Scotland, Calendar Year 2011.

2.3 Assumptions in our calculations

There is very limited data available in Scotland about exercise maintenance uptake and adherence levels, therefore a number of assumptions were essential to the economic calculations. These are as follows:

2.3.1 Eligible cohort

We have assumed that all patients with a cardiac condition¹⁵ or COPD^{16,17} or stroke (including TIA) condition¹⁸ should be eligible for physical activity, therapeutic exercise and physical fitness training unless there are any absolute contra-indications to these interventions. ISD prevalence data allows us to calculate the eligible cohort, however we must note that no account has been made of possible double counting for people with more than one of the cardiac conditions for which data is available:

Table 3 – Prevalence of condition and numbers eligible for rehabilitation

Condition group	Total prevalence (and eligible cohort)
Cardiac ¹⁹	396543
Respiratory ²⁰	115974
Stroke ²¹	116495

¹⁵ Based on SIGN Guideline 57: Cardiac rehabilitation (2002)

¹⁶ Whilst the Scottish Clinical Standards for COPD indicate that rehabilitation should only be offered to people with a MRC dyspnoea rating of 3 or above, it is not possible to disaggregate the number of people with COPD that would fall into this category from the data available. However, there is an argument for offering rehabilitation to all people diagnosed with COPD, to maintain fitness and delay/prevent deterioration.

¹⁷ Some patients with other pulmonary conditions (not COPD) would also be eligible for rehabilitation and exercise maintenance. However data on the potential numbers are not available. COPD would account for the majority of eligible patients, therefore has been used as a proxy.

¹⁸ Based on expert guidance provided by Prof. Frederike van Wijck PhD MCSP FHEA, Professor in Neurological Rehabilitation, Glasgow Caledonian University, Prof. Gillian Meade, MB B Chir, MA, MD, FRCP, Professor of Stroke and Elderly Care Medicine, Honorary Consultant Geriatrician, The University of Edinburgh and Mr Mark Smith Consultant Physiotherapist, Strategic AHP Lead Stroke Rehabilitation - NHS Lothian, based on the following rationale:

Eligibility for physical activity, (therapeutic) exercise and physical fitness training depends largely on the presence of contra-indications. To our knowledge, there are no reliable data on the number of stroke survivors with absolute or relative contra-indications to these interventions. Often, interventions can be tailored to people with relative contra-indications. Additionally, in some cases absolute or relative contra-indications can be treated successfully, after which people may be eligible for one or more of these interventions. (4)

¹⁹ ISD Quality and Outcomes Framework data for Coronary Heart Disease, Left Ventricular Dysfunction, Heart Failure, Atrial Fibrillation 2012/13

²⁰ ISD Quality and Outcomes data for COPD 2012/13

²¹ ISD Quality and Outcomes Framework data for Stroke and TIA 2012/13

2.3.2 Likely uptake

Given the lack of available data on likely uptake of exercise maintenance, we have used figures from the available evidence about:

- ★ likely or target uptake of rehabilitation
- ★ adherence/completion rates for rehabilitation
- ★ likely uptake of exercise maintenance amongst those completing rehabilitation

The expected uptake for cardiac rehabilitation, cited in the Scottish Intercollegiate Guidelines Network (SIGN) guideline for cardiac rehabilitation²², is 80%. Current uptake in Scotland is 58% - an increase on the 45% uptake achieved in 2008²³. Assuming continued increases in uptake, we have used 65% as our estimate for rehabilitation uptake.

Evidence from an evaluation of generic exercise referral²⁴ showed likely adherence and completion at 37 – 48%, although the programmes under review were time-limited and of varying length. We have used the upper end of this range (taking a cautious view of potential costs) in the absence of figures about adherence rates for rehabilitation. Given that the initial uptake figures for exercise referral schemes look broadly similar to the rehabilitation target figures, we have assumed that the adherence to rehabilitation will also be broadly similar. However, it is important to note that exercise referral schemes are focused on primary prevention and therefore tend not to accept referrals for people with the pre-existing conditions that are the subject of this study.

Evidence on uptake of exercise maintenance is taken from the audit of referrals made by pulmonary rehabilitation services in NHS Greater Glasgow and Clyde to Live Active and Vitality services - conducted as part of this BLF evaluation (see chapter 4). This shows a referral rate of 57%. In terms of adherence to exercise maintenance, no Scottish data is available. However, the review of services outside of Scotland, led by BHF as part of the PARCS project, generated anecdotal evidence that adherence at 50-70% could be reasonably expected^{25,26}. Again to err on the side of caution, we have assumed 70% of those who are referred will adhere as they have already demonstrated commitment through their completion of rehabilitation.

Therefore, the cohort for assessing costs and benefits has been calculated using the following process of discounting:

- ★ number eligible for rehabilitation
- ★ discounted by 35% to arrive at 65% uptake
- ★ discounted by 52% to arrive at 48% rehabilitation completion
- ★ discounted by 43% to arrive at 57% referral to exercise maintenance
- ★ discounted by 30% to arrive at 70% adherence to exercise maintenance

²² SIGN Guideline 57: Cardiac Rehabilitation (2002)

²³ ISD Cardiac Rehabilitation Tables 2011/12

²⁴ Pavey TG, Anokye N, Taylor AH, Trueman P, Moxham T, Fox KR, et al. The clinical effectiveness and cost-effectiveness of exercise referral schemes: a systematic review and economic evaluation. *Health Technol Assess* 2011;15(44). (1++)

²⁵ Service Provision Scoping Report - Wales, BHF Scotland, 2014. (Part of the PARCS project)

²⁶ Service Provision Scoping Report - England & Northern Ireland, BHF Scotland, 2014. (Part of the PARCS project)

The table below shows the discounting and end figures for each condition group:

Table 4 – Discounting and end figures by condition

Condition group	Eligible for rehab	Rehab uptake 65%	Rehab adherence 48%	EM referral 57%	EM adherence 70%
Cardiac	396543	257753	123721	70521	49365
Respiratory	115974	75383	36184	20625	14437
Stroke	116495	75722	36346	20717	14502

Whilst this only represents 12.45% of people eligible for exercise maintenance potentially taking it up and adhering, the figure may be lower than this in reality; anecdotal evidence from the PARCS partners indicates that slippage between referral to and initial attendance at exercise maintenance is a significant issue.

These figures were used to calculate costs of service provision and quantifiable benefits. It is important to note that anecdotal evidence²⁷ suggests that there would be variations in uptake and adherence between conditions, but the lack of data on actual uptake and adherence means that we do not have reliable figures on these variations. Therefore we must use the same assumptions across all condition groups.

²⁷ Findings of PARCS scoping research undertaken by CHSS, based on meetings with HCPs and service providers across Scotland and surveys of HCP, GPs, service providers and Managed Clinical Networks to compile regional overview profiles.

3 FINDINGS – COST AND BENEFIT CALCULATIONS

3.1 Calculation of costs

We have estimated the cost of providing exercise maintenance services, based on the likely uptake in a year as calculated in chapter 2. The table below shows how we arrived at our gross class costs using a 'bottom up' calculation methodology.

Table 5 – Cost per class calculations

Salary from current online vacancy for physical activity referral trainer (Bo'Ness)	£ 23,000.00
Salary plus 'on costs' at 30%	£ 29,900.00
Hourly rate based on 37 hour week (46 working weeks after leave)	£ 17.57
Instructor for 1.5 hours (including set up and break down of 1 hour class)	£ 26.35
Venue hire (average of current costs cited by a number of leisure and community venues across Scotland - sourced directly by the Brightpurpose research team)	£ 40.00
Cost per class	£ 66.35

The delivery model we have costed is based on:

1 hour of exercise instruction per week per person for 46 weeks per year, delivered by a qualified instructor, either in a leisure services venue (such as a leisure centre) or a community-based support group (eg in a community venue such as a church hall or community centre).

However, it is important to note that we are aware of other models of delivery that may have higher costs, such as:

- ★ services employing self-employed instructors to run sessions (usually paid in the region of £25 per hour for a phase IV qualified instructor); this provides flexibility to respond to variable demand
- ★ services with a dedicated coordinator acting as a single point of contact for assessing and directing service users into the most appropriate provision (although in some cases the coordinator undertakes this role as part of a wider existing role, such as leisure services manager; in this case there may be limited additional costs, depending on demand)
- ★ services where an instructor conducts an assessment with a service user before inviting them to join the most appropriate provision (again this is sometimes undertaken by a staff instructor as part of their existing role, therefore may have limited impact on cost)

We are also aware that, in some cases, support groups have been able to secure community venues at substantially reduced prices. Where this is possible, the costs of delivery would be lower than the costs set out below. However, it would be unrealistic to assume that these arrangements could be secured at scale across Scotland, therefore they have not been factored into the calculations.

3.1.1 Class/group sizes and unit costs

We have observed classes run by a single instructor, with up to 25 participants. However, we recognise that not all service providers would want to work with those ratios, and indeed in some locations and for some client groups (eg rural and stroke) this would not necessarily be feasible. We have therefore calculated costs per session per person based on class sizes from 5 through to 25. We have also provided a cost for one to one instruction, per person per session²⁸. In all cases, we have assumed that sessions are 1 hour in length. We have also assumed a £2.50 contribution per session per participant, as this was the typical price paid by service users involved in our evaluation (Table 6).

Table 6 – Cost per person by class size

Class size	Gross cost pp	Cost pp (after £2.50 contribution)
5	£ 13.27	£ 10.77
6	£ 11.06	£ 8.56
7	£ 9.48	£ 6.98
8	£ 8.29	£ 5.79
9	£ 7.37	£ 4.87
10	£ 6.64	£ 4.14
11	£ 6.03	£ 3.53
12	£ 5.53	£ 3.03
13	£ 5.10	£ 2.60
14	£ 4.74	£ 2.24
15	£ 4.42	£ 1.92
16	£ 4.15	£ 1.65
17	£ 3.90	£ 1.40
18	£ 3.69	£ 1.19
19	£ 3.49	£ 0.99
20	£ 3.32	£ 0.82
21	£ 3.16	£ 0.66
22	£ 3.02	£ 0.52
23	£ 2.88	£ 0.38
24	£ 2.76	£ 0.26
25	£ 2.65	£ 0.15

The cost of one to one instruction, again for 1 hour assuming a £2.50 contribution by the participant, would be £15.07.

²⁸Using data from one study, inflation-adjusted to 2014 prices: North Lanarkshire Leisure Services. Social Impact Evaluation. 2010.

3.1.2 Delivery costs (after service user contributions)

With a class size of 20, the cost per year across Scotland (after service user contributions) would be as follows:

Table 7 – Annual cost of 20 person class across Scotland by condition

Condition group	Uptake numbers	Annual cost	
Cardiac	49365	£	1,856,518.43
Respiratory	14437	£	542,962.22
Stroke	14502	£	545,401.42

At a class size of 15 the delivery costs (after service user contributions) would rise to:

Table 8 – Annual cost of 15 person class across Scotland by condition

Condition group	Uptake numbers	Annual cost	
Cardiac	49365	£	4,367,676.96
Respiratory	14437	£	1,277,382.20
Stroke	14502	£	1,283,120.69

3.2 Calculation of benefits

Based on the available data, we are able to estimate the value of benefits for exercise maintenance for different condition groups as follows:

- ★ cardiac conditions – maintenance of reductions in readmissions achieved by cardiac rehabilitation
- ★ respiratory conditions – reduced admissions achieved by exercise maintenance
- ★ stroke – no calculation of benefits possible due to a lack of data

3.2.1 Benefits of exercise maintenance for people with cardiac conditions

The principal quantifiable benefit of exercise maintenance for cardiac patients is the preservation of the benefits of cardiac rehabilitation in the longer term. The evidence indicates a potential 30% annual reduction in readmissions arising from cardiac rehabilitation, but evidence relating to the durability of benefits of cardiac and pulmonary rehabilitation shows that benefits can be lost within a 6 month to 1 year period, due to lapse in healthy habits acquired during rehabilitation and forgetting important information learned during rehabilitation. We have therefore assumed that a year of exercise maintenance could preserve the benefits of cardiac rehabilitation for a further year.

As the modelling that provided evidence of a 30% reduction in cardiac readmissions was based on 65% uptake of cardiac rehabilitation, and we are basing our calculations on 12.44% adherence to exercise maintenance, we discounted the potential readmissions from exercise maintenance to reflect these differing levels of uptake.

Table 9 below shows the potential reduction in readmissions based on this proportionate discounting to be 5.75%

Table 9: potential readmission avoidance rate for cardiac patients

	Uptake	Readmission avoidance rate
CR uptake in modelling	65%	30%
Projected uptake of EM	12.45%	5.75%

The most recently available cardiac readmissions data for Scotland, supplied by ISD indicates that there were 1819 cardiac readmissions in the calendar year 2012. A 5.75% rate of avoided readmissions equates to 104 saved readmissions, and approximately 476 bed days saved.

The most up to date figures available for costs of admissions in Scotland are in the Scottish Tariff, published by ISD. There is no single figure for the cost of an average bed day, but the tariff provides costs for non-elective admissions across a range of conditions. We have used these figures to calculate the value of avoided cardiac admissions as follows:

Table 10 - Cost per individual admission for CHD

Condition group	Lower end of range	Upper end of range	Midpoint
CHD	£ 1,829.00	£ 5,087.00	£ 3,458.00

CHD admission costs were calculated using the following tariff codes:

- ★ lower end – cardiac condition without critical care
- ★ upper end – cardiac condition with critical care

Table 11 provides a calculation of the potential financial value of the saved readmissions.

Table 11 – Cost value of readmissions avoided (cardiac conditions)

Rate of readmissions avoided	Value based on lower end	Value based on upper end	Value based on midpoint
5.75%	£ 191,018.17	£ 531,279.08	£ 361,148.63

As the annual cost of providing exercise maintenance for people with cardiac conditions would be between £1.86m and £4.37m, the saved readmissions alone would not recover the costs of the exercise maintenance provision. However, there is an extensive evidence base describing the range positive outcomes of cardiac rehabilitation, together with research that shows these benefits mostly dissipate over a 6 to 12 month period without continued physical activity. We would therefore argue that the reduced admissions, combined with the potential costs of not supporting cardiac rehabilitation completers to participate in exercise maintenance, together justify the expenditure.

3.2.2 Benefits of exercise maintenance for people with respiratory conditions

The principal quantifiable benefit of exercise maintenance for respiratory patients is a reduction in admissions of between 30 and 40%. Based on the uptake and adherence figures shown in Table 4, and the admissions data shown in Table 2, the number of admissions and bed days that could be saved in a year as a result of exercise maintenance would be, as shown in the table below:

Table 12 – Admissions avoided and bed days saved (respiratory conditions)

Rate of admissions avoided	Admissions avoided	Bed days saved
30%	706	5392
40%	941	7190

As described in section 3.2.1, the most up to date figures available for costs of admissions in Scotland are in the Scottish Tariff, published by ISD. We have used these figures to calculate the value of avoided respiratory admissions as follows:

Table 13 – Cost per individual admission for COPD

Condition group	Lower end of range	Upper end of range	Midpoint
COPD	£ 1,482.50	£ 3,182.50	£ 2,332.50

COPD admission costs were calculated using the following tariff codes:

- ★ lower end - average of 'upper respiratory tract condition without critical care' and 'lower respiratory tract condition without critical care'
- ★ upper end - average of 'upper respiratory tract condition with critical care' and 'lower respiratory tract condition with critical care'

Applying these values to the potential admissions avoided figures above, we reached the following potential value of avoided admissions:

Table 14 – Cost value of admissions avoided (respiratory conditions)

Rate of admissions avoided	Value based on lower end	Value based on upper end	Value based on midpoint
30%	£ 1,046,639.58	£ 2,246,833.37	£ 1,646,736.48
40%	£ 1,395,519.44	£ 2,995,777.83	£ 2,195,648.63

Finally, we calculated the potential net savings, assuming the midpoint value of avoided admissions is a reasonable expectation. The table below sets out these savings, based on class/group sizes of 15 and 20.

Table 15 – Net savings (respiratory conditions)

Rate of admissions avoided	Value of avoided admissions (midpoint)	Cost of service delivery (class size 15)	Savings (class size 15)	Cost of service delivery (class size 20)	Savings (class size 20)
30%	£ 1,646,736.48	£ 1,277,382.20	£ 369,354.28	£ 542,962.22	£ 1,103,774.26
40%	£ 2,195,648.63	£ 1,277,382.20	£ 918,266.44	£ 542,962.22	£ 1,652,686.41

4 CONCLUSIONS AND AREAS FOR CONSIDERATION

4.1 Economic evaluation

The data available to date indicates that there is an economic case for investing in exercise maintenance for people with respiratory conditions, in terms of avoidable admissions. The value of those saved admissions would cover the costs of exercise maintenance provision.

The data available in relation to potential savings in cardiac readmissions shows that these alone would not cover the costs of exercise maintenance provision for people with cardiac conditions. However, there is a wealth of evidence relating to other health and quality of life outcomes for cardiac patients participating in cardiac rehabilitation, and other evidence which shows these are largely lost within 6 to 12 months of the rehabilitation programme completing. These have not been economically quantified in this evaluation, but include relative reductions in mortality. We conclude that investment in exercise maintenance for people with cardiac conditions could sustain these benefits for longer periods and therefore generate additional savings for health and social care. However, the data available for this economic assessment did not allow quantification of these.

There is insufficient data to calculate the economic benefit of exercise maintenance for stroke.

4.2 Limitations in data availability

The biggest limitation in conducting the economic analysis was the lack of data on exercise maintenance participation and outcomes in Scotland. To conclusively prove the impact of exercise maintenance, a research and economic modelling project is needed based on real people's participation and outcomes. This would require service providers to collect data in a consistent manner and share it with a central research team. Whilst we understand from the three charities leading the PARCS project that one of the barriers to collecting consistent data is the short term nature of the funding for exercise maintenance programmes (and therefore the relatively low priority of collecting data in such a context), the lack of data is one of the factors contributing to the short term funding: a conclusive economic case (underpinned by local data) would strengthen the ability to secure longer term funding.

Areas for consideration:

- ★ agree (across all service providers) a consistent data set and protocols for collection, storage and sharing
- ★ once the data set is in place, consider commissioning a health economics team to conclusively assess the economic case for exercise maintenance across all three condition groups



PARCS PROJECT - ANALYSIS OF GREATER GLASGOW AND CLYDE PULMONARY REHABILITATION REFERRALS FINAL REPORT

August 2014

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1 INTRODUCTION AND METHOD

One of the key issues identified by the PARCS project is the lack of consistent data about referrals to and participation in exercise maintenance in Scotland. This is an obstacle to understanding more about uptake and adherence, and thus to:

- ★ identifying gaps in provision and obstacles to participation
- ★ designing targeted approaches to improving uptake/adherence
- ★ developing robust business cases for future provision

Through the PARCS scoping exercise, it was identified that NHS Greater Glasgow and Clyde held data on referrals from Pulmonary Rehabilitation (PR) into exercise maintenance across the health board region. NHS Greater Glasgow and Clyde agreed to provide our team with access to the anonymised data, to enable an analysis of referral patterns. This would provide additional data for the wider PARCS project and also inform our assumptions in assessing the economic case for exercise maintenance.

1.1 Method

NHS Greater Glasgow and Clyde holds paper records of all individuals participating in PR. We conducted a quantitative analysis of the anonymised PR records of 578 patients who had successfully completed pulmonary rehabilitation in 2012. These records were reviewed to:

- ★ extract key data from anonymised records of patients referred to exercise maintenance
- ★ produce a spreadsheet of this data, based on a format agreed with PARCS team and PR team
- ★ collate key demographic and condition data for those referred to exercise maintenance, including:
 - the referral pathway to PR
 - how long it took between patients being referred to PR and receiving their first assessment
 - where PR classes were held
 - age of patients completing PR
 - how long it takes patients to complete PR once they started
 - number and proportion of patients referred to Vitality (exercise maintenance programme for people with a variety of long term conditions) or Live Active (health behaviour change GP referral scheme) for support with exercise maintenance
 - where Vitality classes were held
 - reasons patients were not referred to exercise maintenance

Not all of this data is presented in this report, but was provided to the PARCS project and NHS Greater Glasgow and Clyde for their ongoing use. For the purposes of this report, we have presented key findings about numbers and demographics of patients being referred to exercise maintenance, reasons for non-referral and the relationship between deprivation and uptake.

1.2 Acknowledgements

Our sincere thanks to the staff from NHS Greater Glasgow and Clyde, based at Gartnavel General Hospital, who provided access to the pulmonary rehabilitation records and support during the data extraction process. This report would not have been possible without this access and support.

2 FINDINGS

2.1 Referral to exercise maintenance

58.1% (338) of patients were referred to exercise maintenance following successful completion of their PR programme (see Table 1). Of those who were referred to exercise maintenance classes, 97.6% (330) were referred to Vitality and just 2.4% (8) were referred to Live Active. Patients referred to Live Active included those who were more active and able; this offered them a wider option of exercise choice.

Table 1 – Referral to exercise maintenance and gender split

	Number	Proportion
Patients completing pulmonary rehabilitation	578	-
Patients referred to exercise maintenance	338	58.5%
Patients not referred to exercise maintenance	239	41.3%
Patients whose referral status is unknown	1	0.2%
Patients referred to Vitality	330	97.6%
Patients referred to Live Active	8	2.4%
Males completing pulmonary rehabilitation	309	53.5%
Males referred to exercise maintenance	175	48.2%
Female completing pulmonary rehabilitation	309	53.5%
Females referred to exercise maintenance	163	51.5%

Of all the patients successfully completing pulmonary rehabilitation in 2012, 53.5% were female and 46.5% were male. For those who were referred to exercise maintenance classes after completing their rehab, 51.8% were female and 48.2% were male. This suggests that there are broadly similar levels of males and females both completing pulmonary rehabilitation and being referred to exercise maintenance.

2.1.1 Age profile

The average age of patients completing PR was 69 years old. Whilst ages ranged from 33 to 89, the majority were aged between 60 and 69 (34.7%, 200) and 70 and 79 (37.7%, 217).

The age profile of those who were referred on to exercise maintenance was broadly similar, with a slightly higher proportion of those aged 60-69 being referred (41.2%, 139), and a slightly lower proportion of older individuals aged 70+ being referred.

2.2 Reasons for non-referral to exercise maintenance

41.3% of patients were not referred to exercise maintenance. The reason for not referring the patient was not always provided, however the most common reason cited was because the patient

did not want to attend. In many instances they indicated that they would continue a home-based exercise regime instead, though this was not always documented.

In addition, in many cases, the health care professional did not refer a patient to exercise maintenance because of the patient's poor condition. This ranged from patients who were affected by debilitating chest infections, to those who were waiting for surgery, and in some instances the illness related to co-morbidities rather than pulmonary conditions.

In some instances patients stopped coming to PR classes and health care professionals faced difficulties in contacting patients, meaning that there was no opportunity to refer patients to exercise maintenance.

The primary reasons that patients were not referred to exercise maintenance are outlined in Table 2 below.

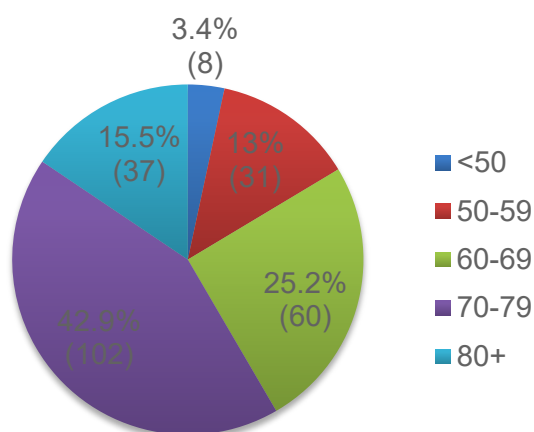
Table 2 – Reasons for not referring patients to exercise maintenance classes (n=239)

Reason for non-referral	Frequency	Proportion of those not-referred
Patient declined to attend exercise maintenance	86	36%
Poor health/worsening condition	52	21.8%
Unable to contact patient	24	10%
Patient already doing exercises at home/in the community	12	5%
Physical activity levels beyond vitality classes	10	4.2%
Work commitments	5	2.1%
Patient doesn't feel a benefit from PR exercises	4	1.7%
No classes available in the patient's area	3	1.3%
Infrequent attendance at Pulmonary Rehab	3	1.3%
Travel/Transport	2	0.8%
Patient has since relocated	2	0.8%
Family commitments	2	0.8%
Referred to exercise maintenance programme through GP practice	2	0.8%
No reason provided	32	13.4%

2.3 Age and referral

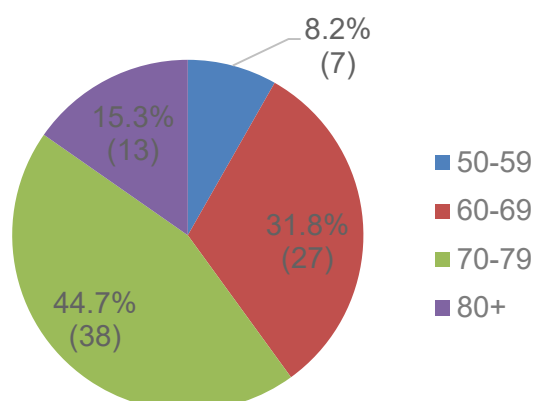
The age breakdown of patients who were not referred to exercise maintenance classes is illustrated in the figure below:

Figure 1 – Age range of participants not referred to exercise maintenance



As shown in Table 2, 36% of those were not referred to exercise maintenance had declined referral. Figure 2 gives the age range of those patients who chose not to be referred:

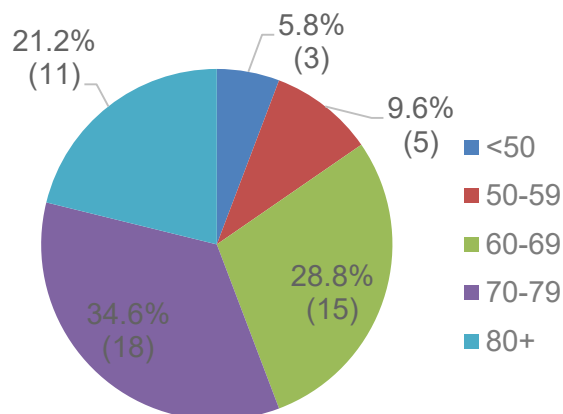
Figure 2 – Age range of patients declining to attend exercise maintenance (n=85)



None of the patients who declined referrals to exercise maintenance were aged under 50. The figure below demonstrates the profile of those declining exercise maintenance was similar to the profile of those referred, although a smaller proportion of individuals aged 50-59 declined. This may suggest that younger individuals are less likely to decline classes.

Poor health/worsening condition was another common reason for non-referral and Figure 3 demonstrates the breakdown of this across the age ranges:

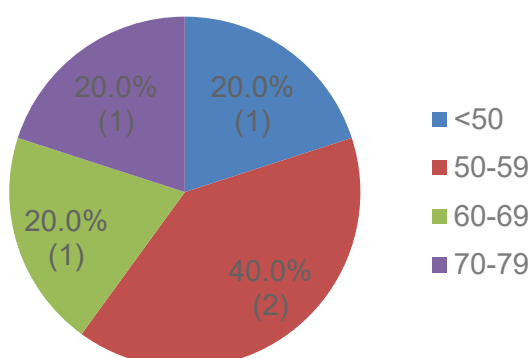
Figure 3 – Age range of patients not referred to exercise maintenance due to poor health/worsening condition (n=52)



As might be expected, the proportion of patients aged 80+ who cited poor health/worsening condition (21.2%, 11) was disproportionately higher than in other age groups. In contrast, few patients under 60 cited poor health as a reason for not attending exercise maintenance.

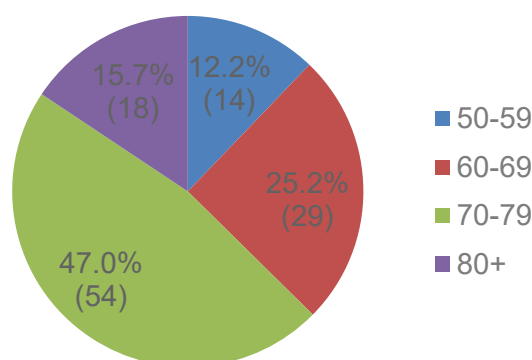
All patients who said they couldn't attend exercise maintenance due to family commitments were aged 80+. Interestingly, those who said they couldn't attend due to work commitments came from a range of ages, including one patient who was in their 70s, as demonstrated in Figure 4 below:

Figure 4 – Age range of patients not referred due to work commitments (n=5)



In some instances, health care professionals recorded whether patients were planning to, or were already, conducting home-based exercises for exercise maintenance (see Figure 5). This was not recorded uniformly across all patient records, but in the records of 48.1% (115) of patients who were not referred to exercise maintenance, health care professionals noted that they either intended to exercise at home, or were already doing so.

Figure 5 – Proportion of patients not taking up exercise maintenance who continued home-based exercise by age range (n=115)



There were no instances where health care professionals had recorded that individuals aged less than 50 were continuing home-based exercises.

2.4 Deprivation

Patients' postcodes were analysed to identify which data zone each patient lived within. The data zone is the key small-area statistical geography in Scotland. By identifying the appropriate data zone for each patient completing PR it is possible to determine how deprived an area they live in, as defined by the Scottish Index of Multiple Deprivation (SIMD). This data was used to calculate the number and proportion of patients who were from the most deprived areas (15% most deprived data zones) and compared with the data from patients who were not from the most deprived areas (ie those who lived within the remaining 85% of data zones). This is presented in Table 3 below:

Table 3 – Deprivation – based on patients' home addresses

	Number	Proportion
Patients from most deprived areas completing PR	203	35.1%
Patients from other parts of the region completing PR	375	64.9%
Patients from most deprived areas who were referred to exercise maintenance	116	57.1%
Patients from other parts of the region who were referred to exercise maintenance	222	59.2%
Patients from most deprived areas who declined exercise maintenance	33	16.3%
Patients from other parts of the region who declined	53	14.1%

exercise maintenance

35.1% (203) of those who successfully completed pulmonary rehabilitation came from the participants living in areas amongst the most deprived in Scotland. There was very little difference in the proportions of patients from deprived areas (57.1%, 116) and those from all other areas (59.2%, 222) who were referred to exercise maintenance. The proportion (16.3%, 33) of those from the most deprived areas who declined exercise maintenance was only slightly greater, compared to those from all other areas (14.1%, 53). Importantly, the data indicates that deprivation does not impact on referral to exercise maintenance or the rate at which patients decline referrals. However the lower proportion of people from deprived areas who then go on to complete maintenance programmes warrants further investigation. This potentially reflects the availability of locally-based exercise maintenance provision within these areas.

3 KEY MESSAGES

The most striking message emerging from this data analysis is the proportionately similar levels of patients from deprived areas that accept and decline a referral to exercise maintenance, compared with the rest of the population.

Based on our own previous research experience and the well-documented public health challenges experienced in the region, we would have expected to see lower uptake rates amongst patients from the most deprived areas.

We conclude that deprivation does not appear to be a barrier to taking up exercise maintenance in this region, and that this may be as a result of NHS Greater Glasgow and Clyde's and Glasgow Life's commitment to locating pulmonary rehabilitation and exercise maintenance services in a range of neighbourhoods including the most deprived: if it's on the doorstep, people are more likely to use service.

The findings from the analysis Greater Glasgow and Clyde's pulmonary rehabilitation referral data also reinforce a specific finding and conclusion, from the PARCS qualitative evaluation. This identified the importance of having 'safety nets' in place – something to ensure that there is a process of follow up in place, which can identify and re-engage people who have fallen out of the standard pathway or disengaged after the initial referral. The analysis of pulmonary rehabilitation data has demonstrated that a significant proportion of people are not referred because the circumstances are not right for them at that time (eg other commitments, poor health). If a safety net were in place, these people would be given the opportunity to re-engage at a later date, when their circumstances enabled them to do so.