PARCS Project Summary Report – October 2014

Chest Heart & Stroke Scotland

British Heart Foundation SCOTLAND

British Lung Foundation Scotland

The PARCS project

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

Summary Report

CONTENTS

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.

ACKNOWLEDGEMENTS

The PARCS Management Group (CHSS, BHF Scotland and BLF Scotland) would like to thank the following groups and individuals for their sterling assistance with the project:

Sarah Florida-James, PARCS Project Manager at CHSS, and Richard Forsyth, PARCS Project Manager at BHF Scotland, authors of this report.

PARCS Advisory Group, PARCS Advisory Sub-Group and PARCS Service User Advisory Group for their expertise and support throughout the project and in relation to key issues.

Glasgow Caledonian University: Professor Frederike van Wijck, Professor Dawn Skelton, Dr Morag Thow and Margaret Brownlee for giving their expertise and steer at the inception of the project, and Professor van Wijck throughout the project in her roles within the advisory group and advisory sub-group.

Other academic institutions, clinical and professional leads, working groups on physical activity, long term conditions and exercise after stroke for sharing their knowledge and expertise in relation to their research and work.

Staff of the three lead charities and other third sector organisations, NHS staff, Leisure Services staff, service users and other people in the community who contributed to the project, in terms of completing surveys and giving their time, experience and expertise.

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 2014 Ten Year Implementation Plan *A more active Scotland: building a legacy from the Commonwealth Games.*

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.

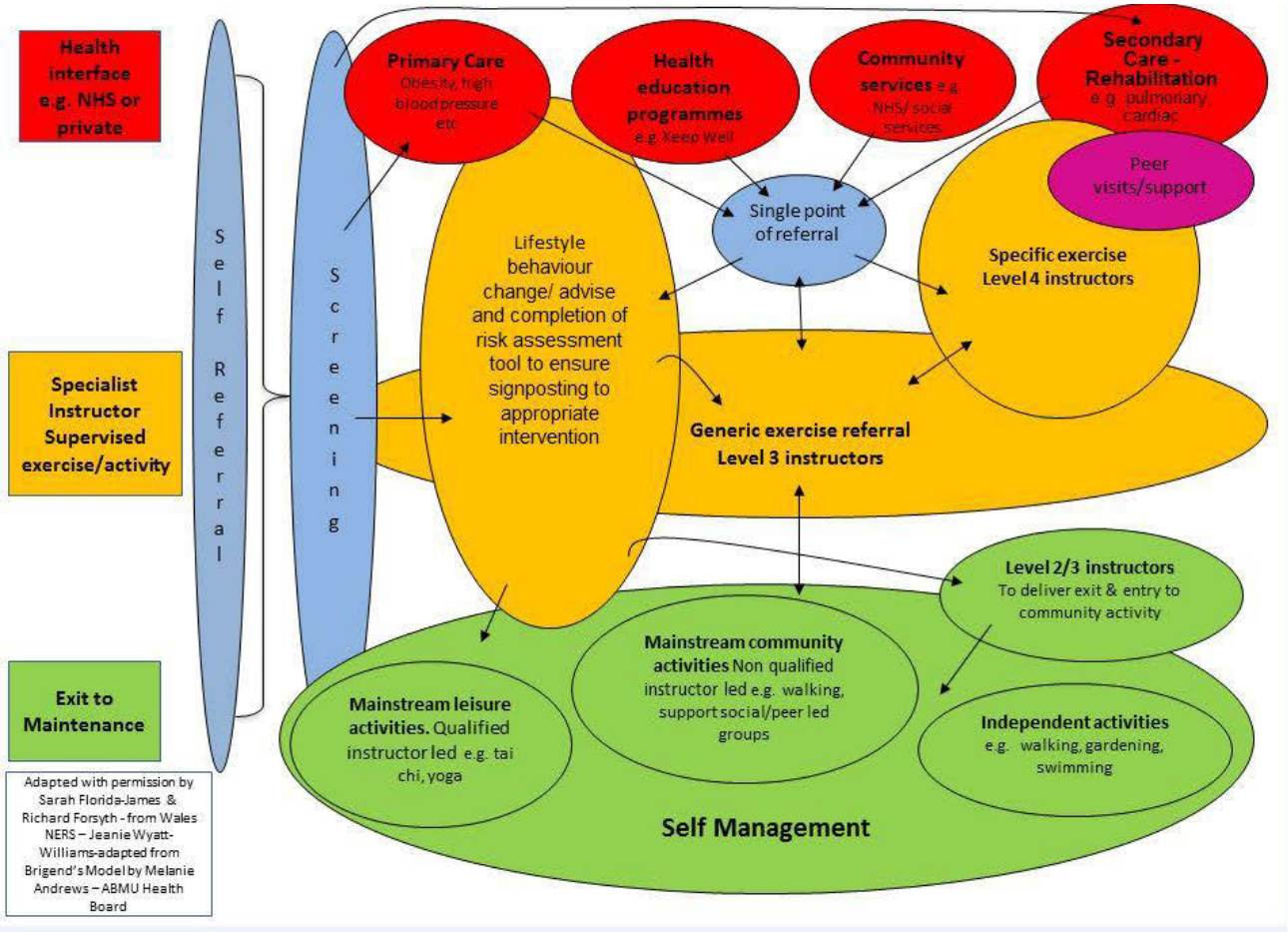
Recommendation 6: Audit and evaluation

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 heath 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)

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 a 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 (BHF) 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.