PARCS PROJECT - QUALITATIVE EVALUATION REPORT

August 2014

CONTENTS

GLOSSARY OF TERMS

The following terms have been used throughout the report. We provide definitions below:

Term	Definition
Exercise maintenance	Sustained community based physical activity, (therapeutic) exercise and physical fitness training for people with long term conditions, undertaken after formal clinical rehabilitation is complete[1].
Exercise referral scheme	Exercise referral schemes (ERS) aim to identify inactive adults in the primary-care setting. The GP or health-care professional refers the patient to a third-party service, with this service taking responsibility for prescribing and monitoring an exercise programme that is tailored to the individual needs of the patient[2].
Journey	The stages a patient proceeds through and their experiences from symptoms/diagnosis to exercise maintenance, the healthcare professionals they encounter at each stage, the care and treatment they receive, the information they are provided and the decisions they make about their next steps
Healthcare professional (HCP)	Any clinical professionals involved in a patient's diagnosis, treatment and care, including: doctors in hospital and community settings (eg consultants and general practitioners (GPs), nurses in hospital and community settings (including specialist nurses), allied health professionals (AHPs) in hospital and the community,
Live Active	A twelve month health behaviour change initiative specifically targeting physical inactivity. Participants are referred by their Allied Health Professional (AHP) and receive an evidence based one-to-one consultation, providing them with the knowledge, skills and confidence required to lead an independent active lifestyle. Service operates throughout NHS Greater Glasgow and Clyde region.
Long term condition	Long term conditions, or chronic diseases as they tended to be referred to, are conditions that last a year or longer, impact on a person's life, and may require ongoing care and support. The definition does not relate to any one condition, care group or age category, so it covers children as well as older people and mental as well as physical health issues. Common long term conditions include epilepsy, diabetes, some mental health problems, heart

[1] In some areas, exercise maintenance can be accessed without having attended formal rehabilitation

[2] Definition taken from: Pavey TG, Anokye N, Taylor AH, Trueman P, Moxham T, Fox KR, et al. The clinical effectiveness and cost-effectiveness of exercise referral schemes: a systematic review and economic evaluation. *Health Technol Assess* 2011;15(44).

	disease, chronic pain, arthritis, inflammatory bowel disease, asthma and chronic obstructive pulmonary disease (COPD)[3].
Non-engager	A person with a cardiac, respiratory or stroke condition who is not currently engaged with organised exercise maintenance services
Pathway	The agreed (locally or nationally) stages to be followed in the care and treatment of patients who have a cardiac, respiratory or stroke condition.
Physical Activity	Any bodily movement produced by skeletal muscles that requires energy expenditure[4].
Rehabilitation (Cardiac)	The coordinated sum of activities required to influence favourably the underlying cause of cardiovascular disease, as well as to provide the best possible physical, mental and social conditions, so that the patients may, by their own efforts, preserve or resume optimal functioning in their community and through improved health behaviour, slow or reverse progression of disease In meeting these defined goals, all cardiac rehabilitation programmes should aim to offer a service that takes a multidisciplinary biopsychosocial approach in order to best influence uptake, adherence and long-term healthier living[5].
Rehabilitation (Pulmonary)	Pulmonary rehabilitation can be defined as an interdisciplinary programme of care for patients with chronic respiratory impairment that is individually tailored and designed to optimise each patient's physical and social performance and autonomy. Programmes comprise individualised exercise programmes and education[6].
Rehabilitation (Stroke)	Stroke rehabilitation is a multidimensional process, which is designed to facilitate restoration of, or adaptation to the loss of, physiological or psychological function when reversal of the underlying pathological process is incomplete. Rehabilitation aims to enhance functional activities and participation in society and thus improve quality of life. Key aspects of rehabilitation care include multidisciplinary assessment, identification of functional difficulties and their measurement, treatment planning through goal setting, delivery of interventions which may either

[3] Definition taken from Improving the Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan (Scottish Government, 2009)

[4] As defined by the World Health Organization

[5] Definition taken from the British Association of Cardiovascular Prevention and Rehabilitation's Standards and Core Components 2012

[6] Definition taken from British Thoracic Society guideline on pulmonary rehabilitation in adults 2013

	effect change or support the person in managing persisting change, and evaluation of effectiveness[7].
Service User	A person with a cardiac, respiratory or stroke condition who is currently engaged with organised exercise maintenance services.
Support Group	A voluntary sector group created to support people with a specific condition; these groups may be affiliated to one of the charities involved in PARCS or not, and generally offer a range of services and support to its members which may or may not include exercise maintenance.
Vitality	The exercise maintenance programme in place across NHS Greater Glasgow and Clyde region for people with a variety of long term conditions; the programme offers four different levels of class, supporting participants to exercise at a level suitable to their functional abilities. Service users are assessed to determine the appropriate level for them.

[7] Definition taken from NICE CG162 Stroke rehabilitation: Long-term rehabilitation after stroke

EXECUTIVE SUMMARY

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

The key findings of the evaluation were as follows.

The current pathways

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

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

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

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

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

Understanding more about why people engage or not with exercise maintenance

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

Motivations – why do people participate in exercise maintenance?

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

People are attracted to exercise maintenance services, as opposed to independent exercise, for the tailoring, supervision and perceived safety it offers, especially if they are new to exercising.

They are also drawn to the social aspects of a group class – our evaluation shows that this social aspect is incredibly important in both attracting and retaining people.

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

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

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

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

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

Barriers – what stops people participating in exercise maintenance?

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

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

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

Why do people stop participating in exercise maintenance?

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

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

Improving provision to enable and maximise engagement

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

Further development of seamless pathways

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

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

Follow-up and safety nets

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

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

Harness the influence of healthcare professionals

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

The role of the third sector

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

1 INTRODUCTION

The PARCS project – **P**erson-centred **A**ctivities for people with **R**espiratory, **C**ardiac and **S**troke conditions – is a partnership project led by Chest Heart and Stroke Scotland (CHSS), the British Lung Foundation (BLF) and the British Heart Foundation (BHF). The overall aim of the project is to promote integrated, community-based, long-term physical activity/exercise throughout Scotland for those with long term conditions (LTC) though with a focus on cardiac, respiratory and stroke conditions.

The findings from the PARCS project are intended to support the Scottish Government to deliver the best quality health care by informing the development of user centred services, with an increased focus on prevention. It is also hoped that through the PARCS project, partnership working between the statutory and voluntary sectors will develop further and enable resources to be used optimally whilst providing value for money.

By achieving those aims the project seeks to support people with long term conditions to enjoy enhanced physical and mental wellbeing. In addition, health care professionals involved in the provision of cardiac, respiratory or stroke rehabilitation will be more aware of the barriers that prevent people from taking up provision as well as gaining new knowledge and good practice relating to models of, and approaches to, service delivery

1.1 The PARCS project

There are four main components to the PARCS project:

- scoping exercise of 14 health boards to identify current service provision - based on a literature review, consultations with Managed Clinical Networks (MCNs), health care professionals, and service providers. Aiming to identify current service provision across differing geographical regions and identify models of good practice relevant to the differing health, social and demographic circumstances across Scotland. CHSS led on this component of the project.
- review of models of delivery outwith Scotland for service delivery and good – identifying good practice relevant to the differing health, social and demographic circumstances across the UK. BHF led on this component.
- qualitative evaluation – conducting qualitative evaluation with people affected by cardiac, respiratory or stroke conditions. BLF led on this component, which was conducted by Brightpurpose Consulting.
- economic evaluation – assessing the economic impact of exercise maintenance. BLF led on this component, which was undertaken by Brightpurpose Consulting.

This report presents the findings of the qualitative evaluation and the economic impact assessment.

1.1.1 Objectives of the qualitative evaluation and economic evaluation

Brightpurpose was commissioned to conduct a qualitative evaluation and economic assessment project as part of the PARCS project. This involved 4 distinct areas of work:

- qualitative evaluation with people affected by cardiac, respiratory or stroke conditions that participate in exercise maintenance provision and who live in Ayrshire and Arran, Greater Glasgow and Clyde and Highland

- qualitative evaluation with people affected by cardiac, respiratory or stroke conditions that do not participate in exercise maintenance provision and who live in Ayrshire and Arran, Greater Glasgow and Clyde and Highland
- analysis of anonymised pulmonary rehabilitation exercise maintenance referral data from Greater Glasgow and Clyde
- economic analysis to build the case for exercise maintenance

The objectives of the work were as follows:

- examine the journeys of both those who do and do not participate in exercise maintenance provision, to understand the principal health care professional and service provider touchpoints (especially entry and exit points) from diagnosis to present day, the seamlessness (or otherwise) of these journeys, and the extent to which provision is person-centred
- explore the different models of service provision in place in the three regions selected for the evaluation, and their impact on patients' journeys
- identify key factors influencing physical activity and engagement with exercise maintenance services:
    - barriers to engagement
    - reasons for disengaging from service provision (recognising that these may be either positive or negative)
    - enablers to engagement
    - motivations to exercise and maintain fitness
- identify potential lessons for improving delivery processes
    - if possible from the findings, identify an ideal pathway for people with cardiac, respiratory and stroke conditions to achieve appropriate levels of physical activity
- identify potential lessons to inform primary prevention interventions
- analyse the patterns of referral from pulmonary rehabilitation into exercise maintenance in NHS Greater Glasgow and Clyde
- establish the economic impact of exercise maintenance
- make recommendations for areas of further exploration, as a result of the evaluation findings

This report sets out the findings from the qualitative evaluation component of the PARCS project.

2 METHOD

2.1 Focus of the evaluation

The purpose of the qualitative evaluation, agreed with the leads from each of the three charities during the initiation phase, was to examine the experiences of service users and non-engagers drawn from three specific geographical regions

- Glasgow and Greater Clyde
- Ayrshire and Arran
- Highland

These three regions were selected to represent:

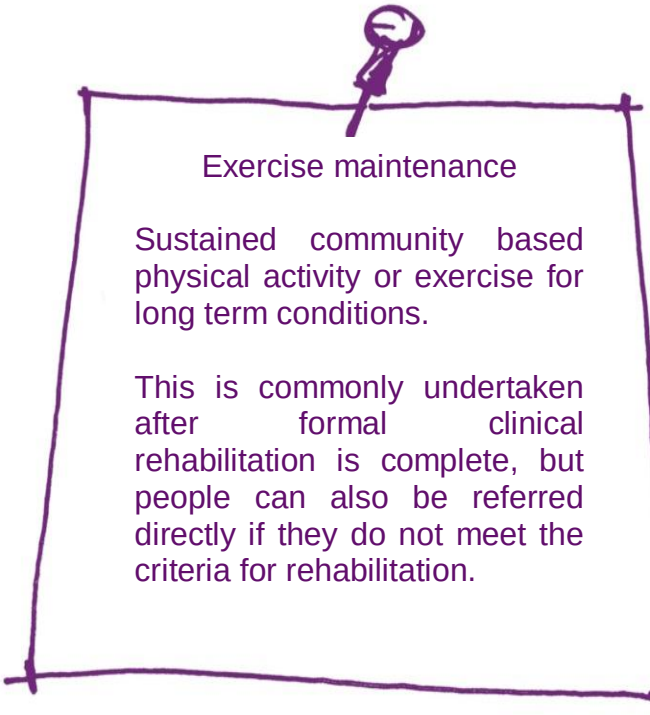
- different geographical factors – specifically the comparison between metropolitan city region, mix of rural and smaller towns, and highly rural, and an examination of how services do or do not transcend local authority boundaries
- different service delivery models – ranging from a comprehensive, highly developed and coordinated service to a very limited service

The lines of enquiry for the regional differences are explained in section 2.2.3.

2.2 The experiences of service users and non-engagers

We carried out semi-structured interviews with exercise maintenance service users and non-engagers:

- service users – individuals participating in exercise maintenance classes or structured exercise programmes supported by a health care professional or exercise instructor to help manage specific cardiac, respiratory or stroke conditions
- non-engagers – individuals who do not currently participate in structured classes of exercise maintenance, including:
  - independent (unsupported) exercisers
  - those who do not do any exercise/physical activity
  - those who have disengaged from service provision



We worked with local healthcare professionals, providers of exercise maintenance services and local support groups, to gain an understanding of the exercise maintenance activities available locally and to identify potential participants. This study was purposely constructed as a Service Evaluation and Audit, in accordance with NHS Health Research Authority's guidance and in

keeping with previous studies of this type undertaken by Brightpurpose. Participants were engaged through voluntary sector support groups, leisure services and other community groups/stakeholders.

2.2.1 Sample sizes and distribution

Our aim was to interview 16 – 22 service users and 36 – 54 non-engagers spread across the three regions and including equal proportions of people with each of the three conditions. These target numbers were based on realistic estimates of how many respondents we would be able to engage with within the timescales whilst at the same time giving us sufficient data from which to draw reliable conclusions.

Within the non-engagers it was important to identify and interview people from 'hard to reach' populations. In the context of this study 'hard to reach' included people:

- from Black and Minority Ethnic (BME) communities
- living in areas of deprivation
- living in rural areas
- experiencing multiple and complex barriers such as substance misuse and homelessness

We therefore subdivided the non-engager targets for the Ayrshire and Arran and Glasgow and Greater Clyde regions to include a proportion of respondents from these hard to reach populations.

Actual numbers achieved are shown in the tables below:

Table 1a – Number of evaluation respondents – Non engagers

Respondent groups	Total
Total non-engagers	30
Of which were from:	
hard to reach groups	9
non hard to reach groups	21

Table 1b – Number of evaluation respondents – service users

Respondent groups	Total
Service users	28

In addition we were able to facilitate two focus groups and a number of shorter informal interviews with service users which we have collated and synthesised as part of our findings.

Table 2 – Number of evaluation respondents by location and condition type

	Cardiac	Respiratory	Stroke	Total
Glasgow and Greater Clyde				
Non-engagers (general)	0	1	0	1
Non-engagers (hard to reach)	0	1	3	4
Service users	4	3	5	12
Ayrshire and Arran				
Non-engagers (general)	1	4	1	6
Non-engagers (hard to reach)	2*	3	0	5
Service users	4*	6	1	11
Highland				
Non-engagers	4	3	7	14
Service users	3	2	0**	5

*1 respondent within these categories has dual condition – cardiac and stroke
** No services for stroke

We discuss our approach to and the challenges in identifying respondents below.

2.2.2 Engaging Respondents

Respondents were identified through a number of channels. The primary routes were:

- CHSS affiliated groups
- BLF affiliated groups
- health care professionals (physiotherapists, nurses)
- leisure services staff (exercise instructors, leisure service managers)

The majority of these contacts were provided by the PARCS Project Manager or BHF and BLF project leads, so many were already aware of the project. These initial contacts were able to facilitate invitations to groups and classes that we then attended to approach potential respondents directly. In some instances, particularly in the Highlands, health care professionals were able to contact potential respondents. Despite the good range of contacts provided, and the willingness of contacts to support our activities, it was still proved extremely challenging to engage with sufficient people. Unsurprisingly, identifying non-engagers proved to be the most challenging aspect, especially in Greater Glasgow and Clyde and Ayrshire and Arran.

We therefore employed a number of routes to attempt to contact non-engagers, including contacting numerous community groups and organisations to assist, with very limited success. We also contacted health centres and hospital clinicians to explore whether they could assist us. In Highland, health centres proved a positive route, and in Ayrshire and Arran we were able to attend a cardiology clinic where the nurses spoke to patients which helped us contact a small number of non-engagers. With this type of approach healthcare professionals would make patients aware of the evaluation being conducted and what they could do to participate in the evaluation if they wanted to.

We spoke with all potential respondents either in person or via an initial telephone call to ensure they were fully informed about the purpose of the evaluation, what was required of them, how their data would be used and to address confidentiality. A written leaflet was also provided to potential respondents and those assisting with contact. Respondents could opt out at any point.

2.2.3 General lines of enquiry

The lines of enquiry for all three regions were similar but each region also had supplementary avenues for exploration identified as specific to that region.

The lines of enquiry for all three regions were:

- the journey: principal health care professional contacts and service provider touch points (especially entry and exit points) and what happens at each of these
- barriers to engagement
- enablers to engagement
- reasons for disengagement
- motivations to exercise and maintain activity levels
- lessons for improving delivery processes from a service user perspective

- exploration of the key themes emerging from the PARCS project so far (fear factor, existence of groups, social aspects, problems at the transition points, how exercise maintenance is packaged, knowledge of what's available, etc)
- lessons that might inform primary prevention interventions

The question frames were kept open to allow free responses from respondents however, we were asked to explore emerging themes from earlier evaluation. Thus topics such as the use of technology and cultural barriers to engagement were highlighted and probed with appropriate respondents. The interviews also aimed to capture specific data using standardised questions from an earlier survey carried out as part of the PARCS project to boost the quantitative dataset.

2.2.4 Geographically specific lines of enquiry

For each of the three regions additional lines of enquiry to address specific questions raised through earlier scoping work by the PARCS Project Manager were pursued.

For Greater Glasgow and Clyde

In the Greater Glasgow and Clyde region there is an established exercise referral programme and exercise maintenance classes are widely available. As a potential model of service provision the aim here was to examine if the pathway is working as well as believed and is that the same across all sections of society.

In addition there was an opportunity to carry out a specific piece of work in relation to referral from Pulmonary Rehabilitation into exercise maintenance to examine what proportion of patients are being referred and when they are not being referred what are the reasons. (See section on NHS GGC PR Referrals).

For Ayrshire and Arran

In this region exercise maintenance is delivered by different providers in each of the different Community Health Partnership (CHP) areas and the evaluation aimed to establish if this subdivision of provision affected the person-centred experience. So for example were people tied to services within their own CHP area or could they attend classes in a different CHP area if it was geographically closer or more convenient.

For Highland

In this region it appeared that there was a lack of access to exercise maintenance in some areas, particularly outwith the urban centres. The aim here therefore was to establish if this was indeed the case and what effect this had on those people living in these areas. It was also an opportunity to gauge demand for local services and what those services should look like.

2.3 Acknowledgements

We would like to thank the following organisations for their assistance in facilitating introductions to potential participants, allowing us to attend and observe exercise maintenance sessions and advising on alternative avenues for connecting with evaluation participants.

- British Heart Foundation
- British Lung Foundation
- Chest Heart and Stroke Scotland
- East Ayrshire Leisure
- Glasgow City Council
- Glasgow Life

- Inverness Leisure
- KA Leisure North Ayrshire
- NHS Ayrshire and Arran
- NHS Greater Glasgow and Clyde
- NHS Highland
- NHS Highland
- Scottish Refugee Council
- South Ayrshire Council Leisure Services

We are also indebted to numerous support groups, some independent and some affiliated to CHSS or BLF, who facilitated introductions to their members and allowed us to visit their groups.

3 FINDINGS – QUALITATIVE EVALUATION

This chapter details our findings from the interviews with service users and non-engagers from all three regions included in the study. We have synthesised the responses into key themes:

- ★ the journey experienced by evaluation respondents
- ★ barriers to engagement
- ★ reasons for disengagement
- ★ enablers for engagement
- ★ motivations to undertake physical activity

Throughout each section we have identified common themes whilst drawing out differences between regions and conditions. We have used case studies to help illustrate key findings and whilst these case studies represent the experiences of the respondents we have changed names and other identifiable features to protect their identity.

3.1 The journey

All respondents were asked to describe their journey from the point of diagnosis to the present day, to gain an understanding of how their experiences varied and also what were the common features. We found that the experiences of respondents into, through and beyond the health care system varied depending upon factors such as:

- ★ the type of condition: cardiac, respiratory or stroke
- ★ the severity of the condition
- ★ their location
- ★ when they were first diagnosed
- ★ time between symptoms/diagnosis and receiving rehabilitation

A significant determinant of the smoothness of the journey post-rehabilitation, was the type of condition people had. Those with pulmonary or cardiac conditions in general had a smoother transition from acute care into rehabilitation and then into community-based exercises maintenance provision, whilst those who had suffered strokes were far less likely to have transitioned into exercise maintenance beyond their initial physiotherapy.

3.1.1 Condition-specific issues

The experience after pulmonary and cardiac rehabilitation

In all three regions, when care pathways are fully in place the journey has the potential to run smoothly and seamlessly. The transition from rehabilitation to exercise maintenance was frequently described by service users as a natural progression, with clear signposting or (more commonly) direct referrals which provided a continuity of service provision and long term support.

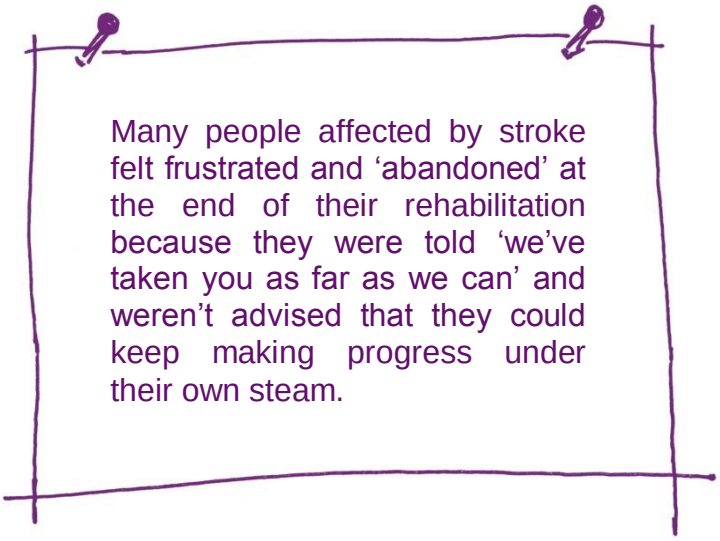
Where care pathways are not complete, particularly in the rural Highlands, the journey post-rehabilitation is somewhat more haphazard; subject to the vagaries of community

provision and available advice and guidance. Even getting to the rehabilitation stage itself can be challenging in some areas and this is explained in more detail later.

The experience after stroke rehabilitation

The experience of respondents who had suffered a stroke was more diverse, and the severity of the stroke certainly seemed to be a significant factor determining their journey and their experience of that journey. Some had been referred to exercise maintenance by their physiotherapist after rehabilitation, but not all had physiotherapy and in these cases they were usually referred on by their GP/practice nurse.

However many told us they felt that following rehabilitation and the initial period settling back into their home they felt 'abandoned'. Many reported getting good rehabilitation in hospital and assistance from occupational therapists to get them back into their homes. Advice and assistance to get alterations to the home were forthcoming, as were care packages to assist with basic needs until they were able to manage themselves.



However at the end of this phase some respondents said they were being told 'we've taken you as far as we can', which was frequently interpreted as 'this is as far as you can go in terms of your recovery'. This was compounded by a message from their physiotherapists that the majority of function would be regained during the first three months after their stroke, which was often interpreted as meaning that no more could be gained beyond that three month period. Many also hadn't heard a message about the need to maintain the levels of function they had regained through rehabilitation and how best to do that. This is not to say that these messages hadn't been communicated, but importantly, they hadn't landed.

Resource limitations within the NHS mean that formal structured rehabilitation can only reasonably be funded for the first three months. However, it seems that even if the information was being communicated, the message was not getting through to many potential service users that there were good reasons to be active and keep themselves as fit as possible. The message respondents who had suffered a stroke received was often demotivating and, whilst it is important not to raise hope beyond realistic expectations, most people respond to having realistic goals even if those goals may take months or even years to achieve. The wife of one respondent who had suffered a severe stroke said:

"no-one would get down to the nitty gritty of what's required which is repetitive, intensive exercise. Only one occupational therapist talked about what could be achieved and in what time"

The road to recovery tends to be slower and longer for people affected by stroke, yet the pathway seems to be the weakest and the one which people are most likely to disengage with little likelihood of return.

3.1.2 General issues (not condition-specific)

People diagnosed longer than five years ago

It appears that the pathways have only been fully established relatively recently, over the last five years or so. This is not to say that provision did not exist prior to this, but the feedback we heard from evaluation respondents suggests that the pathway, and referral mechanisms, were not fully embedded. We found that people who had been diagnosed longer than 5 years ago were much less likely to have had a smooth transition from acute care into community-based maintenance. Some did not receive rehabilitation, let alone referral to exercise maintenance. Whilst in some cases their conditions may not have rendered them appropriate for rehabilitation, this was too common a story to be explained only by that factor. This is borne out by the fact that a number had later been referred into rehabilitation and/or exercise maintenance following more recent admission or outpatient consultations. Some had also taken the initiative themselves, and asked to be referred after hearing from others about rehabilitation and/or exercise maintenance. However, feedback from evaluation respondents suggests that this later access to rehabilitation and/or exercise maintenance seemed to be inconsistent and dependent on either:

- the individual being motivated to seek out support for themselves, or
- the intervention of a proactive health care professional

> "The GP told me I had COPD but didn't give me information on how deal with it"

A system-centred pathway

Our findings indicate that even the well-defined and comprehensive pathways have the potential to break down, most commonly when the patient does not fit with the pathway's timelines or processes. In these cases, people's journeys have either been significantly delayed or not completed. In essence they have 'fallen through the cracks'. The pathways appear to lack processes that act as safety nets, identifying and attempting to re-engage people who have fallen out of the standard pathway. Thus they are often lost from the pathway, unless a particularly proactive health care professional identifies what has happened (often years later) and re-engages them into the pathway, or an exacerbation of their condition leads to readmission.

It took nearly 2 years for Kathleen to be definitively diagnosed with her lung condition, by which time she was having tremendous difficulty breathing even without any exertion. Her physiotherapist advised that she'd benefit from a course of rehabilitation but Kathleen didn't feel ready. She told her physiotherapist "I'm gasping for every breath, there's no way I can do physio or exercise". So Kathleen returned home and didn't participate in rehabilitation.

A couple of years later, at a routine check-up for her lung condition, Kathleen's Practice Nurse suggested rehabilitation again, as a way of helping Kathleen manage her condition. This time Kathleen was feeling well enough to contemplate it, and went ahead. After her rehabilitation programme, Kathleen chose to attend an exercise class run by a local community group rather than a specific exercise maintenance class. She goes regularly and also looks after her grandchildren a couple of days a week.

Key messages

★ timing the message to when the patient is ready to receive it is essential to successful engagement

★ health care professionals need to raise the issue of rehabilitation and exercise maintenance at every contact point, to catch those who have 'fallen through the cracks' due to an exacerbation or other reason(s)

Kathleen's experience is typical of many people we spoke to, who - after their diagnosis - weren't ready for rehabilitation or exercise maintenance. They had their reasons for not being ready, but were not saying never – they were saying not right now; they either lacked confidence that they could exercise at that point or had other more pressing priorities. But unless an individual in the health care system acted as a safety net to get them back into the pathway later, they would not have found their way back.

Current pathways are system-centred rather than person-centred.

Not everyone fits neatly into the pathway; if someone is not ready for exercise maintenance when it's offered, they may not get another opportunity when they are ready.

Feedback from evaluation respondents suggests that the pathways are system-centred rather than person-centred, with trigger mechanisms based on pre-set intervention points rather than patient-readiness. If a person doesn't conform to the process, their chances of a smooth transition are reduced, and getting back on the pathway is not guaranteed and can involve an element of chance.

Role of the health care professional

The role of the health care professional is fundamental to the process. For those who had fallen through the cracks and needed guiding back, a proactive health care professional was often the catalyst. This was often a practice nurse at the local GP surgery, or the health care professionals running outpatient clinics, raising the topic of becoming and keeping active – why it was important, what activity they were doing, the opportunities in the local community. However, feedback from

respondents suggested not all health care professionals actually promoted the benefits of physical activity. We also heard anecdotally from respondents that their health care professionals did not always know what was available or how to access it.

Throughout the journey we were aiming to capture the key touch points and identify the people/HCPs speaking to service users and non-engagers about the importance of physical activity. Physiotherapists were commonly cited as a key source of information and often encouragement and inspiration. Both in hospital during those initial therapy sessions to get respondents back on their feet and during rehabilitation sessions in the community, the message from physiotherapists was consistent. In hospital these messages were also often reinforced by the nurse specialist visiting on the ward. Outside hospital and back in the community, practice nurses were identified as frequently asking about levels of physical activity, encouraging respondents to do more and instigating referral to exercise maintenance classes or signposting to support groups. Practice nurses are the lynchpin for many people, particularly those that have fallen through the cracks – they are the health care professional a patient sees most often about

Touch points

The key people most commonly promoting and encouraging physical activity are:

- Physiotherapists
- Clinical nurse specialists
- Practice nurses

their condition, through regular check-ups and chronic disease management clinics.

The feedback relating to consultants and GPs was not always as favourable. Many respondents did not cite either their consultant or GP as talking to them about physical activity. Some were given very negative messages.

"What are you doing that for?"

a service users' cardiology consultant

"I wouldn't bother with that if it was me"

a service users' nephew (a GP)

Feedback from evaluation respondents suggests that the advice offered by these senior healthcare professionals can carry a significant level of influence so it is vitally important that the right messages are coming from them.

It was not all negative though, others had been referred to exercise maintenance by their GP and had been encouraged to exercise independently to help recovery, improve and maintain the fitness

levels as part of self-management of conditions and general health and wellbeing. Feedback from evaluation respondents suggests that these senior healthcare professionals can carry a significant level of influence so it's vitally important that the right messages are coming from them.

It wasn't all negative though, others had been referred to exercise maintenance by their GP and had been encouraged to exercise independently to help recovery, improve and maintain the fitness levels as part of self-management of conditions and general health and wellbeing.

Earlier intervention

Some respondents whose conditions were less severe, reported that they weren't referred for rehabilitation because they weren't considered unwell enough to need it. As the pathway into exercise maintenance is often via rehabilitation, the opportunity to encourage them to maintain an active lifestyle was often lost, even though this may have helped them maintain function or reduce the risk of a further event. In particular respondents with early onset COPD, were not deemed ill enough to require rehabilitation. This led to the perverse situation where they were not receiving the support and advice to help prevent them from becoming so ill that they did need rehabilitation. If they would benefit from some level of physical activity to maintain their current function they are often not receiving this message.

> Patients with less severe conditions may not have access to rehabilitation and exercise maintenance, because they are not 'ill enough' – but this means they don't get the tools and advice to prevent or slow deterioration.

Busting the jargon

During our interviews it became apparent that the language used by respondents to describe rehabilitation and exercise maintenance is not the same as that used by health care professionals. This is an important point, as language can shape our perceptions of services, and may act as a barrier to some people choosing to access a service.

Rehabilitation was usually described as 'physio' by respondents – they described going to a structured set of physiotherapy sessions after their diagnosis or treatment. Organised exercise maintenance services (delivered by NHS, leisure services or community groups) were described as 'classes' by most respondents or occasionally as 'exercise classes'.

Physical activity is not a phrase that respondents used or recognised as relating to their exercise maintenance; people tended to associate the

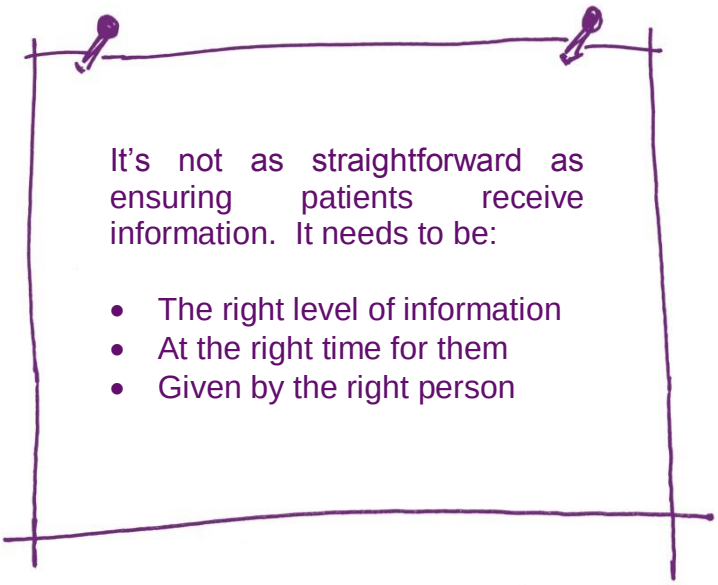
> Respondents tended to use the following terms:
>
> **'Physio'** – for rehabilitation
> **'Keeping active'** – for physical activity
> **'Classes'** - for exercise maintenance services

phrase physical activity with more formal exercise or sport. But they did respond to the term 'keeping active', and when we explained that physical activity included walking, gardening and active household chores, the level of activity reported by respondents significantly increased.

Information provision

We asked respondents to comment on the quality and quantity of written information provided about physical activity in relation to their condition. Again this varied but a number of respondents spoke about having too much information too soon. This was predominantly whilst people were still in hospital. A common theme for those in hospital was that they were just not ready to think about physical activity. They had more pressing priorities and, in some instances, had not fully accepted their situation. Few people said they had gone back to that information at a later time. One cardiac patient said:

"I got an overwhelming amount of information at the time but nothing much after that"



Once in rehabilitation, people seemed more receptive to receiving information and felt that it helped provide structure and greater understanding. Overall respondents seemed satisfied with the quality of information received at that stage in their journeys. The Heart Manual (produced by NHS Lothian) was mentioned a number of times by respondents. It was regarded as a very helpful source of information and helped to provide a structured plan for their recovery. At this phase of the journey people are starting to look forward so they appear to be in a much better position to absorb information and act on it.

3.1.3 Regional differences

In this section we draw out the findings and issues specific to each of the three regions involved in the evaluation.

Greater Glasgow and Clyde

Within Greater Glasgow and Clyde stroke survivors, particularly those with more severe restrictions to their mobility, generally do not have knowledge and awareness of what services are available and are suitable for them. That is not to say that suitable services are not available, it just isn't visible to those that could be accessing it and benefiting from them. The feedback from respondents suggests that this is an awareness issue, arising from a combination of lack of referral/signposting from a health professional and them not seeing any marketing of services.

Another factor is that they have not been proactive in trying to find out what is available, although the feedback suggests that they wouldn't really know what they were looking for.

Respondents were aware of general physical activity provision locally, but were uncertain whether it would be suitable for them. Feedback from the respondents suggests that they do not know what they would be looking for as they have never had a discussion with a health care professional about what they could or should be doing.

This is intertwined with other barriers and issues discussed in this report relating to people affected by a stroke. For some, the belief is that they have got back all of the function they are going to and are therefore not particularly inclined to be proactive in seeking the information they would need.

Beyond this, their restricted mobility means that even if provision was visible and known about, those with the most severe limitations to mobility explained that it would need to be 'on their doorstep' or would need 1-2-1 support to get to and from any provision. Respondents who had severe mobility limitations and who were participating in exercise maintenance were able to because it had been arranged to take place at a support group that they would be attending anyway. These groups tended to be supported by committed volunteers who supported group members to get to the group by providing transport and assistance.

Mary lives in the Govan area of Glasgow and is now confined to a wheelchair after gradual loss of mobility following a stroke in 2005. Prior to her stroke she lived an active life, playing lawn bowls every day of the week. Whilst in hospital after her stroke she received daily physiotherapy sessions in the gym which she really enjoyed – she was having to relearn almost everything. Prior to her being discharged her social worker was able to find alternative accommodation as Mary lived in a second floor flat. At the point of her discharge she was able to walk with the aid of a stick. Mary was provided with some exercises to do and equipment to use and told that she should try to do the exercises to maintain what mobility she had. There was no discussion about available provision that she could access that would support her to participate in exercise maintenance. She found it was difficult to do the exercises she was given by the physiotherapist without someone there to assist her and, because she lives on her own it meant she rarely did them.

Mary's mobility has gradually deteriorated and she is now confined to a wheelchair which leaves her feeling isolated. She is dependent on the free transport service and assistance provided by her local stroke support group for her to attend their sessions. Mary would participate in exercise maintenance if she knew it was going to benefit her, if the support to access it was in place and if there was something suitable for her. Mary feels that her limited mobility means that there is unlikely to be 'anything that she could do". The stroke support group that she attends would love to bring in physiotherapists to take exercise sessions as part of the group but finance prevents this from happening.

<u>Key messages</u>

★ without sustainable, appropriate exercise maintenance opportunities benefits, gained through rehabilitation can be lost

★ support groups want to be able to offer these opportunities but there are significant financial barriers

Ayrshire and Arran

Many respondents in Ayrshire and Arran indicated that waiting times for pulmonary rehabilitation were extremely long, with some respondents indicating that they had heard waiting times were over 40 weeks. Some respondents indicated that they were reluctant to wait for such a long period of time to access pulmonary rehabilitation and therefore opted not to go. This meant that for some non-service users there could be a loss of momentum in exercising, however, some respondents who did not access pulmonary rehabilitation took it upon themselves to exercise independently.

Many respondents also had a perception that there were too few pulmonary physiotherapists in Ayrshire and Arran and that this lack of capacity in turn led to such extended waiting times. Believing there was a lack of capacity, one patient indicated that they felt that their condition wasn't as severe as others and declined to be referred for pulmonary rehabilitation so that they weren't using up the capacity of the limited number of physiotherapists.

> "There was only one physio running the classes at the time [of referral to pulmonary rehabilitation]"

A number of respondents who raised these two issues were patient representatives in groups that had members involved in the Managed Clinical Network (MCN) or other public involvement forums, and we wonder if these perceptions are a result of information heard at these meetings and relayed to other group members.

A number of respondents with different conditions indicated that they felt that not enough classes are available in Ayrshire and Arran, and particularly within their locality. Some non-service users were not aware of classes, or were only aware of one or two classes which were difficult for them to access (for a variety of reasons, most notably transport/distance). In addition, some service users indicated that the classes they attended were the only classes they were aware of which were specifically aimed at their condition (whether it be a cardiac, stroke or respiratory condition). Some service users, particularly attendees of one stroke-specific class indicated that attending classes once a week was not enough, and that they would wish to attend classes more frequently if more classes were available. This was particularly true for attendees who did not exercise independently at home.

While others indicated that one class a week was sufficient for them, for those who wished to attend classes more regularly this was not currently perceived to be an option. In addition to condition specific classes, some service user respondents in Ayrshire and Arran attended Invigorate classes (balance and tone class aimed at falls prevention) as an extra exercise class, and others have also progressed to gym-based classes or to doing independent exercise within the gym.

Despite having their classes based within a leisure centre, one support group in Ayrshire and Arran reported not being aware of other exercise maintenance classes available locally for individuals recovering from their condition. We know from anecdotal feedback and discussions with staff at the centre that other classes are available at the same venue. Therefore there appears to be a disconnect between the group and other existing local provision, which is affecting people's perceptions of available opportunity. This has possibly arisen because the group originated to fill a gap in provision, before the leisure services provider provided anything suitable. The leisure services provider now funds the instructor for the group and is also providing condition-specific training for their other instructors, and rolling this training out to other leisure services providers in Ayrshire.

From our discussions with instructors during our visits to classes in Ayrshire and Arran, there appears to be good co-ordination between the leisure services operating in each of the three CHP areas in Ayrshire and Arran. The lead staff at each centre meet regularly to keep in touch, update each other and share practice. For example, one provider is delivering stroke-specific training for instructors into the other CHP areas. Whilst the referral paperwork is slightly different in each CHP area, all three services accept referrals from all three areas, and if a service user wants to attend classes outside of their resident local authority area this is organised informally and effectively by the leisure services leads. The success of this system appears to be based on excellent relationships and good communication between the staff in the three services. This is potentially vulnerable if staff move on to different jobs and new relationships need to be forged to ensure that the service remains seamless from the service user perspective across the different CHP boundaries.

Highland

In the Highland region, where people live is a key determinant of what happens post-rehabilitation. Opportunities to engage with structured exercise maintenance classes are patchy and focussed in the more populated areas. None of the respondents in Highland outside the Inverness area were able to access exercise referral schemes.

In Lochaber there is a scheme for people completing cardiac rehabilitation which gives them free access to the leisure centre gym as a way on encouraging independent exercise. However, within the Lochaber area individual circumstances play an important part in how accessible that scheme is, as demonstrated in the case study below.

In the Inverness area, local HCPs told us that the exercise referral scheme (a scheme whereby GPs can refer patients at risk of a variety of long term health conditions to a structured, fixed-term programme of assessment and physical activity to encourage long term adoption of a healthier lifestyle) which had been delivered in partnership with the local leisure services was no longer in operation. Respondents who were engaged in structured exercise maintenance were doing so through CHSS affiliated support groups. There were both chest and heart groups in Inverness and a couple of chest groups further north, in Wick and Invergordon, all of which offered weekly exercise sessions. However, the local CHSS co-ordinator reported that there was no stroke group offering exercise maintenance.

David and Michelle are both of working age and live in the Lochaber area of the Highlands. David is in employment, whilst Michelle is in receipt of unemployment benefits. Both had heart attacks last year, in August and September respectively, and each had stents inserted at Raigmore Hospital.

David, who lives in Fort William got onto the cardiac rehabilitation programme straight away. Having completed the six week programme which he described as 'brilliant' he then moved onto exercise independently, taking advantage of the new scheme in Lochaber which offers free membership to the leisure centre following cardiac rehab. When we spoke to David it was his first day back at work, just three months after his heart attack and well before he expected he would be. He is also now regularly walking with his partner and plans to get a bike and cycle to work in the future.

Michelle lives 43 miles from Fort William, and when we spoke to her in November she was hoping to get onto the cardiac rehabilitation programme in January. However, this is a three hour round trip and will cost £7.10 each time. Although Michelle's physiotherapist is helping her to claim travel expenses, "even if I get expenses I still have to find the cash up front, and when you're on benefits there just isn't spare money".

Michelle remains positive and is heeding the advice she has been given about diet and exercise. But there are no local exercise classes, never mind exercise maintenance. She would swim but the local pool has been closed. She has bought a 2nd hand Wii to help her exercise in the house and she takes her dog out for short walks. Even that's difficult though because the weather is poor and Michelle can't afford a decent weatherproof jacket.

Michelle has also applied to the local authority to be rehoused in Fort William. She is prepared to leave her home and her friends to get access to better services. That's how important it is to her.

Key messages

★ people living within the same health board area may not have access to the same services; proximity to services and facilities significantly influences engagement

★ people on low incomes may have reduced opportunities to participate in exercise maintenance

An example of good practice we found was that members of a cardiac support group would go and speak to patients going through cardiac rehab. This approach allowed those with lived experience to paint a positive picture of the future, encourage participation in exercise and introduce them to the group. This particular practice should help address some of the barriers to engagement that we discuss in the next section. That said one of the respondents who delivered these talks did say he was surprised at the number who **didn't** come along to the group. He was unable to offer any reasons why that should be so.

3.2 Barriers to engagement with exercise maintenance

This section describes some of the barriers to both engaging with services and exercising in general that were identified by respondents. Some barriers were identified more frequently and as such, have greater bearing when it comes to recommendations. Some of the less commonly identified barriers have been included here, if only to illustrate the point that we are all different and when designing pathways and schemes, being able to eliminate as many barriers as possible should lead to greater uptake and overall success.

The table below provides a summary of the barriers and which category of respondent they relate to. Each of the barriers are then discussed in the following sections.

Table 3 – Barriers to engagement with exercise maintenance, by respondent group

Barrier	Service Users	Non-engagers who exercise independently	Non-exercisers
Transport Especially: severe stroke, rural areas and night time	X	x	x
Cost Class, equipment, instructor to come to a group	x	x	x
Weather and dark nights (big impact on independent exercisers)	x	x	
Knowledge/awareness of services		x	x
Fear and confidence ("dare I do it?")	x but overcome by class		x
Fear of entering new social interaction	x but overcome		x
Image of group (eg group name or perceived demographic)		x	x
Not a 'joiner'		x	x
Lacking motivation Message eg re stroke Lack of knowledge re benefit			x
Concern about taking another's place – and perception that system isn't coping		x	
Busy life		x	x
Broken routine after exacerbation, hard to get back into it			x
Other co-morbidities	x	x	x
Respiratory patients with portable O2 – it's not that portable		x	x
Concern about activity level affecting welfare benefits			x
Perceptions of what a class might be like, eg Bootcamp		x	x

3.2.1 Transport

Being able to physically get to the exercise class venue was a significant barrier for many non-engagers and non-exercisers. Whilst wanting to take part in exercise classes the responses were often not unlike the one below from a non-exerciser in the Highlands:

"It would have to be nearby and I don't drive. Even then the weather can put me off walking"

Transport issues were also cited by service users as a potential barrier or a barrier which had delayed engagement. For those able to drive and with access to a car it was less of factor, though driving at night and over longer distances on rural roads did put some people off.

For many, driving was not an option either because they were no longer able to drive due to their condition or because they just didn't drive. In these situations there was often reliance on spouse, family member or friend to help with travel. For one service user it was only when her husband retired that she was able to get to the support group and take up exercise. She waited seven years.

Fellow group members and classmates do sometimes help with lifts and this is a spin off benefit from the social engagement that you get by participating in classes rather than exercising independently. However, those that rely on getting a lift from another class member usually can't attend if that person is not able to make it.

For many, public transport was their normal way of getting about and this posed several problems. Firstly, particularly in rural areas was the travel time and frequency of service. One respondent from Ayrshire & Arran indicated that they didn't attend classes because doing so would require them to wake up very early to catch the bus, they had to take 2 buses to get to the venue, and the total travel time was more than an hour. This could make travelling to facilities at worst impractical and at best really tiring. Even in urban areas the need to change buses which may involve waiting and still comparatively long journey times (when compared to travelling by car) could leave people tired. There can be other challenges with public transport for those with restricted mobility. Though low floor buses ease access for those with restricted mobility they are not always routinely used. If not in use a passenger has the option of waiting for another, in the hope it does have a low floor or not making the journey. One respondent said that if the bus did not have a low floor he would have to wait for the next one, and then maybe he wouldn't make the class in time. So was it worth it? Add to that the inclement weather and the challenge of public transport can become a tipping point to non-participation.

There are also difficulties with confidence and mobility, especially for those who have suffered a stroke, which meant public transport for many was not an option. In some areas Dial-a-Bus services and Car Plan schemes can help and provide a more bespoke service but these are patchy and some people still require assistance to get from the house to the vehicle and this is not always available through these schemes. In addition, some classes, such as the Different Strokes group in North Ayrshire, had explored the potential for accessing a bus to support people to get to classes, but hadn't been able to negotiate a bus service. As a result respondents in this group were reliant on access to a car or a lift.

The cost of transport was also highlighted. This is discussed in more detail in section 3.2.3.

3.2.2 Accessibility

Allied to the transport issue is accessibility. In the case of those using public transport the distance from their home to the bus stop or from the bus stop to the venue could be problematic. Even car drivers can face accessibility barriers in terms of available parking and proximity of parking to the venue. Relatively short distances can be problematic particularly for people with mobility problems or who are prone to breathlessness.

On the positive side we didn't hear anything with regard to the venues themselves being difficult to access, for example too many steps.

For some respondents with respiratory conditions, accessibility to venues was constrained by their need to carry portable oxygen cylinders. The problem is twofold. Firstly, there is the practicality of having to carry heavy and bulky cylinders. Secondly, the actual amount of oxygen in the cylinder - usually an hour's supply- restricts the distance that can be travelled. We understand that there is a roll-out of lighter, home fill portable oxygen cylinders underway, but certainly our respondents in this had not yet benefited from this.

3.2.3 Cost

Cost was another frequently identified barrier across both service users and non-service users. The cost of travelling to the venue particularly for those using public transport was a challenge. Even relatively short distances by public transport can be expensive. Whilst the older users may be able to use their bus passes this was not the case for younger people.

Although exercise maintenance classes are often subsidised there is still a fee to be paid by the service user and this can present a challenge, especially for those on low incomes. In addition, many of the classes have developed a social aspect, with class members going for a coffee together afterwards; again this has a cost attached.

In the support groups where an instructor is brought in to deliver exercise, this is paid for by the group. For larger, established groups this appears to be manageable. However, its sustainability is heavily reliant on the size of the group being maintained and the professional fee remaining reasonable. We spoke to two leaders of smaller groups (for different conditions), and both were concerned for the future of their groups, as they were not receiving many new referrals and the group size was shrinking; this may make the cost of a qualified instructor or physiotherapist unsustainable.

A cardiac support group based in Glasgow currently provides people with a cardiac condition the opportunity to participate in up to 2 hours of exercise maintenance once a week. The first hour is made up of gym based exercises taken by a qualified instructor whilst the second gives them access to the swimming pool which is overseen by two qualified[8] lifeguards.

A group lead there is very concerned that the group faces closure in the very near future. Changes to local authority rules regarding the use of the swimming pool means that the group would have to pay for two local authority approved lifeguards which would roughly treble the existing costs for the group. This is because the lifeguards they use currently only charge 'a token amount', and although qualified as life guards are not local authority lifeguards so cannot be used. In addition to this, the group are not receiving enough new referrals to maintain the numbers required to cover costs.

Key message

★ increased costs and/or reduced group size can sharply reduce the financial viability of voluntary sector provision

A few people mentioned the cost of equipment to exercise at home. Whilst most home exercises provided by physiotherapists identify common household objects to use as apparatus some people, particularly those without access to classes had purchased some sort of exercise equipment such as exercise bikes and interactive games consoles. A more fundamental cost

[8] The respondent was not able to distinguish between whether the lifeguard was qualified as a lifeguard or qualified to monitor a cardiac swimming session

barrier to exercising was being unable to afford training shoes or a weatherproof coat to allow them to walk in less clement weather.

3.2.4 Weather and dark nights

For many of the respondents walking was a major element of their exercise regime, and poor weather and dark nights deterred them from their routine because walking was less enjoyable in these circumstances. For independent exercisers this potentially eliminated their sole form of physical activity or at best reduced it. A small number said that if they couldn't walk they would do something else such as dance to music in the house. Whilst this is commendable and a positive finding that people are seeking an alternative form of exercise whether they are able to reach the same level of intensity is questionable.

The difficulty for those that do exercise mainly by walking is that it has the potential to become very much a seasonal activity. The problem then is firstly getting back into the habit once the weather improves and secondly regaining the fitness lost through a period of relative inactivity. Many respondents were also keen gardeners, but again this is largely seasonal.

3.2.5 Knowledge/awareness of services

Fundamental to participation is awareness of services. As discussed in section 3.1 people are not always being referred or signposted to relevant activities. Some of the respondents we spoke to had found out about classes by word of mouth from an existing user or through their own online search. Once they had found out about what was available they had either made contact with the organisation themselves or where necessary approached their GP for further advice or an actual referral.

Other people had stumbled across leaflets or found out about groups from a third party, in one instance their hairdresser. Even when services are not being provided by the local authorities or health sector, such as in the Highlands, many respondents felt they were not even signposted to groups or other professionals who could help them. This has led them to seek services based on their own knowledge and evaluation. However, this takes someone to already be motivated to get active and confident enough to ask the questions.

People did have different levels of expectation:

> "If you want anything you have to ask, shouldn't have to."

> "People are very busy – just have to find out things for yourself"

Regardless of expectations, awareness and knowledge of services is fundamental. It does appear that some groups and organisations providing services are not always getting the message out to the right people at the right time. In other instances, group members take it upon themselves to promote the group amongst local GPs and health centres but are pessimistic about the affect this has.

3.2.6 Fear and confidence

Whilst many service users said they were not concerned about taking up exercise maintenance classes this was usually followed by a comment that they felt confident because they had been

through rehabilitation, knew what their limitations were and what they were capable of doing. They had been given coping strategies should they feel out of breath and they knew that they were being monitored by someone who knew what they were doing. As we discuss in a later section, rehabilitation seems to play a vital role in preparing patients for ongoing exercise maintenance and easing the transition into it.

Several spoke about how fearful they had been before attending rehabilitation or a supervised exercise class if they hadn't been to rehabilitation:

> "I was worried sick – what if I overdid it and dropped dead in the street."

In addition some respondents were unsure whether exercise was beneficial for their condition, or whether it was beneficial where they had a range of co-morbidities. One patient with arthritis indicated that he felt the doctor was focussed on getting him the right medications for his condition, and physical activity was not a priority at this time.

> "No one has suggested I do anything physical"

Those who were exercising independently or not at all tended to report higher levels of fear and uncertainty and were generally less confident about what they could and could not do. For example a couple of respondents specifically mentioned they liked to swim but were unsure if they were 'allowed' to do that now. Certainly many would not have ventured out for a walk without the support of a spouse. One person who had had a stroke said;

> "I wasn't really sure what I should or shouldn't be doing"

It wasn't always cited as a barrier, but could be inferred from responses that without rehabilitation and without appropriate supervision of classes, anxiety levels would be higher. Therefore those people who are not able to access supervised activities and particularly those who do not qualify for rehabilitation, fear may well prevent them from undertaking even moderate independent activity. One respondent who was in principle happy to exercise independently felt she needed professional input, as she put it:

> "someone who knows what's best"

3.2.7 Fear of entering new social interaction

For some it wasn't the fear of physical activity acting as a barrier but the fear and trepidation of new social interaction. Meeting new people and being the 'new person' entering an established group can be a daunting task at any time in our lives. Add to that the vulnerability and lower levels of confidence brought about by their change in health status and all that goes with it, and it becomes even more challenging.

Some said that they had to make themselves go the first few times until they settled in. It wasn't that people were unfriendly just that they weren't always particularly welcoming. By this we mean they were not especially proactive with new members so the level of interaction a new member got might well be dependent on how outgoing and confident they were themselves. As one respondent put it:

"Taking the initial steps is difficult and I can see why some less confident people may not find it easy and may not come back. You need to want to do it."

Those without access to classes, which are at least made up of people with similar conditions and shared experiences, face similar social challenges.

"I would go to the gym but they can be cliquey I enjoyed the class [rehab] because we weren't made to look silly".

3.2.8 Image of group

People can be put off from even going once because of their preconceptions of what the group may be like. Younger people in particular perceived that groups would be full of old people, that would spend time bemoaning their situation and dwelling on negatives. The reality seems to be very different with groups in general having a very positive outlook and whilst they had shared experiences they didn't spend their time comparing symptoms.

We did hear that groups do tend to be dominated by the older generations, so younger people may not feel as comfortable there; one respondent commented on the significant male bias in the group. Another person in the Highlands but who had only relatively recently moved there felt that she didn't fit the 'social scene' so even if there were groups to go to they would not be for her.

A more extreme example, and a view expressed by only one respondent was the image that the name of a group can convey. In this instance a potential service user was put off from attending the local CHSS group because the conjured up an image of

"old men and women coughing, spluttering and moaning".

Whilst this is likely to be a result of a difference in sense of humour, it is an interesting point to note; when people are vulnerable and lacking confidence perhaps even the slightest thing can put them off.

3.2.9 Not a 'joiner'

Some people are simply not 'joiners' – they are not attracted to group activities. A number of independent exercisers when asked would they join a class if there was one locally simply responded no they prefer to exercise alone, or with their spouse. For these people a different approach may be needed, one which offers signposting and support so that they are undertaking the right type of activities and feel confident doing so but that does not require them to exercise with others. However we did receive feedback that, in some instances, when attending their regular check with their practice nurse they did discuss the exercise that they were doing and that the nurse was happy that we they were exercising appropriately.

3.2.10 Lacking motivation

We discuss in a later section what motivates people to exercise so it is relevant to mention here that a lack of motivation, whatever the cause is a significant barrier to engagement. The lack of

motivation may be underpinned by messages received from health care professionals as discussed in section 3.1. The belief that nothing can be done to improve their condition so why bother. A poor understanding of the benefits too will result in low levels of motivation.

For some they know the benefits but they just can't see a reason to try. Typically these are people who are living alone and have limited social and family interaction. One person we spoke to said she had lived her life, it had been a good one and now she was just waiting out her time.

Another responded:

"I know what I should be doing, I need to take responsibility for my own actions"

For these people finding the key which switches their behaviour may be very difficult, if not impossible, to find.

Tam had a stroke in 2001 and is affected by limited movement in his left side. Whilst in hospital he had daily physiotherapy sessions to help him regain mobility and this was followed up with weekly physiotherapy sessions for 2 months after discharge. However, at the end of his rehabilitation programme the only discussion around physical activity was the physiotherapist advising him that he should try to get out and about and keep active.

Whilst he initially had the motivation to be active, shortly after this and in a relatively short space of time Tam experienced a series of serious problems involving close family members. As a result, Tam is simply no longer interested in physical activity. As he put it, after going through what he's been through he is happy to 'dodge away, living out his days'. He struggles to see any reason to make an effort to be any more active than he is already.

Key messages
- ★ motivation is essential to sustaining engagement in physical activity
- ★ once motivation lost it can be difficult to re-establish; finding a reason to carry on can be so hard

3.2.11 Concern about taking another's place – and perception that system isn't coping

In Ayrshire and Arran, some respondents reported that they hadn't engaged with pulmonary rehabilitation or exercise maintenance classes because they felt that there were others more in need of help, others who were worse off and therefore should have their place.

However this view appeared amplified because there was a perception that the system was under-resourced and wasn't really coping with demand. It is interesting that this perception of systemic failure seemed to be prevalent in a particular group in which one of the organisers was involved in a patient involvement group. There is a possibility that they were hearing things at meetings in relation to resourcing and later sharing their interpretation of that with other group members.

3.2.12 Busy life

For some, leading a busy and active life just didn't leave room for an exercise maintenance class. For those living in areas where there was just one opportunity per week this is certainly a potential barrier. One person who was a regular at a CHSS group but chose to stop going to help look after grandchildren said, that if another class was available on another day they would go.

For those where there are multiple opportunities, such as urban centres where classes are delivered in multiple locations and on different days, it should be less of a barrier. Certainly respondents in Greater Glasgow and Clyde were offered different classes and could therefore choose the one which best fitted their routine.

Some may have other priorities in their lives which push exercise to the bottom of the 'to do' list. This in some instances may reflect complex lives where health matters are pushed to the bottom of the agenda.

Kali had moved to Glasgow several years ago as a refugee. She had spent time in low grade accommodation which she believes caused her to have respiratory problems. She has seen a doctor and been diagnosed with a pulmonary condition for which she has been prescribed medication. However, there has been no discussion about exercise and in reality Kali is too busy trying to build a life for her and her young daughter to take time out to gain a full understanding of her condition and what she should be doing to help manage it. She is currently living in emergency accommodation which is not properly heated. She is working part-time whilst attending college in an effort to get qualifications for a better job and a better life. She is worried about her condition, what would happen to her daughter if she became more unwell, but she has no time to exercise.

Key message

★ people with busy lives find it difficult to make time for exercise maintenance, even when they know it's important

3.2.13 Broken routine after exacerbation

Habit, routine and structure are key factors in sustaining a healthy lifestyle. Many of the service users told us that their classes had become part of their weekly routine, and they kept coming back. But when a routine or habit is broken it can be difficult to get back into it. A number of people who had previously been service users or independent exercisers reported finding it difficult to get back into their habits of exercising, whether independently or part of exercise maintenance classes, after an exacerbation in their condition.

Bridget has had COPD for several years. She attended rehabilitation and then began attending multi-condition low intensity exercise maintenance on a weekly basis. She really enjoyed the exercise class, as she felt the benefit, liked the people she met there and the instructor made it great fun. About nine months ago Bridget got a nasty chest infection which aggravated her COPD and she was very unwell. She didn't have to be admitted, but was very limited in what she could manage for several months.

Gradually, she has got better, and taken on more activities again – she's looking after her grandchildren again, doing her housework and getting out and about. However, she hasn't gone back to her exercise class. She's lost confidence in whether she'll be able to do the exercises again, and she's daunted by the idea of going back into the group again after so long away. As she told us: "I know it's up to me and I'd feel better if I did it, but I just can't bring myself to go along"

Key message

★ a relapse or exacerbation can break the habits of exercise maintenance, and knock confidence – this can make it hard to re-engage

Bridget's story highlights just how hard it can be to get back into a routine. Taking that first step back can be almost as much of a barrier as taking the step in the first instance. There is a real risk that once that routine is broken and a person drops out of the pathway they may never get back into it.

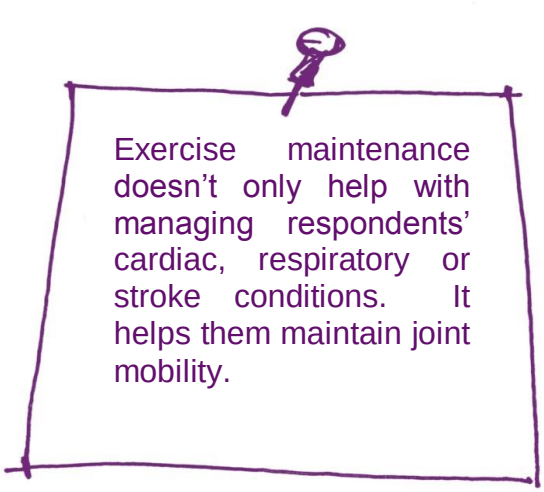
Staff delivering classes may not have the time, or be paid/tasked, to follow up on people who disengage. In some instances we heard that friends from the classes will call someone who has disengaged to see how they are and prompt them to return. This is a positive spin off from the social side of these activities. However we did hear from one group that they had made such welfare calls a couple of times only to find the individuals in question had passed away. This apparently caused some distress for both the caller and the family concerned, and the group has now stopped this type of follow up.

3.2.14 Other co-morbidities

A few of the respondents we spoke to described other health conditions that they were also affected by in addition to either a stroke, cardiac or respiratory condition. Having other co-morbidities appears to, in some circumstances, present additional challenges in relation to engaging with exercise maintenance provision. One respondent was unsure what type of activity would be suitable for his circumstances. Another was still having regular visits to his GP to find a medication regime that best suited his circumstances and until this was done he wasn't really considering participating in physical activity.

A number of respondents had joint issues, to varying degrees of severity, and these conditions made movement and thus exercise more difficult. However, we attended a low intensity multi-condition class where many attendees had joint problems as well as their principal presenting condition, and most indicated that the activity loosened them up and minimised their joint pain and stiffness on the day and for a couple of days after the class.

One respondent who had multiple conditions and as such was receiving disability living allowance was concerned that appearing to be active could have a negative impact on his benefits - that he would no longer be entitled to disability living allowance leaving him financially deprived.



3.2.15 Perceptions of what a class might be like

We have already identified how people's perceptions can become barriers in relation to the image of the group and the other people attending. Perceptions of exactly what's involved can also act as a barrier, both in terms of the perceived format and content of the class in terms of social dynamic, and the type/intensity of exercise. Feedback suggests that this is probably more relevant for those who have led less active lives prior to becoming unwell so they have limited experience of exercise classes. A perception that they will be like 'boot camp' with someone ordering you about was raised by a few respondents.

"I've never been interested in vigorous exercise – I don't want to go to something that's like bootcamp. The class I go to [movement to music] might not be so intensive, but it has lovely music and I enjoy it"

"I don't need someone barking at me, telling me to bend down, stand up"

3.2.16 Multiple barriers

Of course often there is not just one barrier to engagement but a combination of factors each additional one making it harder to reach the final destination. But when they can be overcome the results can be very rewarding.

Susan was 60 when she was diagnosed with COPD 12 years ago. She was given rehabilitation and signposted to a CHSS group offering support and exercise for people with respiratory conditions. She didn't go, she knew she should but she couldn't drive and public transport was unsuitable.

Seven years later she was given a second block of rehabilitation sessions and was signposted again to the group. By now her husband had retired so he could give her a lift. She decided to go because "I missed rehabilitation and I knew I should be doing something" . She was able to take her husband into the class which helped get over those first day nerves. The husband stayed and joined in. He had a heart condition and since retiring wasn't really as active as he would like to be so he was happy to participate.

They never miss it, unless they are on holiday. They are both getting regular exercise which is helping them to manage their conditions they are now enjoying a broader social life, with new friends and regular outings. They look forward to Monday morning – not many of us can say that.

Key messages

★ it's not always a single barrier that prevents engagement, and more barriers make it harder to engage

★ conversely, there is not just a single benefit: participation can lead to multiple benefits and varied rewards

3.3 Reasons for disengaging

A small number of respondents had been attending exercise maintenance classes or support groups but had subsequently disengaged. We discuss the reasons cited in the following sections.

3.3.1 Provision disbanded

In some instances ceasing participation was not a matter of choice but rather a decision forced upon them because the class had stopped. This appears to be a feature of schemes delivered as projects which have a finite life and if a case cannot be made to continue the scheme as part of

business as usual this inevitably results in the provision being disbanded. People may continue to exercise independently but also may not.

> "I really enjoyed classes so I was disappointed when they stopped."

3.3.2 Exacerbation of existing condition

Exacerbation of a condition can also trigger someone disengaging. In these instances the resulting break of habit can re-establish barriers. In some instances the barrier becomes insurmountable and the person just stops permanently.

3.3.3 Using time for other things

Some respondents disengage for more positive reasons either to use their time for other meaningful activities such as volunteering or helping to support the family for example helping to care for grandchildren. In some cases it may be used as a bit of an excuse and there is a risk that some alternative activities will not offer the same physical benefits.

3.3.4 Preference to start exercising independently

The most positive reason we heard for disengaging was because they had started to exercise independently, as they began feeling fitter and wanted to move beyond the level of exertion delivered in the exercise maintenance class. One respondent described the maintenance class as:

> "A useful stepping stone to more challenging exercise"

Interestingly, this particular individual who now exercises for 2½ hours three times per week still attends the support group where the class is delivered. She still joins in but moderates her exercise intensity to fit with her peers, such is the social draw of these groups.

3.4 Enablers to engagement

3.4.1 Having a service to use – and knowing about it

The fundamental enabler to access exercise maintenance services is the existence of a service in the first place. Where services are not available, then people can't access them. Closely allied to this is awareness of the services that are out there. Even if they exist, if potential service users aren't aware of them, then they won't use them. We have already discussed the key role that health care professionals can play in ensuring people are aware of the services available and in motivating them to access these services. The feedback from our evaluation however did not provide any insights into whether other types of marketing of services would deliver the same impact.

3.4.2 Local accessibility

People want services to be as local and accessible as possible, especially when they have limited mobility and/or did not have access to a car or a lift. Even when transport wasn't an issue, some respondents indicated that making sure the service was local was important as it minimised the travel burdens of them.

For respondents with limited mobility, the walking distance required to access classes was often a key consideration. It is important to consider the total walking distance for people travelling to access services. Some respondents indicated that ensuring that parking was available close to the exercise maintenance class was an important consideration – as some respondents indicated they could be fatigued by even short walks which would limit their ability to participate in classes – making them unlikely to attend. In addition, walking distances to access public transport must also be taken into account as some respondents indicated that they could get to facilities using public transport, but often had to change buses and walk between bus stops and often the time and distance were prohibitive

3.4.3 Range of classes and times

To maximise uptake of classes some respondents indicated that it would be beneficial to have exercise maintenance classes available at a range of times, throughout the day and evening. This was especially noted by respondents who had work or other commitments, such as caring for grandchildren. The feedback suggests that what suits people best differs widely and depends on their own circumstances, rather than specific times of day or night being suitable for particular groups.

> "I can't go [to the exercise maintenance class] because I get my shopping on Thursdays and I need to get a lift from my friend"

3.4.4 Perception of being referred

The vast majority of service users we interviewed perceived that they had been referred to exercise maintenance rather than signposted regardless of whether this was the case or not. They felt that their health care professional had endorsed the programme which provided reassurance that it was safe and suitable for them and their condition. Furthermore, feedback suggests that it is presented to them in a way that makes it seem like the logical next step and that it is a natural progression.

3.4.5 Referral/entry process

A smooth referral/entry process encouraged service users to attend in the first place and keep attending. This seemed to work best in the following instances:

- ★ approaching the end of a structured rehabilitation programme, the physiotherapist referred them onto a class and sometimes even took them along to see a class in action (or show them a video of a class)
- ★ when a referral into exercise maintenance led to an initial private meeting and assessment with a class instructor, to determine the right class for the person and explain to the individual what to expect
- ★ when respondents transitioned directly between rehabilitation and exercise maintenance without any break – so they didn't break the habit of exercising, and are therefore more likely to maintain their exercise regime

An effective referral process is crucial to maximising uptake of exercise maintenance:

- People take a referral (or perceived referral) seriously
- A smooth transition from rehabilitation minimises drop out
- One to one assessment ensures the person is matched to the right class
- Opportunities to visit the class in advance de-mystifies it and makes it less daunting

3.4.6 Confidence

Many respondents required a degree of confidence to participate in exercise maintenance classes. In some instances respondents indicated that they were initially reluctant to attend classes, fearing that they would be too challenging, or that they might not enjoy the social aspect. Some service users indicated that this initial reluctance was overcome by attending their first class, where the staff and other class members were welcoming and they were able to see first-hand the range of abilities within the class. In other instances the physiotherapist making the referral had provided enough reassurance that the nature of the activity would be suitable for them.

"I was enthusiastic about attending and I had an idea of what I was going to"

3.4.7 Clear understanding of (and belief in) the benefits

Respondents were more likely to participate in exercise maintenance when the benefits to their health were clearly articulated to them, and particularly where these were validated by a health care professional. Many service users in Greater Glasgow and Clyde indicated that they had been convinced that participating in exercise maintenance would benefit the management of their condition, help them to get better quicker and remain better, and this was a key motivator to participate.

Prior to his heart attack, Brian had been a long time smoker, worked in a high pressure job and didn't have the healthiest of diets. He also did very little in the way of physical activity. Whilst in hospital the cardiac nurses really pushed the importance of physical activity as a means of helping his recovery and in helping him to remain well. This message was reinforced by the physiotherapist during his rehabilitation programme. This really hit home for Brian and he was really starting to feel the benefit of the rehabilitation programme. When his rehabilitation came to an end he jumped at the chance to be referred to an exercise maintenance class and now does more physical activity than he ever did before.

Key message

★ getting a clear and consistent message from professionals, combined with a positive experience of embarking on physical activity, can result in significant positive lifestyle changes

3.4.8 Disposable income

Access to disposable income was another key factor which enabled respondents to access exercise maintenance. Respondents indicated that there were a range of costs associated with exercise maintenance, including:

- ★ travel and transport costs (bus fares, parking, fuel costs, etc)
- ★ class fees (typically £2.50-£4.50)
- ★ equipment costs (e.g. trainers and clothing)
- ★ costs of associated social events (e.g. costs of coffee after classes)

One service user indicated that the cost of classes alone was affordable, but when they factored in costs of having coffee, and getting to and from classes, the costs mounted up. While many of the respondents considered the classes and costs to be very affordable, the extent to which classes were considered affordable varied widely depending on the amount of disposable income available. One respondent in Greater Glasgow and Clyde also indicated that another member of the family controlled the finances, meaning they did not have access to money for classes.

3.4.9 Instructor

Service users often indicated that they were motivated to engage with, and continue to participate in, exercise maintenance classes due to the personality traits displayed by their instructors. Service users indicated that it was important that staff were friendly and approachable and made the class enjoyable. In many of the classes we observed the instructors were proactive in engaging service users in the social component of the classes, whilst also doing their exercises. This often emerged as a friendly 'banter' between service users and the class instructor.

> "She's brilliant! There's always loads of banter. She's so approachable and fun, it hardly feels like we're working"

Many respondents also indicated that they felt encouraged to attend exercise maintenance because the instructor pushed them to do the right level of exercise for them. It is important to note however that the level of exercise that respondents considered appropriate varied widely from individual to individual, with some respondents looking to push themselves hard, and other respondents wishing to get in some exercise without pushing too hard. It was therefore important that the instructor provides the patient with the right level of exercise for them – to ensure they are

challenged where appropriate, and not pushed too hard where this may stop them enjoying classes and ultimately stop them coming, and even exercising.

Alan had a stroke in 2002 and reported that he had received no rehabilitation or advice regarding exercise. Up until recently he did very little physical activity. However, his wife had started attending an exercise class at a local leisure facility that Alan would take her to. He would usually see her to the door and go off and do his own thing until the end of the class. After a while the instructor starting asking Alan why he dropped his wife off then left, and suggested that he should join the class as well. Alan declined the offer, but over the following weeks the instructor kept chipping away and eventually Alan agreed to start. He has now been attending the class regularly for the past 8 months and wishes he had started long before he did.

Key messages
★ people don't always get the message first time, or second, or third…… but sometimes persistence pays
★ proactive professionals get results

3.4.10 Technology

The use of technology to support exercise maintenance was identified by the PARCS Team as a potential area of interest to explore with respondents particularly in areas of poor service provision such as the rural Highlands where the sparseness of population makes providing services difficult. The respondents here gave very mixed responses to questions about how technology could be used to support them.

Some thought that exercise programmes delivered through television or via the Internet would be good and something they would try. For one respondent this was followed by the caveat that it would need to be on Freeview. So cost again is a potential barrier. The respondents who viewed this option more favourably were generally younger. Interestingly, one support group in Ayrshire and Arran had produced a DVD for people to use for home-based exercise.

A good example of where technology is being used to encourage physical activity is with a walking club in the West of Scotland. Although the group and members get together for gym based sessions they also have an online platform where group members can record the walking that they have done outside of the class using pedometers. The group set challenges such as walking the length of Route 66, with all members contributing to achieving the distance. This encourages group members to do more outside of the class than they would otherwise do.

Key message
★ the use of technology can extend exercise beyond the gym and open new horizons

Others were not using technology in other areas of their lives and so for them it was not something of interest.

> "It may have a place, but not for me"

Most were fairly ambivalent, and whilst they wouldn't rule it out didn't seem wholly convinced that it would be for them.

"I have used DVDs before so I would consider something through the TV or computer"

"I wouldn't dismiss it"

"I wouldn't rule it out – could do things in my own time then"

Two respondents north of Inverness had participated in rehabilitation which was delivered at two sites linked by video. Neither respondent seemed to know why the sites had been joined together, and neither felt it was particularly beneficial for them personally. Both stated that having someone in the room when they are exercising was important to reassure them and keep them safe. However, it may be that the staff supporting class participants at 'satellite' sites would not to have the same level of qualifications as the person delivering the class. This may ease some of the resourcing issues and extend reach. The challenge with technology, specifically in these areas, is even if the people will engage the connectivity is often poor so practically it may not be feasible.

Technology may enable people to access exercise maintenance when it is difficult to attend a class. It may also help provide exercise maintenance services in very rural areas.

However, it is not a panacea:

- Many people were negative or ambivalent
- Younger people were more open to the possibility
- Connectivity is an ongoing challenge

3.5 Motivations to exercise

3.5.1 Belief in the benefits

Most respondents indicated that they were motivated to exercise because they believed that exercise was beneficial to their health. Many believed that being active was important for their

general health and wellbeing, however, the extent to which respondents understood that physical activity was beneficial for their condition varied widely depending on the information they had accessed and how proactive their health care professionals were in discussing physical activity.

"My practice nurse said to remain as active as possible and not be afraid of breathlessness at times"

"All of them [health care professionals] have made it clear that if I don't do physical activity my condition will deteriorate"

Where respondents believed that exercise was beneficial for them this meant that they were more likely to exercise.

3.5.2 Desire to get well and 'back to normal'

Linked to respondents' belief that physical activity could support improvement in their health was their desire to get well again. Respondents who were extremely unwell were often motivated by the fact they didn't wish to feel as poorly and immobile as they did, and understood that doing exercise was a way to help themselves recover in the long term. People were motivated to exercise to allow them to enjoy a range of activities which they had previously done, such as:

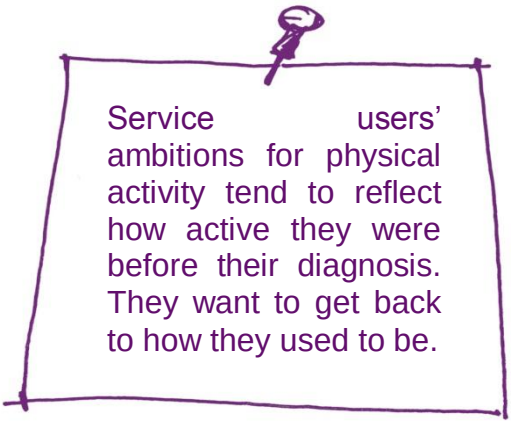
- visiting friends and family
- caring responsibilities
- playing with, and caring for, grandchildren
- walking dogs
- returning to work

The feedback we received suggests that these goals were identified by the individual, rather than a structured goal setting intervention supported by a health care professional or other intermediary.

"I was determined to win back the bowls trophy I won the year before I got ill. And here it is – this year I won it"

3.5.3 Personal aspirations for activity levels

It's important to note that in most cases the service users' ambitions for their activity levels were a direct reflection of their pre-diagnosis activity levels. Many people who were previously very active and sporty aspired to once again participate in these sports. Conversely, those who were less active prior to diagnosis were more likely to aspire to lower activity levels or lower intensity exercise. However we did come across instances where those who were



relatively inactive prior to their health event were doing more now than they had ever done. In these instances the messages about the benefits (and experiencing the benefits through rehabilitation) had sunk in and prompted them to take action.

3.5.4 Influence of spouse/partner/family member

Many of the people we spoke to who were married indicated that their spouse was very influential in encouraging them to exercise, and supporting them to do so. This was observed for both service users, and non-service users, and also extended to the wider family. One person indicated that their daughter would constantly encourage them to exercise and would have been worried if they weren't exercising. Another example given was where someone's daughter actually helped them with chair based exercises when they came round to visit. In addition, some respondents indicated that their spouse didn't just encourage them, but directly enabled them to participate, for example, by driving them to the exercise maintenance classes.

> "We push each other to stay active – we'd feel like we were letting the other one down if we didn't do it"

3.6 Motivations to continue exercise

3.6.1 Enjoyment

Those attending exercise maintenance classes often indicated that they continued to attend classes because they enjoyed them.

> "We have such a laugh. Even if I don't feel in the mood when I arrive, I always feel great by the end because we have such a laugh together"

For many the classes were enjoyable because of the friendly and sociable nature of the classes rather than the physical activity components of the class. For many, this helped to mitigate against isolation and many service users indicated that they saw class members outwith classes, at less formally-organised social events.

> "I'm on my own these days, and if I didn't come here every week, I wouldn't get out at all. I've got friends here and I feel better for being active. I never miss it if I can help it."

Staff running exercise maintenance programmes were important in facilitating this friendly, sociable, and enjoyable environment, as well as developing the social dynamic of the group whilst supporting new members to join.

3.6.2 Feeling the benefit

Many service users and independent exercisers reported feeling the physical and emotional benefit of exercising, and that this kept them going. Many respondents reported that they had more energy and that by exercising they were able to increase the amount of exercise and activity that

they could do – which meant being able to do the things they enjoyed on an ongoing basis. The feedback from respondents seems to suggest that those who exercised independently were more likely to continue to exercise because they had previously led active lives or because they believed that physical activity was important for managing their condition, recovering, maintaining their health, or slowing deterioration.

For some it was just a general feeling of wellbeing:

"I get a good night's sleep, I have a clear conscience, I'm not worried because I know I've done some exercise"

"I hate swimming – but I feel the benefit, know it's doing me good, so force myself to do it"

For others there was more certainty that exercise was having a tangible effect on their condition:

"I feel better and I'm more active than before I had the heart attack"

"I would've had more hospital admissions if I hadn't kept active"

Some respondents indicated that they had stopped doing their exercises on a number of occasions and that they had felt more poorly as a result – for example feeling that they had less energy, or feeling that they had aches from prolonged periods of inactivity.

In addition, respondents cited benefits to their mood and to their mental health from participating. Some respondents indicated that it was good for clearing the mind, while others indicated that it 'makes you feel better – happier'. This often linked to the fun and enjoyment aspect already discussed.

"it's not just the physical benefits, I feel better mentally as well, more upbeat, more positive"

3.6.3 Routine and habit

For some people, attendance had become a part of their routine, with some individuals having regularly attended classes for up to 10 years. They can't think what it would be like to not do it, and emphasises the importance of sustained long term service provision.

3.6.4 Lack of time limit

Respondents in exercise maintenance classes were often motivated to continue by the knowledge that their classes were not time limited – and that their exercises could be done on an ongoing basis to continually support them to improve or manage their health.

3.6.5 Mutual support

Some respondents were inspired to participate by peers in their class, and seeing them managing their condition. They indicated that they were motivated by their peers when they saw:

- improvement in the condition of their peers
- that there are others with conditions more serious or debilitating than their own who are exercising and working to improve their condition

> "When someone new comes along, I can say to them: look, I've been where you are, and I never thought I'd be able to do this, but now I can – and you can too."

Others reported that they were motivated to continue exercise maintenance to support others, and to act as an example. In these instances they had often benefited in the same way when they had first started the class and they wanted others to receive the same welcome and support.

3.6.6 Continued progress and self-efficacy

For some individuals it was important to prove to themselves that they could do it, and that exercise could make a difference to their condition. For example, for one service user who had a stroke said it was important to show that it was possible to continue increasing their function beyond the early stages of recovery (which respondents reported that many health care professionals emphasised as the most important period for recovery).

3.7 Motivations to engage with organised classes/services

3.7.1 Safety, tailoring and supervision

One of the key reasons many service users indicated that they were motivated to participate in exercise maintenance classes was because the classes offered a safe environment in which they could exercise. Many respondents were reluctant to exercise at home, or to push themselves, due to fear of over-exerting themselves and exacerbating their condition. This fear was often mitigated in exercise maintenance classes by the presence of a trained instructor or health care professional who knew about the respondents condition and could tailor and supervise their exercise to ensure it was done at a safe and appropriate level. It is important to highlight that respondents trusted both health care professionals and instructors of classes aimed at people with long term conditions, to understand their condition and devise appropriate exercises for them.

> "the exercise instructor has a good knowledge of my condition, medication and what exercises are appropriate for me"

"Classes give you a better understanding of your condition and what you can and can't do to help"

3.7.2 Social benefits

Whilst most service users did not join classes specifically for social interaction, for some the social aspect made classes more appealing and motivated them to participate. For others, particularly those who were socially isolated, the opportunity to join a social group was both motivational and rewarding.

"I'm on my own these days, and this class is one of the few things I go out for. I wouldn't miss it, the social bit is so important."

One stroke support group that we visited have a qualified physiotherapist come in and run exercise sessions for the first hour, with different areas of the venue being used for different types of exercise and intensity. The second hour is 'tea, cakes and games' – and if you want to attend the social aspect you need to come along for the exercise. The attraction of the social element is enough to get those that are a bit more resistant to exercise to come along and participate during the first hour. As one group member put it:

"I hate the exercise – I know it is good for me but it reminds me of all the things I can't do anymore. I'm really here to socialise but I do the exercises as well"

3.7.3 Stepping stone to other types of exercise

Some service users were also motivated to attend structured exercise maintenance classes as a pathway to allow them to access further classes, or as a platform to support themselves to build up their fitness and be able to exercise independently. Some service users indicated that being in a class opens up doors, helping them to learn about, and progress onto other classes. One service user in Ayrshire and Arran indicated that they had graduated to a higher intensity class, however, they only became aware of this class through their initial engagement in the exercise maintenance classes. However, this was not always the case, and was dependent on the number and type of classes available in each area, as well as the health of the individual and the range of classes they might potentially move onto.

One respondent who had progressed onto independent exercise indicated that they had benefited from building a rapport with the exercise maintenance instructor, who had helped them develop a tailored plan for exercising independently. This individual was now happy to exercise independently, knowing they were doing exercises which were suitable for them, and had been approved by an instructor who understood their condition and the appropriate exercises to manage their condition.

4 CONCLUSIONS AND AREAS FOR CONSIDERATION

4.1 The journey

In this section we present our conclusions about the patient journey into exercise maintenance.

4.1.1 Touchpoints

Our findings suggest that there are specific touch points between service users and healthcare professionals that can greatly influence the decision to engage with physical activity:

- Physiotherapists - in hospital during initial therapy sessions and during rehabilitation sessions in the community
- Clinical nurse specialist – in hospital, on ward
- Practice nurses – during routine appointments and chronic disease management clinics

Positive messaging, reassurance, inspiration and encouragement provided by healthcare professionals at these key touch points are often the catalyst for a engagement with rehabilitation and/or exercise maintenance.

However, they are not the only health professionals that have a role to play and consistent positive messaging across all roles is essential. In particular consultants, other hospital doctors and GPs can play a role in instigating the idea of physical activity as part of their recovery and ongoing management. Whilst these health professionals often can't have the same depth of discussion as those at the key touch points, they can be beginning to encourage their patients to consider physical activity. For instance, a consultant mentioning to their patient that a nurse or physiotherapist would be speaking to them about rehabilitation sessions and why rehabilitation is important, would be enough to plant the seed and place added emphasis on its importance.

4.1.2 Continuity of pathway

Our evaluation has shown that a cohesive and continuous pathway is critical in influencing and enabling people to have a sustained engagement in physical activity beyond their diagnosis and/or treatment. We heard from several respondents who had experienced a seamless transition from the point of diagnosis and/or treatment, through rehabilitation and into community exercise maintenance provision. Where this seamless pathway is in place it greatly increases the potential and likelihood for continued engagement in physical activity.

Our evaluation suggests that in recent times the cardiac and pulmonary pathways have become increasingly cohesive and largely effective in providing a continuous journey. However, the experiences of those people affected by stroke were more varied, and suggested a more fragmented and inconsistent pathway with many experiencing a successful entry into rehabilitation but little support, advice or signposting thereafter.

4.1.3 A system-centred pathway

A consistent theme from our evaluation has been that the pathways into rehabilitation and exercise maintenance are system-centred rather than person-centred; the pathway works well provided the service user is ready to proceed at the same timetable as the pathway proceeds. If a patient is unable or unwilling to proceed at that pace, this acts as a barrier to remaining on the pathway and

making a successful transition into rehabilitation and/or exercise maintenance. Once off the pathway there is no guarantee that a person will find their way back.

4.2 Regional Specific points

Our evaluation specifically aimed to investigate differences in services, from the service user perspective, in three different regions of Scotland. Our conclusions in relation to these differences are presented below.

4.2.1 Greater Glasgow and Clyde

Greater Glasgow and Clyde has an established and mature exercise referral scheme, Live Active, which Allied Health Professionals can refer in to and caters for a wide range of long term conditions. In addition, Vitality is an exercise maintenance programme in place across NHS Greater Glasgow and Clyde region and can also be accessed by people with a variety of long term conditions. However, during our evaluation we found that those with the most restricted mobility, specifically those severely affected by stroke, perceived a lack of provision available and suitable for them. This was compounded by barriers and challenges relating to transport and assistance as well as a lack of knowledge and understanding about the benefits of physical activity in relation to their condition and what exercise would be appropriate for them.

This evaluation did not involve a mapping element, but we are aware of peer mentors being available in some but not all Vitality classes. There appears to be a need to make available provision more visible and consider how the additional support needs of this client group can be provided for if it does not already exist eg greater access to buddying and practical support to get to classes.

Many support groups have access to volunteers that help their members with mobility challenges to get to and from the group. Where these groups are not in a position to provide their own exercise maintenance activities it would be worth exploring with the groups whether this can be facilitated through existing community resource/provision. As we discuss later in this section, support groups have the potential to be a key vehicle for and enabler to engaging with exercise maintenance for their group members, particularly those with the most severe barriers to engagement.

Areas for consideration:

- ★ conduct a scoping/mapping exercise to fully understand what provision is available and suitable for people affected by stroke, particularly those with severe mobility restrictions; in addition this scoping should explore the extent of potential needs for these services including additional assistance requirements of the potential service users
- ★ where gaps in terms of required service provision and additional support needs are identified during the scoping/mapping exercise referenced above, work with statutory and voluntary sector providers to explore how these gaps can be filled
- ★ explore how third sector support groups (those that do provide exercise maintenance activities for members and those who do not), and their volunteer resource, can support members to access existing exercise maintenance provision
- ★ work with HCPs to ensure the messages regarding the importance and potential benefits of physical activity participation are being delivered to those affected by Stroke

4.2.2 Ayrshire and Arran

Across Ayrshire and Arran there appeared to be good interaction amongst lead staff in leisure services, most strongly across the south and east of the region. This has enabled good practice to be shared and provision to be co-ordinated. Whilst this way of working is potentially helping to ensure that good quality and suitable provision is available, and that movement between the provision is possible, it does seem to be reliant on the long term relationships formed by the leisure services leads. Therefore it is potentially vulnerable to changes in staff.

Although our discussions with leisure services staff indicate there is good interaction and collaboration across the different leisure services providers, our meetings with support groups indicate there is a need for those providing leisure services to make local support groups, and other potential service users, more aware of the full range of provision available.

The evaluation also found that there were perceptions that capacity was lacking or stretched:

- **Shortage of physiotherapists** – We heard several stories relating to the waiting times (in some instances over 40 weeks) to access pulmonary rehabilitation. As well as this creating a barrier in itself it has also contributed to the perception that there just aren't enough physiotherapists.
- **Insufficient classes** – Although there were instances of service users moving across geographical boundaries in order to access provision, others indicated that they felt that not enough classes are available in Ayrshire overall, and particularly within their locality. Either greater awareness of existing provision or additional provision to meet need is required.
- **Shortage of suitably qualified instructors** – There is a perception that there are not enough qualified instructors to run exercise classes for people with long term conditions. If there was sufficient provision available to meet the needs of the local population this would go a long way to removing this perception

Consequently there are people who would like to be participating in exercise maintenance but aren't, and others who would like to do more than they already are, but feel they can't.

Areas for consideration:

- encourage closer interaction between third sector support and/or exercise groups and leisure services providers in Ayrshire and Arran to ensure that groups and their members are fully aware of all existing provision
- ensure HCPs at the key touch points on the pathway are fully aware of all available provision and the mechanism for making referrals
- review data from the PARCS CHSS scoping exercise to understand whether there is a real shortage of classes and qualified professionals to take rehabilitation and/or exercise maintenance. If gaps are identified, work with relevant partners and stakeholders from the statutory and third sector to identify how gaps will be filled.

4.2.3 Highland

Perhaps unsurprisingly the main challenge specific to the Highlands was the distinct lack of service provision outwith the main urban centres, with those living in the more rural and isolated areas facing significant barriers to access.

The challenges around transport and accessibility for regions with a high proportion of rural areas mean that there is a real need, and demand, for services to be truly local. The main challenge in addressing this need, however, is that smaller populations make it more difficult to provide a cost effective high quality provision that meet the needs of the local population and can justify the

investment. Our evaluation suggests that technology does not currently offer a suitable solution to this challenge, due to a combination of ambivalence amongst the target population and a lack of appropriate connectivity infrastructure.

Areas for consideration:

- ★ explore and identify areas outwith the main urban centres that could act as a hub for several surrounding areas with smaller populations
- ★ if any areas are identified, work with the necessary statutory and third sector organisations to explore how and what services can be delivered
- ★ when designing services for areas with smaller populations, where possible these should be suitable for a wide range of long term conditions, perhaps combined with a general exercise referral service, therefore maximising the potential pool of service users

4.3 Key factors influencing physical activity and engagement with services

The diagram below provides an overview of the key factors that our findings indicate influence initial engagement and continued participation in physical activity including:

- ★ Barriers – what gets in the way of people engaging
- ★ Reasons for disengaging - what is it that makes people stop their participation
- ★ Enablers – what is it that makes it possible for people to engage
- ★ Motivators – what makes people want to exercise generally, what makes them engage with available services and why do they continue

Figure 11 – Factors influencing engagement with exercise maintenance

Barriers	Reasons for disengaging	Enablers	Motivators to start and continue

• transport
• accessibility
• cost
• weather and dark nights
• lack of awareness of service
• fear and confidence
• fear of entering a new social interaction
• image of group
• not a joiner
• lack of motivation
• concern about taking anothers place
• busy life
• broken routine
• other co-morbidities
• perceptions of exercise
• compound effect of multiple barriers
	• broken routine
	• provision disbanded
	• exacerbation of condition
	• using time for other things
	• preference to start exercising independently
		• having a service available
		• local and accessible
		• range of classes and times
		• perception of being referred
		• referral/entry process
		• confidence
		• clear understanding and belief of the benefits
		• disposable income
		• instructor qualities
			• **to exercise**
			  • belief in the benefits
			  • desire to get well again and 'back to normal'
			  • influence of spouse/partner/ family
			• **to engage with services**
			  • safety, tailoring and supervision
			  • social benefits
			  • a good place to start their exercise
			• **to continue:**
			  • enjoyment
			  • feeling the benefit
			  • routine and habit
			  • lack of time limit
			  • mutual support
			  • continue to see progress

4.4 Lessons for improving delivery processes

Whilst our evaluation only focused on the respondents' perspectives we have identified a number of lessons for improving delivery processes.

4.4.1 Suggested pathways

We were asked to consider whether our findings suggested an ideal pathway that service users should experience as they proceed from symptoms/diagnosis into exercise maintenance. Much work has already been done through the PARCS project to develop ideal pathways in detail. The figures below provide an overview of the suggested pathways generated as our interpretation of our findings. However, as already discussed, whilst these are simple and logical, the timetable for an individual's journey through the pathway will not be consistent and this is where complexities arise. If a service user is unable or unwilling to engage with the next step in the pathway at the logical time of first offering, there need to be processes in place to ensure they can re-engage easily with the pathway when the time is right.

Figure 12 – Suggested pathway – new event/diagnosis or worsening/change in condition

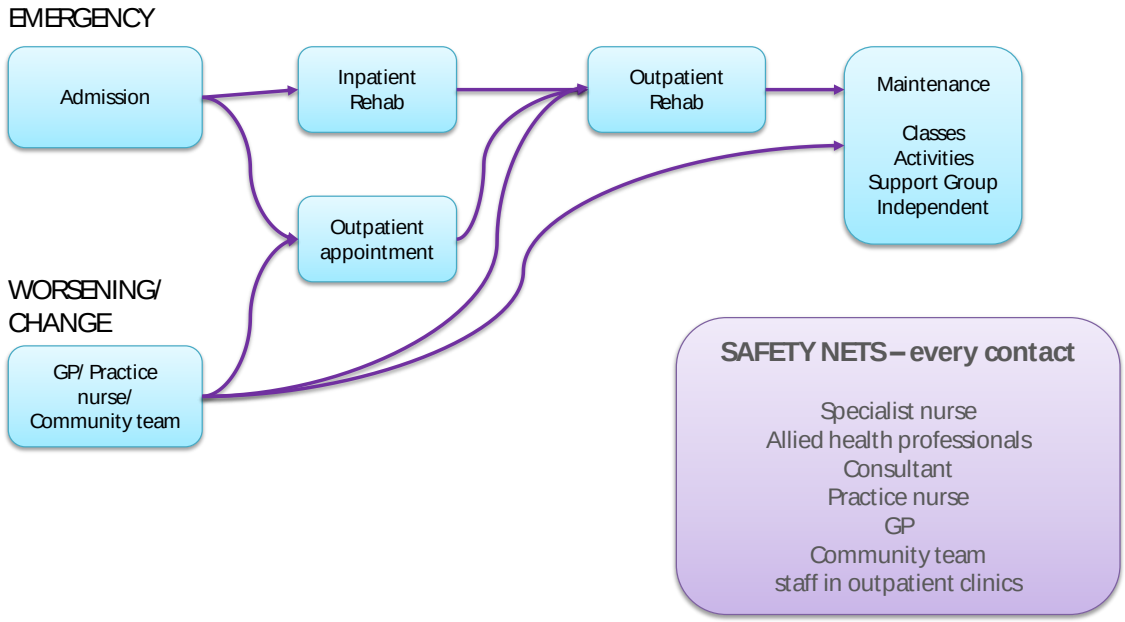
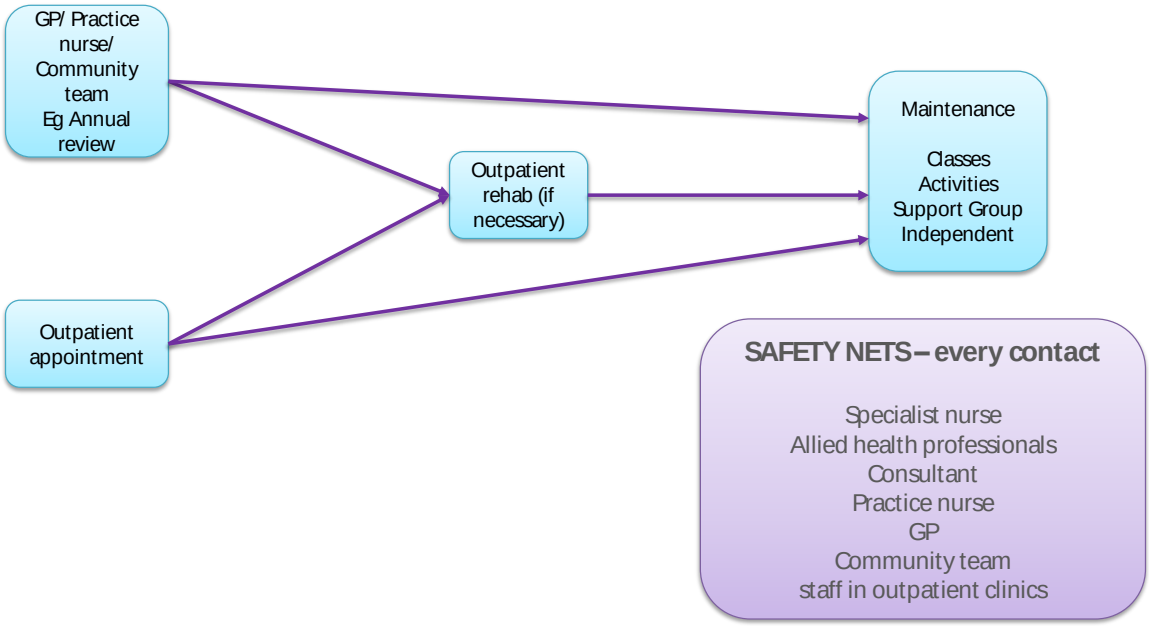


Figure 13 – Suggested pathway - existing condition but not currently involved in exercise maintenance



To maximise the effectiveness of these pathways, 4 key components must be embedded:

Figure 14 – key components affecting effectiveness of pathway

Introduce it early	Keep reinforcing	Avoid hiatus/breaks	Provide safety nets
• HCPs need to be discussing physical activity and communicating positive messages regarding physical activity with the patient and at the earliest point. eg diagnosis or post treatment • Initial message from a senior HCP (eg consultant) can carry more weight • At this stage the focus is selling the benefits of physical activity	• Throughout the patient journey it is critical that the messages in relation to physical activity and exercise maintenance are continually reinforced • Mix of health care professionals providing a consistent message - nurses, physiotherapist, doctors - at every contact	• Seamless transition between recovery, rehabilitation and exercise maintenance gives highest chances of continued and sustained engagement • Any delays at the transition points can lead to disengagement and people leaving the pathway • Vital that, when an individual is ready to make the next step on the pathway, that this is facilitated with as little break in time as possible (no break at all is the ideal)	• People disengaged for a variety of reasons - there needs to be safety nets in place, to ensure they are re-engaged when the time is right for them • This will require a proactive approach from HCPs in the primary and secondary care settings • For those that disengage from exercise maintenance a process for 'follow up' should be introduced to encourage/ease re-engagement as approapriate

Areas for consideration:

★ Ensure that the following 4 components are embedded in the patient pathways:

1. Introducing physical activity early – introducing the benefits and importance of physical activity in relation to the patient's condition at the earliest point
2. Reinforcing the message – consistent and positive messages delivered at key points along the patient pathway by a variety of HCPs
3. Avoiding breaks – seamless transition into and from the different stages on the pathway
4. Providing safety nets - ensure the appropriate systems and follow up is in place to act as safety nets for those that do not engage through the pathway or disengage following referral

★ the pathway for stroke patients appears to be in greatest need of improvement. Therefore a priority is to work with relevant HCPs to ensure that the pathway for Stroke patients is as cohesive and seamless as that of the cardiac and respiratory pathways

4.4.2 The role of the HCP

The role of the HCP is a critical one. They are in a position of key influence and are facilitators along the patient pathway. Whether it is a nurse in a GP practice, or a physiotherapist taking rehabilitation classes, they have the greatest opportunity to encourage and enable a patient's participation in physical activity.

But to do that, HCPs at the key touch points on a patient's journey (and beyond) need to understand and be convinced of the importance of physical activity, have good information about options and local provision, and provide positive and consistent information to their patients.

Areas for consideration:

- ★ ensure HCPs understand the critical nature of their role in influencing patients' propensity to engage with physical activity
- ★ ensure HCPs are equipped with the skills, knowledge and confidence to deliver the necessary messages and discuss the various options available with their patients

4.4.3 Communication

Our evaluation suggests that to maximise engagement in rehabilitation and subsequently exercise maintenance, all HCPs involved in a patient's journey need to be delivering a consistent and positive message. The vast majority of service users that we spoke to took motivation from the messages they received from HCPs about the importance and associated benefits of physical activity participation. Conversely, many of the non-service users that we spoke to reported a lack of communication, or mixed messages, in relation to physical activity. This meant that many were unaware of how physical activity could benefit them and also what was appropriate for them to be doing.

Our evaluation also shows a disconnect between the terminology used by HCPs relating to physical activity and the language used by respondents. Where HCPs refer to rehabilitation, our respondents tended to refer to this as 'going to physio'. Where HCPs talk about exercise maintenance our respondents tended to refer to exercise classes. The term most open to different interpretations though was 'physical activity'. This conjured up a range of different meanings to different people, with most seeing it as some form of formal, organised sports. Things like gardening and walking were often not considered as physical activity. 'Being active' seemed to be the catch all that people related to.

Whilst this may seem a relatively minor point it is important to be delivering a clear message and in terms people can understand and relate to. This can potentially reduce some of ambiguity and misconceptions that prevent people from participating

Areas for consideration:

- ★ work with HCPs that are engaging with patients at the key touch points along the pathway to ensure that the right messages are being delivered at the right time and in the right way; this should include the language and terminology being used

4.4.4 Role of third sector support groups

Many support groups are already adding to the range of services available to people with long term conditions (eg social and peer support) and there are more that, with the right support, could expand this further. During our evaluation we have visited support groups that have made arrangements to bring in qualified instructors and/or physiotherapists to deliver some form of exercise maintenance activity. This is providing a valuable service to group members, many of whom would not be able to/want to access other provision. Some of these groups see it as a constant struggle to get new members and question how often health care professionals actively refer or signpost to their groups.

More groups would like to be able to offer exercise maintenance. We visited support groups that would really like to be able to bring in qualified physiotherapists and/or instructors for their group members. The group leads are aware that their members would benefit greatly from it and currently are unable to access any other existing provision. The problem appears to be one of

finance, with groups unable to finance the additional costs associated with providing the service. This is a real missed opportunity to integrate exercise maintenance into existing activities and routines, which group members are therefore likely sustain.
Often it is these support groups that have also catered for the additional support needs of their members – for example, assistance to get out the house or transport to the venue – and therefore removed the practical barriers that would otherwise prevent their group members from participating. Other types of provider are unlikely to be able to offer this level of assistance and support, so individuals with additional support needs group would often be unable to access exercise maintenance otherwise.

Areas for consideration:

- ★ explore ways to ensure the third sector support groups offering structured exercise maintenance, overseen by a suitable person/professional, is embedded in the referral options and pathway to help ensure new people are going to the groups and they are able to retain a sufficient member base to make the groups financially viable and sustainable
- ★ assist support groups in identifying and applying for/accessing funding opportunities relating to the provision of physical activity
- ★ identify and work with existing support groups that have a desire to provide 'in-house' exercise maintenance to overcome the barriers that are currently preventing them from doing so
- ★ identify and work with existing support groups to explore how their volunteer resource can support group members to access existing provision
- ★ explore whether there is scope to achieve greater integration between third sector support groups and other service providers; eg could leisure services provide or 'loan' specialist instructors to third sector groups?

4.4.5 Service Design

The way a service is designed will have a significant impact on whether it is successful or not. An ill-designed service can unwittingly create barriers that need not be there. Our findings from service users indicate the following design issues should be considered when designing exercise maintenance services:

Continuity

Continuity of provision is critical for individual service users as well as health care professionals. Individual service users take great comfort and confidence in knowing that they do not have a defined time limit on their attendance. It is not just a 13 week programme or the provision is not going to disappear in a few months' time because it has been funded through a pot of money that is no longer available. It enables them to build a routine and develop relationships with other service users which can sustain participation. From a health care professional's perspective it is impossible for them to remain up to date with provision that is here today and gone tomorrow. There needs to be a fairly stable and visible provision that they feel confident referring into. Whilst we appreciate that short term pilot provision does have its place in terms of its value in evidencing need and impact, the finite nature of it can cause issues and prevent it from being as successful as it could be.

Accessibility

The extent to which a service is accessible by the target audience will have a huge influence on whether people will engage with it or not. Accessibility need to be considered from two different yet related aspects. The first is in terms of accessibility to the venue – is it linked by public transport, how long will the journey be from intended catchment areas, should the provision be

made available during the day or in the evening, do the buses run at the right times to get there and back, what additional support might service users need? The second aspect is access into the venue itself – is there enough car parking overall, is there enough parking near the entrance to the venue, are there hills or steps that make it more difficult to access?. In considering accessibility it is worth seeing it through the eyes of the service user. Therefore we would recommend that service users are involved in the design of services particularly in relation to assessing the accessibility of proposed provision, and that exercise maintenance services should be subject to equality impact assessment.

Integration into the referral pathway

Whilst we came across a few evaluation respondents that had been proactive in seeking out a referral to exercise maintenance provision, they were the exception rather than the rule. More often than not service users had been signposted or referred by a health care professional. This suggests that any new service being designed (or existing service being redesigned) needs to be integrated into the pathway. Essentially this means that the appropriate health care professionals need to be aware of it, be confident that it is safe and appropriate provision and understand the referral process.

Data collection

Most services currently collect very limited (if any) data about service uptake, attendance, characteristics of service users, continuity of attendance and disengagement. The lack of local data has proved an obstacle to the economic impact assessment, and we understand it has also been a challenge to the PARCS scoping exercise. Without accurate and appropriate data collection, it is impossible to assess the capacity, effectiveness and efficiency of services. It is equally challenging to plan for future services.

Areas for consideration:

- ★ ensure that these 4 design issues (ie continuity, accessibility, integration into the referral pathway and robust data collection) are considered in the design of future services and the further development of existing services
- ★ ensure that development of consistent data collection is prioritised for existing services across Scotland

4.5 Lessons to inform secondary prevention

4.5.1 Getting the timing right

The point at when someone is referred/signposted to rehabilitation or exercise maintenance does seem to have one rather striking peculiarity. Our evaluation suggests that in most instances referrals are made at the point of diagnosis or shortly after treatment. However, our evaluation revealed a number of instances where patients had been diagnosed with a condition (eg COPD) that was not considered severe enough to warrant signposting/referral to rehabilitation or exercise maintenance. This is perhaps understandable due to resource constraints, but these individuals were later referred to rehabilitation and exercise maintenance due to a deterioration in their condition. An earlier referral may have helped them manage their condition and remain at a less severe end of the spectrum for longer, therefore may have represented a saving in the longer term.

This evaluation project was not extensive enough to conclusively prove that earlier referral/signposting would deliver benefit.

Areas for consideration:

- ★ to understand the extent to which 'delayed' referral (in relation to severity of condition and rehab/exercise maintenance offered) is taking place and whether there would be health and economic benefits associated with earlier referral.
- ★ if the health and economic case is proven then the evidence should be used to influence a change in practice

APPENDIX 1

TOPIC GUIDE FOR INTERVIEWS WITH SERVICE USERS

Background details

Name:	
Age:	
Gender:	
Ethnicity	
Work status:	
Postcode:	
Region: e.g. Angus, Tayside	
Condition(s):	
Date of Diagnosis:	
Contact email/telephone:	

Health context

1 **Can you tell me a little bit about your condition from when you were diagnosed?**
Get the interviewee to tell their story in their own words -use pathway template
Ensure the following is also captured

- Do you still attend hospital as an outpatient – if yes who do you see (which clinics)
- How often do you visit your GP for your condition

Never		3 x per year	
Annually		4 x per year	
2 x per year		> 4 x per year	

- How many times have you been admitted to hospital over the last year, and were these related to your condition

None		Three	
One		Four	
Two		> four (how many)	

No. related to condition	

2 When you were being seen by health care services (NHS) for your condition, were you advised about the importance of physical activity in relation to your condition?

Yes		No	

3 Who talked to you about the importance of physical activity/exercise? (Tick all that apply)

GP		Peer	
Hospital doctor		Support group	
physiotherapist		Charity (pls name)	
Occupational therapist		You, yourself	
Nurse		Other (pls state)	
Exercise instructor		Don't know	
Family			

4 What did they tell you?
Make sure you capture who said what.
Probe if there were options, 'a menu' were they helped to navigate around the options, were they getting the same message from all, or was it mixed messages?

5 What did you think about that?
Probe around quality and quantity of information, the way it was presented, was there anything to take away for reference. What information did they not get, would they like options to choose from?

6 What other advice were you given with about looking after yourself?
Prompt for healthy eating, smoking cessation, weight loss etc

7 Have you acted on any of the advice given?
What, why, why not?

Current situation

8 Can you tell me what exercise and activities you participate in on a regular basis as part of an organised group/class?

In relation to any organised class/groups:

- Who provides it and where

Name of Group	Location

- Is it condition specific or generic?
- How long have you been attending the class?

< 6 months		6 mths – 1 yr		1- 2 yrs		2-3yrs		> 3yrs	

- How often do you attend this class?

< 1 per month		1 per week	
1 per month		2 per week	
2 per month		> 2 per week	
Other:		State:	

- How long is the class?

9 Does the activity or group you participate in do anything other than physical activity?

10 Physical activity includes walking, active household chores, and sport and leisure activity. How much time do you spend on these activities per week and what are they?

- What else?

Exercise maintenance		Walking independently	
Walking in a group		Golf	
Gardening			
Others:			

- How much per week

None	
< 30 mins	
30 – 60 mins	
1 -2.5 hrs	
> 2.5 hrs	

The journey

11 How was it you came to be at the class/group?
Probe for was it referral or signposting, by who and at what point in the patient journey?

- How did you find out about your exercise class suitable for your condition in your area?

Via NHS		Other	
GP		Exercise instructor	
Hospital doctor		Family	
Physiotherapist		Peer	
Occupational therapist		Support group	
Nurse		Charity (pls name)	
		You, yourself	
		Other (pls state)	
		Don't know	

- If NHS did someone formally refer you or tell you about an exercise maintenance class?

Referral	
Told	

- Where did you find out about your exercise class?

When attending cardiac rehab		When attending routine review with GP/nurse	
When attending stroke rehab		When attending consultant specialist review	
When attending pulmonary rehab		I found out myself	
never		Other pls state	

- When in relation to your diagnosis did you find out about a suitable class?

When diagnosed		1-2 years after diagnosis	
Within 6 months of diagnosis		2-3 years after diagnosis	
6-12 months after diagnosis		More than 3 years after diagnosis	

12 **How did you find the process from being referred/signposted to actually getting to the class?**
Probe for how information was passed, how much and quality of information; any delays in accessing services, was there any follow up.

- Was it an easy move from hospital/health to community support (including maintenance exercise activity and advice on self-management)? **Yes/No**
- If no – what were the issues/difficulties?

No advice on exercise maintenance groups		Advice and support ended after hospital care finished	
No exercise maintenance groups in area		Advice and support ended after rehabilitation finished	
Lack of advice and information about how to manage my condition in the community		Advice and support ended after I went home	
No advice about support groups		Other (please state):	

- What was good about it? What went well?

13 **Were you referred/signposted to any services that you have been unable to access?**

The experience

14 **How did you feel about being referred to a class?**

15 **Did you have any concerns?**

16 **How did you feel when you arrived at the class for the first time?**

17 **How is it now?**

18 **Has there been anything which has made it more difficult for you to participate in the class?**
If yes, how have you overcome these difficulties?
Probe – travel, accessibility, cultural factors

19 **Have you seen some other people who attended disengage?**
If yes, why do you think that might have happened?

Outcomes

20 What have been the benefits of being part of this exercise class?
Probe for general health and wellbeing, specific improvements such as see GP less, reduced medication, mobility, spin offs such as increased social contact

None		Helped me to remain independent	
Social support/interaction		Motivation to exercise	
Helps well being		Encouraged me to do more physical activities independently	
Feel part of community		Helped me to maintain my activity levels	
Helps understand and manage my condition(s)		Increased my activity levels since having this condition / diagnosis	
Helps mental health (better mood)		Allowed me to achieve my goals e.g. play with grandchildren	
Improved function – able to do day to day tasks more easily e.g. walking		Helps me to remain active whilst I have changes in my condition	
Helped me to remain more active		Others pls state	

21 How do you feel your condition is since joining?

Worse	
Much the same and how I manage it has remained unchanged	
Much the same but I can manage it better	
Better	
Not applicable	
Other (please state):	

22 Would you recommend the class to a family member or friend who had a similar condition?
Why do you say that?

APPENDIX 2

TOPIC GUIDE FOR INTERVIEWS WITH NON-ENGAGERS

This topic guide should be used in conjunction with the patient pathway template.
It is also important to ensure all the boxes are completed as these will supplement the PARCS questionnaires.

Background details

Name:	
Age:	
Gender:	
Ethnicity:	
Work status:	
Postcode:	
Region: e.g. Angus, Tayside	
Condition(s):	
Date of Diagnosis:	
Contact email/telephone:	

Health context

1 **Can you tell me a little bit about your condition from when you were diagnosed?**
Get the interviewee to tell their story in their own words -use pathway template
Ensure the following is also captured

- Do you still attend hospital as an outpatient – if yes who do you see (which clinics)
- How often do you visit your GP for your condition

Never		3 x per year	
Annually		4 x per year	
2 x per year		> 4 x per year	

- How many times have you been admitted to hospital over the last year, and were these related to your condition

None		Three	
One		Four	
Two		> four (how many)	

No. related to condition	

2 **When you were being seen by health care services (NHS) for your condition, were you advised about the importance of physical activity in relation to your condition?**

Yes		No	

3 **Who talked to you about the importance of physical activity/exercise? (Tick all that apply)**

GP		Peer	
Hospital doctor		Support group	
Physiotherapist		Charity (pls name)	
Occupational therapist		You, yourself	
Nurse		Other (pls state)	
Exercise instructor		Don't know	
Family			

4 **What did they tell you?**
Make sure you capture who said what.
Probe if there were options, 'a menu' were they helped to navigate around the options, were they getting the same message from all, or was it mixed messages?

5 **What did you think about that?**
Probe around quality and quantity of information, the way it was presented, was there anything to take away for reference. What information did they not get, would they like options to choose from?

6 **What other advice were you given with about looking after yourself?**
Prompt for healthy eating, smoking cessation, weight loss etc

7 **Have you acted on any of the advice given?**
What, why, why not?

Current situation

Service available – not used (Use this section if service is within 5-6 mile radius)

8 **What do you know about physical activity or support groups available in your area for people with your condition? Are you aware of other groups and services which exist to help you manage your condition?**

9 **Have you ever attended? Tell me about your experience.**

10 **If attended and dropped out - why did you stop going?**
If never attended - what stopped you attending?
Are there any cultural issues at play?

11 **What or who would encourage you to participate (again)?**
Are there key people?

12 **Is there anything that could be done practically that would help you to participate?**
Explore:

Attitudes to use of technology –explore attitudes to support delivered through TV, any experience of tele-health internet (eg Skype) – is the infrastructure in place to facilitate this e.g. broadband, satellite, cable
Accessibility – travel to location, time of day, venue e.g. perceived exposure to public, other users (cultural)

13 **Do you do any sort of other physical activity? Tell me about it?**
Define physical activity as including walking, active household chores, and sport and leisure activity. How much time do you spend on these activities per week and what are they?

Exercise maintenance		Walking independently	
Walking in a group		Golf	
Gardening			
Others:			

- How much per week

None	
< 30 mins	
30 – 60 mins	
1 -2.5 hrs	
> 2.5 hrs	

Go to 23

No service available

14 **Do you do any sort of physical activity? Yes/No If yes go to 15, if no go to 17**

15 **Tell me about it?**
What, how much, how often, challenges, motivation?

Define physical activity as including walking, active household chores, and sport and leisure activity. How much time do you spend on these activities per week and what are they?

Exercise maintenance		Walking independently	
Walking in a group		Golf	
Gardening			
Others:			

- How much per week

None	
< 30 mins	
30 – 60 mins	
1 -2.5 hrs	
> 2.5 hrs	

16 **What have been the benefits of physical activity?**

17 **Would you like to do some form of physical activity /Is there any other physical activity you would like to do?**

18 **If there was an appropriate exercise class or activity group available in the area would you attend?**
If no, why do you say that? (Go to 21)

Are there any cultural issues at play?

19 **What sort of exercise class or group would you like to see in the area?**

20 **What else would be needed to enable you to access such a group?**
Accessibility – travel to location, time of day, venue e.g. perceived exposure to public, other users (cultural)

21 **What or who would encourage you to participate in physical activity?**
Are there key people?

22 **Is there anything that could be done practically that would help you to participate in physical activity?**
Explore:
Attitudes to use of technology –explore attitudes to support delivered through TV, any experience of tele-health internet (eg Skype) – is the infrastructure in place to facilitate this eg broadband, satellite, cable
Accessibility – travel to location, time of day, venue eg. perceived exposure to public, other users (cultural)

Perceptions of exercise

23 **Do you have any concerns about physical activity? What are they?**

24 **Do you think not taking any physical activity has had/is having a negative impact on you condition or general health and wellbeing?**
With care and if appropriate rapport has been established probe re possible depression, medication

25 **What do you think the benefits of participating in physical activity are?**