

### The PARCS project

<u>Person-centred</u> <u>Activities</u> for people with <u>Respiratory</u>, <u>Cardiac</u> and <u>Stroke</u> 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

### <u>Person-centred Activities for people with Respiratory, Cardiac and Stroke</u> 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 (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

#### 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, cares, service providers and third party sectors.

#### 2020 Vision Route Map

 integrated health and social care, a focus on prevention, anticipation and supported selfmanagement.

#### 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 activity<sup>1</sup> 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'.

#### <u>A more active Scotland: building a legacy from the Commonwealth Games – Ten-year</u> 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 page12.

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

<sup>&</sup>lt;sup>1</sup> '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) <u>http://www.scotland.gov.uk/Resource/Doc/47032/0017726.pdf</u>). '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 do at least 150 minutes of moderate-intensity aerobic physical activity throughout the week or do at least 160 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 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); 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/

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, semirural 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-coordinator appears to addresses 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 coordinator 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.

### <u>Results:</u> 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 many 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.

<u>Results/Outcomes:</u> 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

<u>Methods</u>: 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:

<u>Surveys</u>: 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).

<u>Meetings</u>: 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-toface 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 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 responses 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 thorough 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 is 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 4<sup>2</sup> instructor qualifications pathways and evidence based exercise

<sup>&</sup>lt;sup>2</sup> **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. <u>http://www.exerciseregister.org/resources/exercise-referral</u>

Exercise should be specifically adapted to meet the meets 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 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 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 polices
- 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 polices.

#### 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:

- 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


#### 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 targets** <sup>3</sup>**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.



<sup>&</sup>lt;sup>3</sup> 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) <u>http://www.scotland.gov.uk/Resource/Doc/47032/0017726.pdf</u>). '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 do at least 75 minutes of vigorous-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 obesity); bone health and osteoporosis; breast and colon cancer and prevention 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, depr

#### Comparison of the amount of physical activity per week of those attending CHHSaffiliated 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 selfmanagement 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. Lifechanging"

"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)<sup>4,5</sup> in the PARCS economic report (see Section E).

Admitted patients as % of total Mean bed days per Mean admissi						
Condition group	Admissions	Patients	prevalence	Total bed days	admission	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

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

Self-reported data on admissions from the 221 PARCS survey respondents attending a CHSSaffiliated 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

<sup>&</sup>lt;sup>4</sup> Cardiac and Stroke data taken from ISD Table: Number of bed days, admissions and patients for selected conditions, NHS Scotland, Calendar Year 2011.

<sup>&</sup>lt;sup>5</sup> 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 or 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 <u>www.paha.org.uk/CaseStudy/silver-deal-active</u>
- 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 <a href="http://www.nisg.scot.nhs.uk/currently-supporting/sci-gateway">http://www.nisg.scot.nhs.uk/currently-supporting/sci-gateway</a>

# 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 <a href="http://worldwalking.org/">http://worldwalking.org/</a>

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. <u>http://www.sctt.scot.nhs.uk/living/ https://portal.livingitup.org.uk/</u>
- 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 <u>ALISS Engine</u> 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 selfmanagement 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
   <u>http://www.sctt.scot.nhs.uk/archive/health/remote-pulmonary-rehabilitation/</u>
- 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 <u>http://www.chss.org.uk/education\_and\_training/heart\_e.php</u>

# 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.

# <u>Results:</u> 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 many 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, semirural, 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 coordinator 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 in 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

<u>Method:</u> The PARCS Advisory Sub group consisted of NHS: MCN manager, HCPphysiotherapists, 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



Proposed national framework for the transition from health to community based activity 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 4<sup>6</sup>) 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 coordinators, 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)<sup>7</sup>. 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

<sup>6</sup> 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 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. <a href=http://www.exercise

<sup>&</sup>lt;sup>7</sup> 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 (<u>http://www.exerciseregister.org</u>)

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 heath 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 delver 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

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- 2. http://nos.ukces.org.uk/Pages/index.aspx;
- http://nos.ukces.org.uk/Pages/results.aspx?u=http%3A%2F%2Fnos%2Eukces%2Eorg%2 Euk&k=exercise%20referral#Default=%7B%22k%22%3A%22exercise%20referral%22%2 C%22r%22%3A%5B%7B%22n%22%3A%22RefinableString00%22%2C%22t%22%3A% 5B%22%5C%22%C7%82%C7%82536b696c6c73416374697665%5C%22%22%5D%2C %220%22%3A%22and%22%2C%22k%22%3Afalse%2C%22m%22%3Anull%7D%5D%7 Dhttp://www.exerciseregister.org/resources/exercise-referral

# **OBJECTIVE 7**

Address issue of instructor training and make recommendations for SGHD

<u>Method:</u> 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

<u>Methods</u>: 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
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- 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 <u>http://whqlibdoc.who.int/euro/-1993/EUR\_ICP\_CVD\_125.pdf</u>
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- 8) <u>http://www.exerciseregister.org/resources/exercise-referral</u>
- 9) 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
Objective 1 Review the evidence in relation to the project	Identify of key literature – academic/ professional guidelines and strategies	<ul> <li>Key strategies</li> <li>NHS Quality Strategy</li> <li>2020 Vision Route Map</li> <li>Heart Disease Improvement Plan</li> <li>Stroke Improvement Plan</li> <li>Key evidence</li> <li>LTC have a high prevalence, with almost half the Scottish population effected, cardiovascular and respiratory diseases are amongst the most prominent</li> <li>Cardiovascular and respiratory diseases have place a huge economic burden on NHS services</li> <li>Physical activity is of benefit for individuals with cardiac, stroke and respiratory conditions (COPD)</li> <li>Individuals with cardiac, respiratory (COPD) and stroke in Scotland are well below PA targets</li> <li>Cardiac and pulmonary rehabilitation are clinically effective and cost effective</li> <li>Individuals with these conditions largely do not maintain physical activity after NHS rehabilitation</li> <li>Global strategies, national strategies and clinical guidelines advocate ongoing/long term PA/ exercise for individuals with these conditions</li> <li>Cardiac and pulmonary rehabilitation are clinically and cost effective</li> <li>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</li> <li>Exercise after stroke is beneficial at improving function</li> <li>Exercise after stroke services in Scotland – lack of current service provision and service development in needed to ensure equity</li> </ul>

		<ul> <li>Optimal PA/ exercise maintenance interventions are likely to include exercise training, with self management and behaviour change supported by professionals and peers</li> <li>Barriers to exercise maintenance: <ul> <li>Access – availability of groups and transport</li> <li>Motivation</li> </ul> </li> <li>Benefits of exercise maintenance: <ul> <li>Advocated by service users</li> <li>Social support influences PA and increases motivation to exercise</li> </ul> </li> <li>Enablers <ul> <li>Professional support</li> <li>Social interaction and peer support</li> <li>Follow up/ongoing communication between individuals/service users and professionals</li> </ul> </li> </ul>
Objective 2	SURVEYS	SERVICE DELIVERY
Produce overview profiles for 14 Health Board regions across Scotland in relation to exercise maintenance/ physical activity opportunities	Managed Clinical Networks $n = 11/14$ responded to the initial survey with 13/14 responding to the draft overview profiles HCPs $n = 274$ 'hits' GPs $n = 146$ 'hits' Service Users $n = 221$ responses Service Providers $n =$ 40 'hits' MEETINGS with service providers/ stakeholders in service provision $n = 63$ HCP $- n = 42$ (35 face to face, 7 telecoms) Leisure services $n = 20$ (face to face, 7 telecoms)	<ul> <li>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.</li> <li>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.</li> <li>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 <ol> <li>Health Boards regions that had no instructors trained at a level able to deliver (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.</li> </ol> </li> <li>Collaborative partnership working and working groups involving all stakeholders for service delivery and governance appear effective.</li> </ul>

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	Local Authority n= 1 MEETINGS with	PATHWAY JOURNEY
	service users /potential	Effective referral and signposting are key- barriers to
	service users total with	this are lack of knowledge from referrers e.g. GPs and
	LTC n= 33 (included	HCPs and/or lack of availability of services to refer to.
	areas of social	No single point of referral - Majority have no single point
	deprivation and ethnic minority group)	of referral across the Health Board (13 out of 14). 6 out of
	minonty group/	14 have a regional (CHP, Leisure or Local Authority)
		referral point. 4 Health Boards have a referral point or co-
	<b>IDENTIFICATION &amp;</b>	ordinator in one or some geographical locations only areas
	EXTRAPOLATION OF	of the Health Board region lacking this. These Boards
	EXISTING DATA	cover large geographical area and are in rural/semi rural
	Post Pulmonary Rehab	regions. This importance of the referral point is in relates to the key issue of lack of knowledge of services by the
	Data x 4 regions	referrer. Having a referral point/co-coordinator appears
	Data X Trogiono	effective in addressing this
	Pilots of community	
	exercise for stroke	<b>Inconsistency in pathways</b> –Differences in pathways to
	programmes x 2	EM both within and between Health Board regions.
	regions	Cardiac and exercise referral appear as most well established/available, stroke least.
	Academic research	
	funded by CHSS into	Importance of clinical rehabilitation overall, and the
	optimising engagement	delivery of this in the community, particularly Pulmonary
	into Physical Activity	and Cardiac Rehabilitation
	after Stroke x 1 region	ECONOMICS/IMPACT
	Leisure services	
	evaluations x 4 regions	Data collection inconsistent – in terms of collection,
		collation and the role or service undertaking this. There are
	Person centred groups	often inconsistencies within Health Board regions as well
	evaluations in conjunction with HCP	as between regions.
	or Academic institutions	Funding for instructor training - large variation -
	x 2 regions	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.
		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.
		Person Centred 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
		Conditiono
l		

		<ul> <li>Exercise group linked to improvement in condition: 76% (n=165) report feeling their condition has improved since joining the exercise group</li> <li>Benefits of exercise class: motivation to exercise, remain more active and social support</li> <li>Potential link to reduced hospital admissions: 74% (n=165) of service users reported having no hospital admission in the last year</li> </ul>
Objective 3 Identify relevant innovations/ technology for exercise maintenance/ physical activity opportunities	Meetings as detailed above, internet searches and networking, attendance at relevant conferences/launches throughout the duration of the project	Telehealth         Podcasts for delivery of home based exercise for long term conditions, academic research in partnership with Lanarkshire MCN. Protocol for COPD underway         Telehealth for Pulmonary rehabilitation with a relationship to post rehab physical activity         Telehealth option for delivery of Cardiac Rehabilitation (Activate your Heart         Living It Up Project – connections to information, products & services in the community         ALISS – resource with information and services for LTC         Active Scotland – resource of activities and activity venues throughout Scotland         CHSS – Self management for COPD and asthma - My lungs, My life and self management for stroke - online service user resources         NHS inform in deprived area         Sound Doctor – England – Resource for those with LTC         Innovations         To address health inequalities, access and knowledge of services identified
Objective 4 Identification of resource need, service user and/or	Identification of resource need - based on findings of project and discussion with service user advisory group	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.
service		1) A web-based resource, with sustained funding
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provider	Identification of service provider resource – based on the data/meetings undertaken from PARCS CHSS and linking with PARCS BHF and BLF work	<ul> <li>for this, which acts as a repository of information with a person to facilitate and maintain/update this. Although this many not be suitable for all.</li> <li><b>2)</b> 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.</li> <li>Production of service provider resource for LTC PA in the community – for action by BHF as part of project</li> </ul>
Objective 5		
i) <b>Identify good</b> <b>models of</b> <b>practice</b> in differing geographical areas of Scotland – urban, semi- rural, rural	Synthesis of data surveys and meetings and visits as detailed in objective 2	Diagrammatic representation of <b>good practice models</b> <b>produced</b> for provided to BHF for adaption by BHF project lead in the PARCS resource
ii) <b>Identify</b> <b>critical</b> <b>success</b> <b>factors</b> in relation to NHS quality strategy	ii) Synthesis of data surveys and meetings and visits as detailed in objective 1	<b>Critical success factors produced</b> in line with NHS strategy provided to BHF for adaption by BHF project lead in the PARCS resource
iii) <b>Person</b> <b>centred</b> <b>pathway</b> to maintenance in the community for LTC, based on user need	Initial service user focus group n= 8 to develop pathway Further focus group n=	Work on <b>service user pathway provided</b> to British Lung Foundation strand prior to their qualitative PARCS work
	12 to feedback After BLF qualitative work complete and pathway adapted discussion with service user advisory group on pathway and their recommendations adapted	Finalised pathway provided to BHF for use/ adaption by BHF project lead in the PARCS resource

Additional Objectives/Outcomes as a result of from key issues identified throughout the duration of the project.

OVERVIEW OF KEY OBJECTIVES	METHODS	OUTCOME/RESULTS
Objective 6 Produce an ideal framework for transition from health to community based activity in the prevention and management of chronic conditions framework for delivery	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: Identify key models of delivery structures/ framework and discuss adaption for the Scottish context, based on models out with Scotland and PARCS findings	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
Objective 7 Address issue of instructor training and reach conclusions and recommendations for SGHD	Identify of issues economic factors impacting on instructor training- cost of course for each specific condition 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	Consensus reached on recommending to SGHD a standardised national approach to specialist instructor training

To improve knowledge of current service delivery of exercise maintenance in Scotland – amongst various stakeholders	Promotion of PARCS project Surveys as detailed above Presentations/workshops by PARCS project manager to: clinicians – respiratory and cardiac, other stakeholders - physical activity and Leisure	<ul> <li>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</li> <li>Various stakeholders have greater awareness of issues and good models of practice – verified by feedback from working groups and individuals</li> <li>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</li> </ul>
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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
Objective 1 Review the evidence in relation to the project	Identify of key literature – academic/ professional guidelines and strategies (for	<ul> <li>Key strategies</li> <li>NHS Quality Strategy</li> <li>2020 Vision Route Map</li> <li>Heart Disease and Stroke Disease Improvement Plans</li> <li>Key evidence</li> <li>LTC have a high prevalence, with almost half the Scottish population effected, cardiovascular and respiratory diseases are amongst the most prominent</li> <li>Cardiovascular and respiratory diseases have place a huge economic burden on NHS services</li> <li>Physical Activity is of benefit for individuals with cardiac, stroke and respiratory conditions (COPD)</li> <li>Individuals with cardiac, respiratory (COPD) and stroke in Scotland are well below PA targets</li> <li>Cardiac and pulmonary rehabilitation are clinically effective and cost effective</li> <li>Individuals with these conditions largely do not maintain physical activity after NHS rehabilitation</li> <li>Global strategies, national strategies and clinical guidelines advocate ongoing/long term PA/ exercise for individuals with these conditions</li> <li>Cardiac and pulmonary rehabilitation are clinically and cost effective</li> <li>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</li> <li>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</li> </ul>

Strong evidence that exercise after stroke is beneficial at improving function Exercise after stroke services in Scotland – lack of current service provision and service development in needed to ensure equity
Optimal PA/ exercise maintenance interventions are likely to include exercise training, with self management and behaviour change supported by professionals and peers
Barriers to exercise maintenance: • Access – availability of groups and transport • Motivation
<ul> <li>Benefits of exercise maintenance:         <ul> <li>Advocated by service users</li> <li>Social support influences PA and increases motivation to exercise</li> </ul> </li> </ul>
<ul> <li>Enablers         <ul> <li>Professional support</li> <li>Social interaction and peer support</li> <li>Follow up/ongoing communication between individuals/service users and professionals</li> </ul> </li> </ul>

## **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
<ul> <li>LTC have a high and increasing prevalence in Scotland, particularly in the elderly</li> </ul>
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
<ul> <li>LTC have a major impact on personal and social health well being, as well as wider societal impact</li> </ul>
LTC, in particular cardiovascular disease and chronic obstructive pulmonary disease, have a major impact on costs for health service provision
<ul> <li>Physical activity positively contributes to the prevention and management of over 20 chronic conditions, including CHD</li> </ul>

## 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 <sup>(9)</sup>

- 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 <sup>(1)</sup>

 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. <sup>(12)</sup>
- 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 <sup>(14)</sup>

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 recommend 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
  - o has a positive effect on functional capacity
  - $\circ$   $\;$  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 slow 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 trails (RCTs) and concluded that pulmonary rehabilitation was effective at reliving 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
  - o improves quality of life
  - improves exercise capacity
  - reduced hospital admissions
  - o reduced hospital days per person
  - o 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
Integrated disease	Cochrane systematic review	1 ++
management interventions for patients with chronic obstructive	26 RCTs N=2997	High to moderate methodologically quality
pulmonary disease (49)	Mild, moderate and severe 3- 24 months follow up	quanty
	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,	
	Including exercise, self management, education, follow up	
	IDM exercise was most dominant component (13 studies), followed by Self management (5 studies)	
	Studies in primary, secondary and tertiary care	
Supervised exercise programs after PR in	One systematic review	1- (Meta analyses,
COPD (46)	7 RCTs	systematic
appear to be     more effective	N=619	reviews with a high risk of bias)
than usual care	Moderate to severe COPD	,
for preserving exercise capacity in the medium	6 and 12 month follow up	
term (6 months)	Supervised exercise training	
Longer term     benefit is     inconclusive due     to lack of     evidence	Interventions: comparing post-PR maintenance with post-PR usual care, providing the initial and maintenance programs included supervised	
There was no	exercise training	
difference for quality of life	Usual care:	
	Maintenance: Outpatient-, community-, or home-based maintenance that included directly supervised exercise after PR with or without education and	

	psychological	
	support	
	Lack of blinding in some studies	
	Some studies potential for bias	
	(Beaucamp et al 2013)	
Effect on exercise training on physical	One systematic review :	1+ (Well conducted
activity levels in COPD (50)	7 studies, 2 RCTs, 5 single interventions	meta-analyses, systematic reviews,
	N=472	or RCTs with a low
Overall, there was a significant positive effect	Moderate to severe COPD	risk of bias)
on physical activity after supervised exercise	Interventions: Supervised exercise training with a	
activity- significant but small increase	duration range from 6 weeks to 6 months	
	Control groups, where present, included a general exercise programme, counselling and pedometer	
	in addition to exercise	
	Quality of studies assessed using recognised scales/tools	

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 selfmanagement 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

- $\circ$  Tailored supervised exercise from professionals with knowledge of COPD
- $\circ$   $\,$  Social interaction and peer support  $\,$
- Ongoing communication and support across the wholes 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 <sup>(58-62)</sup>

## **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 group 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. 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 as 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 <sup>(24)</sup>

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 was 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 quantative 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

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## <u>APPENDIX 3 - PARCS Project Aims and Alignment to Government Strategies and Standards and Clinical Guidelines</u> (Compiled near commencement of project in January 2013)

A :	Strategy, Standards and Guideline				
Aim	this relates to				
1) To assist the	NHS Quality Strategy 2010				
Scottish	Person centred safe, effective, efficient, equitable and timely				
Government to deliver the best quality healthcare	<b>THE NHS Quality Outcomes Framework 2011/12</b> – Domain 2, Enhancing quality of life for people with long term conditions				
to the people of Scotland	2.1 Ensuring people feel supported in managing their condition				
	<b>Better Health Better Care Action Plan</b> 3.1 <i>Improving Quality</i>				
	<ul> <li>Spread best practice in care for people with long term conditions</li> <li>Bring a more systematic approach to clinical effectiveness</li> <li>3.4 Effectiveness, evidence based care</li> </ul>				
	<b>Delivery Framework for Adult Rehabilitation Plan</b> 4. Comprehensive evidence based services – consistent with best practice				
2) To contribute to	NHS Quality Strategy 2010 – Person centred				
the achievement of the Quality	NICE- CG138 – Patient experience in adult NHS services				
Ambitions by:	1.3 Tailoring health care service needs for each patient – listen to patient views and preferences				
a) developing a	1.5 Enabling patients to actively participate in their care				
service based on user-articulated need and	The 10 National Standards for Community Engagement				
preference (Person-centred)	Scottish Health Council – Participation Standard Healthcare Improvement Scotland – User involvement and Person Centeredness				
	Heart and Stroke Action Plan				
	4.33 Improving patient experience of cardiac rehabilitation-MCNs encourage heart manual to ensure people receive structured information & mentoring/ 'braveheart'				
	Better Health Better Care Action Plan				
	1.1 Towards a mutual NHS – embedded patient experience information				
	1.3 <i>Delivering Together</i> – embedding patient experience data in NHS targets				

	3.1 Enable patients to be partners in their care				
	<b>Delivery Framework for Adult Rehabilitation Plan</b> 3. Enablement and self managed care – volunteer and specialist interest support groups involved in designing, evaluating and delivering services. Use of a buddy system explored.				
2) To contribute to	NHS Quality Strategy 2010 – Effective				
the achievement of the Quality Ambitions by:	Heart Disease and Stroke Care Action Plan				
b) increasing focus	3.7 Promoting healthy lifestyles – all GPs and practice nurses to undertake training on brief intervention to help support lifestyle changes & a health				
on preventative services and	promoting health service				
interventions (Effective)	3.34 Flexible and culturally sensitive programmes				
	4.24 Developing public access to defibrillation				
	4.24 Improving access to cardiac rehabilitation				
	5.1 Improving stoke services				
	5.62 Improve stroke research				
	7.7 Improving HD data collection				
	SIGN 57 – Cardiac Rehab				
	Phase 3 Exercise training/community setting				
	<i>Phase 4</i> Long term follow up in cardiac support group, which involves exercise in a community centre, leisure centre				
	Self help groups should be encouraged and enabled to use the same evidence based approach to cardiac rehabilitation as advocated by professionally led programmes				
	SIGN 108 – Management of Patient' with Stroke or TIA				
	SIGN 118 – Stroke				
	5.6 Moving on after stroke – support and voluntary services				
	5.6.4 Physical activity after stroke – through stroke MCNs work with leisure industry to improve access to exercise and physical training for those with stroke				
	Stroke Quality Standards				
	7. Ongoing Rehabilitation QS2 – active therapy for those with stoke as long				
	as they continue to benefit from it				

	Good Practice Guidelines for Exercise after Stroke
	NICE 101- Chronic Obstructive Airways Disease (COPD)
	Pulmonary rehabilitation for all those who need it
	Tailor the programme to individual needs, and include physical training,
	Hold pulmonary rehabilitation sessions at a practical time in a conveniently located, accessible building to increase concordance
	NICE 108 – Chronic Heart Failure
	Offer a supervised exercise base rehabilitation group for patients with heart failure
	NICE 48 – MI Secondary Prevention
	Patients should be physically active for 20- 30 minutes per day
	The benefit of exercise may be enhanced by tailored advice from a suitably qualified professional
	NHS QIS-Cardiac Heart Disease Clinical Standards 3. <i>Regular HD updates</i> for staff – CPD
	BACPR - Standards and Core Competencies 2012
	Patients and their families should be signposted and encouraged to join local heart support and community exercise and activity groups
3) To develop	Heart Disease and Stroke Care Action Plan
partnership working between	4.45 Improving heart failure services (support)
the statutory and voluntary sectors	5.12 Raise public awareness of stroke – local communication strategy
in order to improve	
the patient experience and achieve optimal	NHS QIS-Cardiac Heart Disease Clinical Standards 1.1 Pt information – available from voluntary sectors
use of resources and value for money	NICE - CG138 – Patient experience in adult NHS services 1.4 Continuity of care and relationships particularly at transition points
	Better Health Better Care Action Plan 1.1 <i>Towards a mutual NHS</i> strengthen collaboration and integrated approach to service improvement

	<ul> <li>1.2 Delivering together - Collaborative contracts within community health partnerships</li> <li>1.3 Co-Operation and Collaboration – MCNs and partnerships with voluntary and community organisations</li> <li>2.4 Tackling Health Inequalities – multi agency approach involving public private and third sectors</li> <li>3.4 Effectiveness - More efficient management of patient journey through the care pathway</li> <li>4.63- MCNs are fully integrated with local and regional planning</li> <li>Delivery Framework for Adult Rehabilitation Plan</li> <li>1. Access – transitions between care better managed and use mainstream leisure facilities</li> <li>2. Local service provision - better links between rehabilitation services and community services</li> <li>3. Comprehensive evidence based services – cater for distinct phases of care &amp; identify models to seamless transitions</li> <li>4. Sustainable multi professional teams – all informed about roles &amp; services, with joint training</li> </ul>
	<ul> <li>5. Capacity – review of staff resource – service redesign and skill mix. Integrated service across health and social care.</li> <li>AHP Delivery Plan</li> <li>3.2. – AHP directors and leads to work in partnership with local third and private sectors to enhance community capacity building and enabling services</li> </ul>
	3.4 – AHPs to improve overall health and wellbeing and include signposting to relevant resources
4)To improve	Heart Disease and Stroke Care Action Plan
quality of life for people with long- term conditions by	6.5 <i>Improving Patient Information – make communication issues a priority</i> <b>HEAT target</b> <i>treatment (9) –</i> reduction in hospital admission bed days for
reducing unscheduled admissions to acute services and	those with COPD, Asthma and CHD
delayed discharge	<b>The NHS Quality Outcomes Framework 2011/12</b> 2.3 Reduce time spent in by people with hospital with long term conditions
	<b>Delivery Framework for Adult Rehabilitation Plan</b> <i>1. Access</i> – rehabilitation services should be accessible to service users
5) People with	Heart Disease and Stroke Care Action Plan
long-term conditions who	3.34 <i>Improving mental health</i> – holistic assessment of physical and mental health needs to improve detection and support
access the services provided will be assisted to:	5.40 <i>Improving rehabilitation and recovery- NHS</i> Boards should work with leisure industries to improve access to exercise training for stroke

r						
	NHS QIS-Cardiac Heart Disease Clinical Standards					
	1.1 Provision of information to patient – self mgt					
a) enjoy enhanced						
physical and	The NHS Quality Outcomes Framework 2011/12					
mental health and	2.2 Improving functional ability for people with long term conditions					
wellbeing	3.3 Improving recovery from stroke					
	Delivery Framework for Adult Rehabilitation Plan					
	2. Local service provision - strong community focus					
5) People with	Heart Disease and Stroke Care Action Plan					
long-term						
conditions who	5.34 <i>Improving early supported discharge</i> – community teams integrated					
access the	and accessible					
services provided						
-	5.39 – consider self referral to AHP services by those recovering from stoke					
will be assisted to:						
	5.40 Improving rehabilitation and recovery Boards should work with leisure					
	industries to improve access to exercise training for stroke					
b) remain more	Better Health Better Care Action Plan					
active and	Fourier brooking down bowiers for provide concerting and include					
	Equity- breaking down barriers for people accessing services					
independent	4.22 all NUS boards abould implement the Heart manual for nations					
through the greater	4.33 – all NHS boards should implement the Heart manual for patient					
support offered	information education and to encourage self management					
	Delivery Framework for Adult Rehabilitation Plan					
	3.Enablement and self management -promote independence and self					
	management					
	management					
	NES - Supporting People to Self Manage					
5) People with	Better Health, Better Care Action Plan-					
long-term						
-	2.2 An Enabling Health service					
conditions who						
access the	Heart Disease and Stroke Care Action Plan					
services provided						
will be assisted to:	4.45 – NHS boards through their cardiac MCNs should work with CHSS to					
	address social isolation through support including meetings, befriending					
	4.34 – NHS board through their cardiac MCNs should adopt a Braveheart					
c) enjoy greater	(Mentoring) approach by Dec 2009					
social engagement						
and reduced social						
isolation						

5) People with	Heart Disease and Stroke Care Action Plan
long-term conditions who access the	5.34 Improving early supported discharge
services provided will be assisted to:	
d) Be enabled to continue living at home or in a	
homely setting	

### APPENDIX 4 – SUMMARY OF PARCS MCN, HCP, GP AND SERVICE USER SURVEYS

#### <u>Green – Key Data/Themes</u>

#### SCOPING PARCS SURVEYS

OVERVIEW OF KEY OBJECTIVES	WORK STRANDS IN RELATION TO OBJECTIVE- SURVEYS	NUMBERS/ REPSONSES	STATUS / PRELIMINARY RESULTS
<b>SCOPING</b>	MCN survey	MCN survey	MCN survey
SCOPING MC Produce overview profiles in relation to 14 Health Board Regions across Scotland in relation to exercise maintenance/ physical activity opportunities		11/14 returns - some incomplete or one clinical area detailed only	<ul> <li>DATA COLLECTION - INCONSISTENT - inconsistency in data collection and collation and the role undertaking this</li> <li>NO SINGLE POINT OF REFERRAL - Majority have no single point of referral across the health board</li> <li>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</li> <li>FUNDING FOR INSTRUCTOR TRAINING - LARGE VARIATION - regional variation</li> <li>SPECIALIST INSTRUTOR TRAINING - LARGE VARIATION - regional variation large regional variation in number and levels of specialist trained instructors</li> </ul>
	HCP (Health Care Professional) survey	HCP survey 274 'hits'	<ul> <li>REFERRAL - GOOD TO LEISURE, POOR TO COMMUNITY SERVICES</li> <li>Majority of HCP DO refer to leisure services 75.6% (n=161)</li> <li>Majority of HCP DO NOT refer to community services 54.5% (n= 111)</li> </ul>

Main reasons for lack of referral – no service provision and lack of knowledge of services
SELF REFERAL 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
<ul> <li>NO SINGLE POINT OF REFERRAL –No single point of referral across the Health Board reported by 79.5% (n=128)</li> </ul>
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)

	1	
		<ul> <li>KEYTHEMES</li> <li>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.</li> <li>Pathway – effective referral and signposting, knowledge of services and importance of clinical rehabilitation – e.g. cardiac &amp; pulmonary rehab and community delivery of rehabilitation.</li> <li>Economics- service funding, cost to service user.</li> <li>(From free text comments- in relation to service provision &amp; access, successes and challenges, in order of prevalence)</li> </ul>
GP survey	GP survey 146 'hits'	<ul> <li>REFERRAL – limited service provision, inability to refer and knowledge of services</li> <li>Referral to exercise maintenance by GPs across Scotland (n= 121)</li> <li>DO refer to exercise maintenance - 52% (n=63)</li> <li>DO NOT refer to exercise maintenance - 48% (n= 58)</li> </ul>
		<ul> <li>in regions with lack of or poor service provision, largely rural, this increases and ranges from 80% -100% DO NOT refer</li> <li>Not able to refer - 56.91% (n=70)</li> <li>GP primary reasons for not referring (Total responses n= 70)</li> <li>no service in the community -56% (n = 39)</li> <li>lack of knowledge of services - 56% (n=31)</li> <li>no service in leisure services - 44% (n=31)</li> </ul>

[]		
		<ul> <li>SERVICE DELIVERY – lack of involvement in collaborative working groups GPs are not members of a collaborative group for exercise maintenance – 89.5% (n=111)</li> <li>KEY THEMES</li> <li>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</li> <li>Pathway – knowledge or lack of knowledge of services and importance of clinical rehabilitation, barriers to referral – systems and processes</li> <li>Economics/Impact – service funding, particularly short term funding and service removal of services due to funding</li> <li>(From free text comments in relation to service provision and access/impact in order of prevalence)</li> </ul>
Leisure services/ Service provider survey	Leisure services 40 'hits'	<ul> <li>SERVICE DELIVERY- exercise referral and LTC are the most available types of classes, followed by cardiac specific, stroke and respiratory specific least available</li> <li>NO SINGLE POINT OF REFERRAL –No single point of referral across the Health Board reported by 79.% (n=23)</li> <li>PATHWAY – established pathways for exercise referral, exercise referral for older adults, exercise referral for LTC, cardiac, respiratory and stroke (in order of prevalence)</li> <li>SERVICE CO-ORDINATOR - low responses, was most reported for exercise referral,</li> </ul>

		exercise referral for older adults, exercise
		referral for LTC
		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
		<b>Pathway</b> – effective referral and signposting, importance of clinical rehabilitation, lack of knowledge of services
		Economics/Impact - service funding
		(From free text comments- in relation to service provision & access, successes and challenges, in order of prevalence)
Service user survey (PARCS - British Lung Foundation to complement with non- engagers and hard to reach)	Service user survey 221 returns (CHSS affiliated groups) Cardiac: n = 143, Respiratory: n = 53, Stroke: n = 25 Or which co – morbidities n = 21	<ul> <li>ATTENDANCE /ADHERENCE HIGH - majority members of exercise group for more than 3 year (56% n=100)</li> <li>PHYSICAL ACTIVITY TARGETS ACHIEVED         <ul> <li>69% (n=124) meet physical activity targets compared to national averages of 15%</li> </ul> </li> <li>EXERCISE GROUP IMPORTANT CONTRIBUTOR TO PHYSICAL ACTIVITY &amp; IMPROVEMENT OF CONDITION - exercise group 2<sup>nd</sup> largest reported type of physical activity after walking &amp; 76% (n=136) report feeling their condition has improved since joining exercise group</li> </ul>
		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,

feel part of a community
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
Comparison with national averages planned – awaiting ISD data set
CLINICAL REHABILITATION, SELF REFERAL 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)

### 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 maintanance classes are available in your region?





**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 – 52.54% 31	
No service is available from leisure services in my region		
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 of exercise maintenance?



Q18. Who are the funding partners for service delivery of exercise maintenance in your region? Please tick any/all that apply.


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.









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









**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







#### 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)













Q2. What types of follow on exercise maintenance classes are available in your region? Please indicate the year established if known.





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?



# 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.







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.









### 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:










# 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
<b>Co – morbidities</b> – classified as those with a combination or 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 are a 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 you 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





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?





# 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: <u>sarah.florida-james@chss.org.uk</u>

# <u>APPENDIX 6 – MEETINGS/FOCUS GROUPS WITH SERVICE USERS AND</u> <u>POTENTIAL SERVICE USERS</u>

# 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

**MOTIVATIORS/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'

#### **MOTIVATIORS/ENABLERS**

**SOCIAL** Social and peer support increases confidence

SUPERVISION/DELIVERY Instructor relationship with group important

#### SEEMLESS 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 advise 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

BOARDTROTIEE	
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
<b>Cardiac Rehabilitation</b> (6) (numbers referred following a heart attack or revascularisation procedure and as a percentage of eligible patients)	831 (79.9%)		
<b>Pulmonary Rehabilitation</b> (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)	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

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

#### SERVICE DELIVERY OF EM

\*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	No. There is a single point of contact and service
Term Conditions to Exercise Maintenance	co-ordinator in each Local Authority/Community
	Health Partnership area North, East & South.

# DATA COLLECTION FOR EM

Data Collector Data Collected	Not Collected	Leisure Services	Commissioned By Third Sector/ Other	NHS – HCP	Other
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	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
of exercise maintenance	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

<u>Cardiac Rehabilitation</u> 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).

<u>Pulmonary Rehabilitation</u> 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).

<u>Stroke Rehabilitation</u> 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.

<u>Cardiac Exercise Maintenance</u> 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.

<u>Respiratory Exercise Maintenance</u>, 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.

<u>Stroke Exercise Maintenance</u>, 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 cheeking 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 r esources ( 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)) (<u>http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html</u>)
- 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: <u>http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification</u>
- 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: <u>http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp</u>
- 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

#### Statistics from other sources (as not collected by ISD)

 Health Improvement Scotland Costing Report – Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) <u>http://www.healthcareimprovementscotland.org/our\_work/longterm\_conditions/copd\_implementation/implementing\_copd\_standar</u> <u>ds.aspx</u>

- 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.
- Register of Exercise Professionals (REPs) is an independent, public register which recognises the qualifications and expertise 9. 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 I 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
<b>Cardiac Rehabilitation</b> (6) (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	153* (44.9%)		
<b>Pulmonary Rehabilitation</b> (7) (estimated total number of patients per year)		199	
<b>Stroke Rehabilitation</b> (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)

participating in community based	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	No. A small number of regions have a service
Term Conditions to Exercise Maintenance	co-ordinator.

#### DATA COLLECTION FOR EM

Data Collector	Not	Leisure	Commissioned By	NHS –	Other
	Collected	Services	Third Sector/	HCP	Private
Data Collected			Other		Provider
Follow up data		No		No	
Cost effectiveness					
		No		No	
Person centred data		One		One	One region
		region		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	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
of exercise maintenance	Some		One			One
	regions		region			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

<u>Cardiac Rehabilitation</u> 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.

<u>Pulmonary Rehabilitation</u> (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)

<u>Cardiac Exercise Maintenance</u> is delivered by Third Sector (CHSS affiliated) delivery in one location, which was initially led by a HCP, now peer led.

<u>**Respiratory Exercise Maintenance**</u> is delivered by Third Sector (CHSS affiliated groups) in two locations in two locations which are peer led.

<u>Stroke Exercise Maintenance</u> 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 cheeking 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.

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

- Source: 2012 mid-year population estimates (National Records of Scotland (NRS)) (<u>http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html</u>)
- 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: <u>http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification</u>
- Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <u>http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp</u>
- 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) <u>http://www.healthcareimprovementscotland.org/our\_work/long\_term\_conditions/copd\_implementation/implementing\_copd\_standa\_rds.aspx</u>

- 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.
- Register of Exercise Professionals (REPs) is an independent, public register which recognises the gualifications and expertise q 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 I 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) Pulmonary Rehabilitation (7) (estimated total number of	320 (97.6%)	270	
patients per year)		210	
<b>Stroke Rehabilitation</b> 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	No. Some regions have a regional point of contact				
Term Conditions to Exercise Maintenance	/referral or service co-ordinator				

# DATA COLLECTION OF EM

Data Collected	Not	Leisure	Commissioned		Other:
Data Collector	Collected	Services	By Third Sector/ Other	HCP	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	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
f exercise maintenance	Some	Some	Some	Some	Some	Some
	regions	regions	regions	regions	regions	regions

# INSTRUCTORS WITH SPECIALIST TRAINING

4											
	REPS	REPS	BACPR	Otago	Postural	Exercise	Wright	Seated	NHS	Data	
	Level 4	Level		(falls)	Stability	After	Foundation	Exercise	In	Sources	
	(9)	3 (9)		<b>、</b>	Instructor	Stroke			house		
	(-)	- (-)			(falls)						
					(/						
	0-1 (i)	2	1			1	1-5 (i)	1		MCN, HCP, Leisure services	

Different regions have variation in numbers trained, overall total of known instructors shown

(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

<u>Cardiac Rehabilitation</u> is delivered within hospital and community settings. The exit strategy is signposting to Third Sector (CHSS) affiliated groups or Leisure services, where available.

<u>Pulmonary Rehabilitation</u> (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.

<u>Stroke Rehabilitation</u> 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.

<u>Cardiac Exercise Maintenance</u> is delivered in some regions by Leisure services/LA and in eight locations by Third Sector (CHSS affiliated) peer led exercise and support groups.

**<u>Respiratory Exercise Maintenance</u>** 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.

<u>Stroke Exercise Maintenance</u> 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 cheeking 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 reported 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, 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)) (<u>http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html</u>)
- 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: <u>http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification</u>
- Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <u>http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp</u>
- 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

Statistics from other sources (as not collected by ISD)

- Health Improvement Scotland Costing Report Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) <u>http://www.healthcareimprovementscotland.org/our\_work/long\_term\_conditions/copd\_implementation/implementing\_copd\_standa\_rds.aspx</u>
- 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.
- Register of Exercise Professionals (REPs) is an independent, public register which recognises the qualifications and expertise 9 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 I 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
## <u>FIFE</u>

**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
<b>Cardiac Rehabilitation</b> (6) (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	Not published		
<b>Pulmonary Rehabilitation</b> (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)	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	Yes. All referrals from NHS Fife are sent to the
Term Conditions to Exercise Maintenance	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.

## DATA COLLECTION FOR EM

Data Collector	Not	Leisure	Commissioned By	NHS –	Other
	collected	services	Third Sector/	HCP	
Data Collected			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	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
of exercise maintenance		Yes	Yes	Yes	Yes	Yes

### INSTRUCTORS WITH SPECIALIST TRAINING

Different regions have variation in numbers trained, overall total of known instructors shown

REPS Level <sup>(9)</sup>	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

<u>Cardiac Rehabilitation</u> 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.

<u>Pulmonary Rehabilitation</u> (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.

<u>Cardiac exercise maintenance</u> 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.

<u>Respiratory exercise maintenance</u> 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)

<u>Stroke community based exercise maintenance</u> 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 cheeking 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 , 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)) (<u>http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html</u>)
- 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: <u>http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification</u>
- Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <u>http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp</u>
- 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: <u>https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf</u>

Statistics from other sources (as not collected by ISD)

- Health Improvement Scotland Costing Report Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) <u>http://www.healthcareimprovementscotland.org/our\_work/long\_term\_conditions/copd\_implementation/implementing\_copd\_standa\_rds.aspx</u>
- 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 I 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 gualified 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
<b>Cardiac Rehabilitation</b> (6) (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	276 (49.6%)	N/A	N/A
<b>Pulmonary Rehabilitation</b> (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)

			<u> </u>			
participating in	Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral Generic	Exercise Referral Older Adults/ Older Adults Activities
(snapshot/estimated per annum) (8) 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	No, there is a single point of referral for each
Term Conditions to Exercise Maintenance	Region/ service, one for Falkirk and one for Stirling.

## 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	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	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
of exercise maintenance	Yes	Yes	Yes			Yes
	(n=1)	(within ex referral, n=1)	(n=1)			(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

<u>Cardiac Rehabilitation</u> (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 cheeking 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 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 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

- Source: 2012 mid-year population estimates (National Records of Scotland (NRS)) (<u>http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html</u>)
- 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: <u>http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification</u>
- Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <u>http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp</u>
- 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) <u>http://www.healthcareimprovementscotland.org/our\_work/long\_term\_conditions/copd\_implementation/implementing\_copd\_standa\_rds.aspx</u>
- 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 I 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
<b>Cardiac Rehabilitation</b> (6) (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	459 (35.6%)		
<b>Pulmonary Rehabilitation</b> (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)**

participating in	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				507 (BALL)i)		
provided (Moray				56 (S&B) i)		
council – older						
people's developmer						
team) (attendees, 2014)						
Total Known	405	40	30	563		
(attendees)						
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**

•	No, there are regional service co-ordinators/single point of contact/referral in some
	regions

# DATA COLLECTION OF EM

Data Collector Data Collected	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		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	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
of exercise maintenance	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 Foundati on	Seated Exercise	NHS In- house	Data Sources
		14	<b>3-6</b> (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

**<u>Cardiac Rehabilitation</u>** 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.

<u>Stroke Rehabilitation</u> 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.

<u>Cardiac Exercise Maintenance</u> 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).

<u>Stroke Exercise Maintenance</u> 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 cheeking 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= 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)) (<u>http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html</u>)
- 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: <a href="http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification">http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification</a>
- Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <u>http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp</u>
- 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)

- Health Improvement Scotland Costing Report Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) <u>http://www.healthcareimprovementscotland.org/our\_work/long\_termconditions/copd\_implementation/implementing\_copd\_standar</u> ds.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.
- Register of Exercise Professionals (REPs) is an independent, public register which recognises the qualifications and expertise 9 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 I 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 gualified 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
- (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
	55,686	31,201	27,295
Hospital Discharges (5) (number of patients)	4,879	3,777	2,044
<b>Cardiac Rehabilitation</b> (6) (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	1,771 (61.2%)		
<b>Pulmonary Rehabilitation</b> (7) (estimated total number of patients per year)		1,916	
<b>Stroke Rehabilitation</b> (number of patients per year)			Not collected by ISD

#### AVAILABILITY OF EXERCISE MAINTENANCE (EM)

		(=)			
Long	Cardiac	Respiratory	Stroke	Exercise	Exercise Referral
Term				Referral	Older Adults/
Conditions				Generic	Older Adults
				Ex Ref	Activities
				generic	(Silver Deal)(iv)
				9	<b>x y x y</b>
	419 (i)	338 (ii)		5,286 (iii)	
61,667					
(IV)					
	230	20			
					1,500 (v)
					, ,,
	Long Term Conditions 61,667	Long Term Conditions 419 (i) 61,667 (IV)	Term Conditions         419 (i)         338 (ii)           61,667 (IV)	Long Term ConditionsCardiacRespiratoryStroke419 (i)338 (ii)61,667 (IV)61,66761,667	Long Term ConditionsCardiacRespiratoryStrokeExercise Referral Generic Ex Ref generic419 (i)338 (ii)5,286 (iii)61,667 (IV)Image: CardiacImage: Cardiac

(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) Vitally lighted for autoritations, right 2012 December 2012
   (v) Sliver 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 Service Co-ordinator	2006 or earlier Yes	2006 or earlier Yes	2006 or earlier Yes	2006 or earlier Yes	2006 or earlier Yes	2006 or earlier Yes	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 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.

## DATA COLLECTION FOR EM

Data Collector	Not Leisure		Commissioned	NHS –	Other
	collected	services	by academic	HCP	
Data Collected			institution		
Follow up data		Yes		Yes	
Cost effectiveness		One		No	
		region			
Person centred data		One		Some	
		region		regions	

## FUNDING FOR EM

Funders	Local Authority	Leisure Services	Short Term Government Grant		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	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
of exercise maintenance		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)	<b>3-20</b> (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

<u>Cardiac Rehabilitation</u> 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.

<u>Pulmonary Rehabilitation</u> (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.

<u>Stroke Rehabilitation</u> 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.

<u>Cardiac exercise maintenance</u> 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.

**<u>Respiratory exercise maintenance</u>** is delivered within ERS and Vitality and can be supported by Live Active. PR also signpost to two Third sector (CHSS affiliated) support groups.

<u>Stroke exercise maintenance</u> 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 cheeking 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, 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)) (<u>http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html</u>)
- 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: <u>http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification</u>

- Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <u>http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp</u>
- 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)

- Health Improvement Scotland Costing Report Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) <u>http://www.healthcareimprovementscotland.org/our\_work/longterm\_conditions/copd\_implementation/implementing\_copd\_standar\_ds.aspx</u>
- 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 I 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
<b>Cardiac Rehabilitation</b> (6) (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	400 (45.4%)		
<b>Pulmonary Rehabilitation</b> (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

participating in	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	No. Some regions have a service co-ordinator
Term Conditions to Exercise Maintenance	

## 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	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
of exercise maintenance	Some	Some	Some	Some	Some	Some
	regions	regions	regions	regions	regions	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

<u>Cardiac Rehabilitation</u> 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 cheeking 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 (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)) (<u>http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html</u>)
- 2. Source: 2011/12 version of the Urban Rural Classification (Scottish Government) and the 2012 mid-year population estimates (National Records of Scotland).
- 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: <u>http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification</u>
- 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: <u>http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp</u>
- 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: <a href="https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30/Cardiac-Rehab-Summary.pdf">https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30/Cardiac-Rehab-Summary.pdf</a>

Statistics from other sources (as not collected by ISD)

 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\_c opd\_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.
- Register of Exercise Professionals (REPs) is an independent, public register which recognises the qualifications 9. 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 I 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
<b>Cardiac Rehabilitation</b> (6) (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	641 (49.8%)		N
<b>Pulmonary Rehabilitation</b> (7) (estimated total number of patients per year)		953	
Stroke Rehabilitation (total patients per year)			Not collected by ISD

### AVAILABILITY OF EXERCISE MAINTENANCE (EM)

participating in	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 <sup>(18 i) +</sup> 71 ii )	3043 Total (2079 i) 964 ii)	

Leisure services provided (attendances per annum)	19,894 (Total)	3305 i)	412 i)		
(2 out of 2 known providers)	(5673 i) + 14,221 ii) )	(1 out of 2 known providers)	(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.

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	Long	Cardiac	Respiratory	Stroke	Exercise	Exercise	Other:
Delivery	Term				Referral	Referral	Third
	Conditions				Generic	Older	Sector/
						Adults	Charity Affiliated
Type of Delivery	Yes	Yes for	Yes for	Yes for	Yes	Yes	Some regions
(Generic or		LTC	LTC	LTC			
Condition Specific)							
Established	Yes	Some	Some	Some	Yes	Yes	Some regions
Pathways to		regions	regions	regions			
Exercise		-	_	-			
Maintenance							
Earliest year a	2006 or				2006 or	2006 or	2012
Scheme	earlier				earlier	earlier	
Commenced							
Service	Yes	Yes for	Yes for	Yes for	Yes	Yes	Some regions
Co-ordinator		LTC	LTC	LTC			

\*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	No. There is a single point of contact/referral
Term Conditions to Exercise Maintenance	and a service co-ordinator for each CHP
	region i.e. North and South Lanarkshire
	5

## 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	REPS	BACPR	Otago	Postural	Exercise	Wright	Seated	NHS	Data
Level 4	Level		(Falls)	Stability	After	Foundation	Exercise	In-	Sources
(9)	3 (9)			Instructor	Stroke			house	
				Falls					
25	48	21		19	1	12		30	Leisure services – North & South , HCPs, MCN

## KEY CONTEXTUAL OVERVIEW - 2 CHP Regions

<u>Cardiac Rehabilitation</u> is delivered for in hospital and community based settings. The exit strategy is referral to the exercise referral scheme Active Health.

<u>Pulmonary Rehabilitation</u> 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.

<u>Stroke Rehabilitation</u> 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.

<u>Cardiac exercise maintenance</u> 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).

<u>Pulmonary exercise maintenance</u> 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 cheeking 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)) (<u>http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html</u>)
- 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: <u>http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification</u>
- Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <u>http://www.isdscotland.org/Health-Topics/General-</u> Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp
- 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: <u>https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf</u>

#### Statistics from other sources (as not collected by ISD)

- Health Improvement Scotland Costing Report Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) <u>http://www.healthcareimprovementscotland.org/our\_work/long\_term\_conditions/copd\_implementation/implementing\_copd\_standards.aspx</u>
- 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.
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### **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
<b>Cardiac Rehabilitation</b> (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

participating in	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) (estimat ed 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

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	No. There are regional referral points for each
Term Conditions to Exercise Maintenance	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.

# DATA COLLECTION FOR EM

Data Collector	Not	Leisure	Commissioned	NHS –	Other
	collected	services	by academic	HCP	
Data Collected			institution		
Follow up data		Some		Some	
		regions		regions	
Cost effectiveness		Some		Some	
		regions		regions	
Person centred data		Some		Some	
		regions		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(	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
for governance	Yes	Yes		Yes	Yes	Yes
of exercise maintenance	(this may indicate that some regions have none)					

#### 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	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

<u>Cardiac Rehabilitation</u> 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

<u>Pulmonary Rehabilitation</u> (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.

<u>Cardiac Exercise Maintenance</u> 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.

<u>Stroke Exercise Maintenance</u> 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 cheeking 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
- 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)) (<u>http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html</u>)
- 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: <a href="http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification">http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification</a>
- Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <u>http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp</u>
- 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: <u>https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30-Cardiac-Rehab-Summary.pdf</u>

#### Statistics from other sources (as not collected by ISD)

- Health Improvement Scotland Costing Report Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) <u>http://www.healthcareimprovementscotland.org/our\_work/longterm\_conditions/copd\_implementation/implementing\_copd\_standar\_ds.aspx</u>
- 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)
- Edinburgh Leisure Social Impact evaluation of certain projects using social return on investment (January 2012) Baker Tily. 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, Psvchological/Mental Health Conditions, Metabolic/Immunological Conditions e.g. Diabetes Type I 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

# <u>ORKNEY</u>

**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
<b>Cardiac Rehabilitation</b> (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	
<b>Stroke Rehabilitation</b> (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	Referral	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	No
Term Conditions to Exercise Maintenance	

#### DATA COLLECTION FOR EM

Data Collector	Not collected	Leisure services	Commissioned by academic	NHS – HCP	Other
Data Collected	conceted	30111003	institution		
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	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
of exercise maintenance		Yes	Yes - MCN	No	No	

#### INSTRUCTORS WITH SPECIALIST TRAINING

REPS	REPS	BACPR	Otago	PSI	Exercise	Wright	Seated	NHS	Data
Level 4	Level		-		After	Foundation	Exercise	In-house	Sources
(9)	3 (9)				Stroke				
	3					1			Leisure services

Different regions have variation in numbers trained, overall total of known instructors shown

### KEY CONTEXTUAL OVERVIEW - 1 Community Health Partnership Region

<u>Cardiac Rehabilitation</u> 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.

<u>Pulmonary Rehabilitation</u> 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.

<u>Stroke Rehabilitation</u> 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.

<u>Cardiac Exercise Maintenance</u> 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.

<u>Stroke Exercise Maintenance</u> 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 indentified 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 cheeking 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 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 pop ulated 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, 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) (<u>http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html</u>)
- 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: <a href="http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification">http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification</a>
- Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <u>http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp</u>
- 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)

- Health Improvement Scotland Costing Report Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) <u>http://www.healthcareimprovementscotland.org/our\_work/longterm\_conditions/copd\_implementation/implementing\_copd\_standar\_ds.aspx</u>
- 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.
- Register of Exercise Professionals (REPs) is an independent, public register which recognises the qualifications and expertise 9 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 I 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 Multidisciplinary 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
Dravalance	040	0.40	200
Prevalence (4)	813	240	369
Hospital Discharges (5) (number of patients)	85	24	27
Cardiac Rehabilitation (CR) (6) (numbers referred following	20*		
a heart attack or revascularisation procedure & as a percentage of eligible patients)	(attendances at Phase 3)		
*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			
<b>Pulmonary Rehabilitation</b> (7) (estimated total number of patients per year)		15	
Stroke Rehabilitation (estimated patients per year)			Not collected by ISD

#### AVAILABILITY OF EXERCISE MAINTENANCE (EM)

participating in	Long Term Conditions	Cardiac	Respiratory	Stroke	Referral	Exercise Referral Older Adults/ Older Adults Activities
Leisure services provided (attendances)		245*		195*		784*
CHSS affiliated groups (attendees)						
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**

long term neurological conditions and another person who co-ordinates exercise maintenance for cardiac conditions	Term Conditions to Exercise Maintenance	
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# DATA COLLECTION FOR EM

Data Collector	Not	Leisure	Commissioned	NHS –	Other
Data Collected	collected	services	by academic institution	HCP	
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	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
of exercise maintenance	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	REPS	BACPR	Otago	Postural	Exercise	Wright	Seated	NHS	Data
Level 4 (9)	Level 3 (9)		(falls)	Stability Instructor (falls)	After Stroke	Foundation	Exercise	In- house	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

<u>Cardiac Rehabilitation</u> 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.

<u>Stroke Rehabilitation</u> 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.

<u>Cardiac Exercise Maintenance</u> 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 cheeking 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)) (<u>http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html</u>)
- 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: <u>http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification</u>
- Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <u>http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp</u>
- 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: <a href="https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30/Cardiac-Rehab-Summary.pdf">https://isdscotland.scot.nhs.uk/Health-Topics/Heart-Disease/Publications/2013-05-30/2013-05-30/Cardiac-Rehab-Summary.pdf</a>

#### Statistics from other sources (as not collected by ISD)

 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\_c opd\_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.
- Register of Exercise Professionals (REPs) is an independent, public register which recognises the qualifications 9. 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 I 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

# <u>TAYSIDE</u>

**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
<b>Cardiac Rehabilitation</b> (6) (numbers referred following a heart attack or revascularisation procedure & as a percentage of eligible patients)	623 (72.4%)		
<b>Pulmonary Rehabilitation</b> (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, neurologic al)	294 ii)	

Leisure Services provided (attendances)	Included within 11,311 for exercise referral iii)				11,311iii ) (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.

i/ 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 , Strachthro 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)

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

#### SERVICE DELIVERY

\*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	No. Angus has a project co-ordinator who works
Term Conditions to Exercise Maintenance	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.

#### 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

ſ	Collaborative working	None	Long Term	Cardiac	Respiratory	Stroke	Exercise
	group(s) for governance		Conditions				Referral
	of exercise maintenance		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

in different geographical locations within the Health Board.

of instructors

# KEY CONTEXTUAL OVERVIEW - 3 Community Health Partnership Regions

<u>Cardiac Rehabilitation</u> (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.

<u>Stroke Rehabilitation</u> 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.

<u>Cardiac exercise maintenance</u> (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.

<u>Pulmonary exercise maintenance</u> 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).

<u>Stroke exercise maintenance</u> 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 cheeking 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 '*one region*' (as appropriate). If no responses, the section was left blank.

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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)) (<u>http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html</u>)
- 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: <u>http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification</u>
- Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <u>http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp</u>
- 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)

- Health Improvement Scotland Costing Report Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) <u>http://www.healthcareimprovementscotland.org/our\_work/longterm\_conditions/copd\_implementation/implementing\_copd\_standar</u> <u>ds.aspx</u>
- 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 I 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 gualified 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
<b>Cardiac Rehabilitation</b> (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	
<b>Stroke Rehabilitation</b> (estimated total patients per year)			Not collected by ISD

# AVAILABILITY OF EXERCISE MAINTENANCE (EM)

Known numbers	Long	Cardiac	Respiratory	Stroke	Exercise	Exercise
participating in	Term				Referral	Referral
community based	Conditions				Generic	Older Adults/
maintenance exercise						Older Adults
(snapshot/estimated per annum) (8)						Activities
Leisure services provided	Not	Not	Not	Not	Not	Not collected
	collected	collected	collected	collected	collected	
Numbers undertaking PA						
in affiliated CHSS groups						
Charity community group						
(cardiac, stroke,						
pulmonary specific)						
Total Known						

#### SERVICE DELIVERY OF EM

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	No single point of referral/contact and no
Term Conditions to Exercise Maintenance	service co-ordinator

#### DATA COLLECTION FOR EM

Data Collector	Not	Leisure	Commissioned	NHS –	Other
	collected	services	by academic	HCP	
Data Collected			institution		
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	None	Long Term Conditions	Cardiac	Respiratory	Stroke	Exercise Referral
of exercise maintenance	No					
	group					

# INSTRUCTORS WITH SPECIALIST TRAINING

 Different regions have variation in numbers trained, overall total of known instructors shown									
REPS	REPS	BACPR	Otago	Postural	Exercise	Wright	Seated	NHS	Data
Level 4	Level		(falls)	Stability	After	Foundation	Exercise	In-	Sources
(9)	3 (9)			Instructor	Stroke			house	
. ,				(falls)					
0	4 4			Training			0		MCN
3	1-4 (i)			pending (8)			3		

Different regions have variation in numbers trained, overall total of known instructors shown

(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

<u>Pulmonary Rehabilitation</u> 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.

<u>Cardiac exercise maintenance</u> 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 cheeking 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)) (<u>http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html</u>)
- 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: <a href="http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification">http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification</a>
- Source: 2012/13 Quality & Outcomes Framework (QOF) prevalence data (ISD). More information, including information on the limitations of the data, can be found here: <u>http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2012-13/Register-and-prevalence-data.asp</u>
- 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
- Source: Cardiac Rehabilitation in Scotland (2011/2) 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)

- Health Improvement Scotland Costing Report Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) <u>http://www.healthcareimprovementscotland.org/our\_work/longterm\_conditions/copd\_implementation/implementing\_copd\_standar\_ds.aspx</u>
- Health Improvement Scotland Costing Report Pulmonary Rehabilitation (2011) (based on figures from QOF, 2009-10) <u>http://www.healthcareimprovementscotland.org/our\_work/long\_term\_conditions/copd\_implementation/implementing\_copd\_stand\_ards.asp</u>
- 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 I 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 gualified 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

### <u>16/01/2014</u>

#### 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 School<sup>8</sup>

# 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

<sup>&</sup>lt;sup>8</sup> 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 (<u>http://www.exerciseregister.org</u>)

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.

 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 (<u>http://www.exerciseregister.org</u>)

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
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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 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 heath 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 delver 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-coordinator 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

education component of this were reported to be very influential in uptake of services as relationships and contacts are made.

#### References

1. <u>http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandst</u> <u>atistics/Publications/PublicationsPolicyAndGuidance/DH\_4009671;</u>

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%2C%22r%22%3A%5B%7B%22n%22%3A%22RefinableString0 0%22%2C%22t%22%3A%5B%22%5C%22%C7%82%C7%82536b696c6c73416 374697665%5C%22%22%5D%2C%22%3A%22and%22%2C%22k%22%3 Afalse%2C%22m%22%3Anull%7D%5D%7Dhttp://www.exerciseregister.org/reso urces/exercise-referral

Register of Exercise Professionals (REPs) is an independent, public register 2. which recognises the gualifications 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 I 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 10 -SERVICE USERS ADVISORY GROUP MINUTES

## 26<sup>th</sup> 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

Breathtakers 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 – Themes
Blue - work strands			Green – themes in different geographical locations
<ul> <li>1) Person centred pathway for LTC for         <ul> <li>i) new health event</li> <li>ii) existing long term condition</li> </ul> </li> <li>from all entry points to an exit point of community maintenance</li> </ul>	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 ii) Identify on a regional basis where drop outs/ or gaps are along the pathway	<ul> <li>X 1 focus group n= 8 (From differing geographical regions with respiratory and heart conditions)</li> <li>Development of 2 LTC pathways</li> <li>Piloting &amp; subsequent amendment of pathways of these pathways with n = 15 (average age 65 - Asthma, Bronchiectasis , ILD, COPD (Fife)</li> </ul>	<ul> <li>Date of diagnosis, condition and region are important factors as to if you reach exercise maintenance in the community</li> <li>General consensus from focus group 6/8 did not reach exercise maintenance activities</li> <li>Transition from health care services to community maintenance main transition barrier in pathway</li> <li>Transition to exercise maintenance more difficult for those with respiratory conditions with a less defined pathway and episodic nature of symptoms and care</li> </ul>
2) Person centred questionnaire s in relation LTC exercise maintenance	To gather data to establish baseline on current service provision in 12 geographical regions from a patient/service user perspective	<ul> <li>Questionnaire developed and piloted x 2 phases initial piloting focus groups n=8 from differing geographical regions with respiratory and heart conditions</li> </ul>	

3) Extrapolation of	To gather data	Key Person Centre	d In geographical regions where
existing patient/	to establish	Data extrapolated i	
person centred	baseline on	relation to 3	delivered service (NHS, L.A,
data			
	current service	conditions	Leisure services, user groups)
	provision in 12	Extrapolation of	specifically for exercise
	geographical		maintenance for LTC (2-
	regions from a	patient centred data	
	patient/service	existence in 7 health	
	user	board areas	Benefits – improved functional
	perspective	○ Service	ability, liked exercising with
		<ul> <li>Service evaluation by</li> </ul>	, people with different conditions
		leisure servic	
		of exercise	r sychological - Improved
		maintenance	confidence, improved ability to
		classes for	cope Behavioural – enabled better
		LTC – South	self management of condition
		Lanarkshire	NHS Service Usage – reduced
		n=362 with	GP visits
		LTC, focus	Infrastructure – local access to
		group with	classes/services
		LTC n= 20	
		(South	
		Lanarkshire)	in goog aprilour arous more
		○ Service	the service is integrated as
		<ul> <li>Service</li> <li>evaluation n:</li> </ul>	part of the exercise referral
		402 people	
		with LTC in	regions) focus groups were held
		exercise	for all patients for exercise referral, so data for LTC difficult
		maintenance	to extrapolate
		classes,	
		questionnai	
		for LTC n=3	6 improved relationships with
		(Tayside)	others, support of professionals
		(2.2)	helpful
		o <b>n =(30)</b>	
		telephone	
		interviews with Exercis	
		referral	
		participants	
		as part of Liv	
		Active	-
		(Glasgow) –	
		not	
		specifically	In geographical areas where
		LTC	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

<ul> <li>n= 319 current cardiac exercise maintenance group members, n=68 ex cardiac exercise maintenance members (Grampian)</li> </ul>	leisure services positive feedback from cardiac service users Barriers – knowledge of classes for users and HCP Benefits - supervised tailored exercise, social aspects important follow up important, encouraged other physical activity in current and ex members NHS Service Usage – reduced GP visits
• <b>n= 107</b> Questionnaire on completion of <i>Pulmonary</i> <i>Rehabilitation</i> <i>evaluation</i> <b>(Borders)</b>	In geographical regions where there is minimal/nil regional service (small independent patient groups in certain regions and condition specific , mainly pulmonary) (Borders) Barriers - wanting to join an exercise group consisting of previous pulmonary rehabilitation members, what happens next ?, wanting to set up a group Stroke specific exercise maintenance services x2 regions – Data from piloting only
<ul> <li>Stroke Specific Exercise after stroke pilot n= 27 (Tayside)</li> <li>Lothian Service Evaluation pilot of exercise after stroke n= 14</li> </ul>	<ul> <li>Barriers - location or transport issues, want long term service, chance to attend more often</li> <li>Benefits - social interaction important, less anxious and depressed (Angus n=13)</li> <li>Positives</li> <li>89% keen to be referred for exercise after stroke (Lothian n=14)</li> </ul>

4) Patient Focus Groups conducted by PARCS Project Manager	To gather data to establish baseline on current service provision in 12 geographical regions from a patient/service user perspective	<ul> <li>X 2 focus groups for those <i>leaving</i> <i>CR n=9</i> <i>region and</i> <i>PR n= 2 h</i> (n=11) (Borders)</li> </ul>	In geographical regions where there is minimal service provision small independent patient groups in certain regions and condition specific, mainly pulmonary) (Borders) Barriers Physical -identifying suitable exercise groups, appropriate exercise intensity groups need tailored exercise as per specialist rehab Systemic setting up a group Social not wanting to go to gym alone with a condition
		<ul> <li>X 1 focus group n= 17 with Cardiac Support Group attending leisure services exercise maintenance classes (Lanarkshire)</li> </ul>	<ul> <li>Transport, location, can only travel as far as oxygen will allow</li> <li>In geographical regions where there is a service specifically for exercise maintenance for LTC</li> <li>Barriers – knowledge of groups from HCP, correct levels of exercise, hardest step through front door</li> <li>Physical improved confidence to exercise, supervised tailored exercise,</li> <li>Psychological - improved confidence to formidence, averted onset of depression</li> <li>Social - social support, not isolation &amp; community involvement</li> <li>Positives – seamless transition from NHS to community</li> </ul>

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	

## APPENDIX 12 – GOOD MODELS OF PRACTICE – DIAGRAMATIC REPRESENTATIONS



## SEMI RURAL DIAGRAMATIC REPSENTATION OF GOOD PRACTICE

## URBAN DIAGRAMATIC REPSENTATION OF GOOD MODEL PRACTICE



#### S Ð Ð Ð L <u>-</u> ø \_ \_ 4 ъ ч-Screening Rural model for the transition from health to community based activity in the prevention and Factor Assessment LTC Review / Risk Primary Care \*Integrated service offered by both third sector and leisure services (some Independent Activities Moderate may be offered in social care/residential setting depending on capacity) MCN Governance or Multi Agency Working Group Specialist Instructor Led Generic Maintenance Classes Active living, walking, Circuit management of chronic conditions gardening Self Management Low- Moderate Circuit **instructor led)** e.g. Walking groups, support/ social groups – peer led activities. (Non-qualified Mainstream community 4 Pulmonary Rehab Secondary Care Cardiac / Stroke / Exercise Seated ط ш ш с S ⊃ ط 4 O ۲ ⊢ Maintenance E.g. NHS or supervised **Specialist** instructor exercise / interface Exit to activity private Health

## RURAL DIAGRAMATIC REPSENTATION OF GOOD MODEL PRACTICE

## APPENDIX 13 – TABLE SUMMARY OF CRITICAL SUCCESS FACTORS

# Critical Success Factors in the transition from health to community based <u>activity for long term conditions</u>

## DRIVER /GOVERNANCE

MCN Collaborative working group e.g. MCNs/ Physical Activity Group

APPROACH TO DELIVERY Collaborative with Key Stakeholders	<ul> <li>RESOURCES / FUNDING</li> <li>Joint / Collaborative</li> <li>NHS / Local Authority / Voluntary Sector</li> </ul>	SYSTEMS IN LINE WITH NHS QUALITY STRATEGY
<u>NHS</u> E.g.	JOINT FUNDING	<u>SAFE</u>
<ul> <li>MCN group</li> <li>MCN Managers</li> <li>AHP/Clinical lead(s)</li> <li>Health Improvement Lead</li> </ul>	<ul> <li>NHS</li> <li>Local Authority</li> <li>Leisure Services</li> <li>Voluntary / 3<sup>rd</sup> Sector</li> </ul>	<ul> <li><u>Governance</u> – via steering group e.g. MCN or physical activity group</li> <li><u>Standardised Referral Process</u> <u>and Pathways</u>,</li> <li><u>Screening</u> for 'safe to exercise' / and flage</li> </ul>
LOCAL AUTHORITY / LEISURE SERVICES • Service Co-coordinator	<ul> <li>TRAINING FOR INSTRUCTORS</li> <li>Funding for this- often collaborative e.g. NHS,</li> </ul>	red flags • <u>Instructor Trained –</u> at appropriate levels • <u>HCP⇔Instructor Working</u> <u>Relationship:</u> dialogue • <u>Content and delivery of classes</u> – appropriate and tailored
THIRD SECTOR         • Third Sector Support e.g., Support Group (peer support) Patient Representative.         ACADEMIC INSITUTIONS	<ul> <li>Leisure Services, Third sector, and Local Authority</li> <li>HCP work support of this</li> </ul>	<ul> <li>PERSON CENTRED</li> <li>Peer Support ideally for whole pathway NHS to community</li> </ul>
<ul> <li>E.g. to lead /support research, innovations</li> </ul>	<ul> <li>for exercise/support group e.g. clinical rehabilitation delivered in leisure facility</li> </ul>	EFFECTIVE
PRIMARY CARE REP	<u>USE OF</u>	<ul> <li><u>Data collection/ Audit of Service</u> <ul> <li>ideally standardized</li> </ul> </li> <li><u>Default Referral</u> from condition specific mainstream rehabilitation</li> </ul>

• e.g. GP, specialist/community nurse	• Often supported by third sector training, e.g. going to clinical rehabilitation to support and encourage others	<ul> <li>Integrated Rehabilitation, NHS rehabilitation e.g. PR and CR delivered in community venue with peer visit to support maintenance</li> <li>Education/Behavioural change <u>component/ support e.g.</u> within rehabilitation or in community, peer and support ,</li> <li><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</li> </ul>
		TIMELY         • Default Referral – to community maintenance exercise group         EQUITABLE         • Make services accessible to all, perform assessment of this         • Consider innovations and technologies for hard to reach groups

## 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