Introduction

Chest Heart & Stroke Scotland provides advice, support and services to people affected by heart and lung disease, or living with the effects of stroke. With a decreasing mortality rate from previously life-threatening disease such as heart attack and stroke, increasing rates of lung disease, and an ageing population, more people than ever in Scotland are living with the impacts of these life changing conditions. We conservatively estimate that over half a million people are living with these conditions; and when considering the wider impact on families and carers, the impact is in reality far greater.

Physical activity is a core component of the rehabilitation which our service users need, and is vital in maintaining their long-term health and wellbeing. Our community services include exercise opportunities and peer support to give people the confidence to be physically active, and help ensure that the benefits of rehabilitation programmes are not lost. The support we provide is person-centred and helps people identify and achieve their own goals; for some, being physically active means enabling them to live independently within their own home; for others, it means returning to sports participation.

1. Can you provide examples where a community based approach has been successful in removing barriers to participation in sport and physical activity?

Around one in ten of Scotland's population are living with lung disease, heart disease, or have had a stroke. Whilst the mortality rates from cardiac disease and stroke continue to decline, the numbers of people living with the long-term effects are increasing, due to our ageing population and the improvements being made to medical treatment. Similarly, there are more people than ever living with lung disease, but in contrast mortality rates are not declining.

The benefits of physical activity to this population are well documented. There is a substantial body of evidence on the impact on physical and mental recovery, health and wellbeing, and cognitive function. It helps enable people to better self-manage their conditions, and can reduce hospital admissions and GP visits, proving to be cost-effective.

However for people living with long-term conditions such as lung or heart disease, or having had a stroke, the challenges they face in being physically active are significant. They may be living with health impairments or physical disabilities which limit their day to day activities, or coping with fatigue and fluctuating conditions, and often there will be an impact on their mental health too leading to low confidence and self-esteem. Some disabilities can be hidden, particularly after stroke where communication and cognitive difficulties are common, affecting around one-third of stroke survivors.
NHS Health Boards generally offer rehabilitation programmes for people diagnosed with lung disease, after a heart attack, or after a stroke. These programmes incorporate exercise, advice and information to help people be better able to self-manage their conditions. Through regular group activities provided over a number of weeks by a multi-disciplinary team, rehabilitation builds people’s confidence in their ability to get active and helps their overall health and wellbeing. Rehabilitation is proven to improve the lives of people recovering from stroke or heart attack, living with COPD and other lung conditions such as pulmonary fibrosis, stable asthma and bronchiectasis. The format and duration of programmes varies between health boards; referrals are usually made by a GP or other health professional, and the programmes last for a fixed period of weeks.

However the rates of referral to these programmes can be low, levels of take up limited, and completion rates low. Those who complete the programmes have told us they sometimes then feel ‘abandoned’ by the system afterwards, and the evidence suggests that the health benefits they have gained can be lost within 6-12 months if they are not able to maintain the levels of physical activity they gained during the programme. Ideally, in order to continue being physically active, there needs to be a pathway from NHS treatment and rehabilitation programmes through to exercise maintenance in the community.

In 2012-2014 Chest Heart & Stroke Scotland was funded by the Scottish Government in partnership with other third sector organisations to explore how to address the barriers to being physically active for people living with long-term health conditions. The project (known as ‘PARCS’ - Person-Centred Activities for people with Respiratory, Cardiac and Stroke conditions):

- Scoped the provision of multi-condition and single condition exercise based activities across regional health boards for people with heart and lung disease, or after a stroke;
- Evaluated the success factors and motivations needed for those participating in exercise;
- Identified key barriers to engagement in exercise maintenance;
- Developed a national Service Framework and resource pack for community-based physical activity, which underpins the transition from health-based (such as physio-led rehabilitation) to community-based physical fitness and activity.

The national Service Framework was designed to be promoted to NHS Boards, Local Authorities, and Health and Social Care Partnerships, but on completion of the project, the findings were not subsequently taken forward by the Scottish Government. The **key recommendations** within the Framework included:

- Integration of community-based exercise opportunities into a referral ‘pathway’ which extends from NHS Rehabilitation programmes through primary care and into communities;
- Community-based physical activity services which are focused on people, rather than health conditions;
- The importance of collaboration and partnership working across NHS, third sector, local authorities and other agencies;
- The better use of telehealth and other innovative approaches to support people to be physically active;
Development of a specialist exercise instructor training course for multi-condition groups (expanding the current courses available for single health conditions eg stroke, and cardiac);

- Development of a national dataset to standardise the approaches taken to data collection, evaluation and audit; and

- NHS Boards to have nominated single points of contact who can ensure consistent referral to the exercise opportunities and support available.

The main success factors found to be instrumental in exercise participation included:

- Highlighting the benefits of physical activity at the earliest point, and reinforcing that message at key points by health professionals along the patient’s journey. Sometimes a discussion does not take place with a patient about what they could or should be doing physically;

- Avoiding breaks between different stages of that journey, for example after formal rehabilitation programmes are complete and shifting into community based exercise;

- Providing a ‘safety net’ to allow for follow up of patients who disengage with services;

- Providing a self-referral system for those who do not follow the rigid rehabilitation pathway;

- Awareness of exercise maintenance opportunities which are available – through health professionals onward-referring, or patients being aware of them.

Third sector organisations like Chest Heart & Stroke Scotland are key providers of community based support for people living with long-term conditions. Amongst our 160+ community groups ‘affiliated’ to CHSS are a number which offer exercise to their participants. These range from classes provided by physiotherapists or qualified exercise instructors in gyms and halls, through to lower level exercise (such as seat-based). Support groups such as these have typically removed some of the barriers to participation by catering for the additional support needs for their members, for example with transport assistance, or peer support. People want services to be as local and accessible as possible. By meeting with a group of people with similar health experiences, people feel comfortable in their surroundings, and there are important social benefits particularly for people who are at greater risk of isolation due to their health. Where qualified exercise instructors are available, our service users have greater confidence in participating than they would do attending a ‘normal’ exercise class or gym.

Evaluation of the benefits of attending these community-based groups illustrate the physical and emotional benefit that attendees feel, reporting greater energy and activity levels.

Comments include:

- ‘I’m on my own...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.’

- ‘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.’

- ‘It’s not just the physical benefits, I feel better mentally as well, more upbeat, more positive.’

- ‘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.’

2. What were the key ingredients to that success?
As described above, the third sector is often uniquely placed to help remove barriers to engagement in physical activity. We have existing supportive relationships with vulnerable individuals, expertise in supporting them to self-manage their health conditions, community support in place which limits barriers to attendance, and a network of trained volunteers to help provide that support. Amongst the ‘ingredients’ to success are:

- the community based provision of services;
- peer-support, including providing people with opportunities to visit groups/classes to make them less daunting;
- the use of goal-setting to help people identify what matters to them and take the steps needed to achieve them; motivations for exercising often include returning to activities previously enjoyed, returning to employment, and being able to care for family;
- providing solutions to transport;
- raising awareness of the problems encountered by those living with a long term condition e.g. communication awareness training, in staff working in the leisure industry.

There are greater opportunities though within the system for better utilising the third sector and scaling up our existing networks. In particular, through better partnership working between sectors (local authority, health boards, leisure sector and third sector) and integration with the ‘pathway’ of rehabilitation from NHS care to community exercise, a stronger network of exercise opportunities can be developed.

With sufficient resources and trained instructors, there is a significant opportunity to reach more people with exercise maintenance through our existing support structures. The PARCS project identified the challenges of accessing trained instructors who must presently undertake several health-condition-specific streams of training (e.g. cardiac, stroke, falls) rather than just one generic course. The provision of generic exercise instruction is particularly important in areas of low population, where there is more limited capacity to resource specialists.

3. **Were there any approaches that were particularly successful in increasing participation among certain social groups, like women, ethnic minorities, certain age-groups?**

The PARCS project evidences the approach needed in order to enable people living with long-term conditions be physically active through limiting barriers to participation, and enabling more opportunities to be accessed. The health impairments of such conditions are defined as a disability under the Equalities Act 2010, though many of our service-users may not necessarily describe themselves as such.

4. **To what extent are these approaches unique to a particular area and set of circumstances, or replicable in other parts of the country?**

Rural areas present their own challenges in delivery of exercise opportunities for people living with long-term health conditions. The challenges of transport and accessibility create a demand for services to be very local, but smaller and more dispersed populations make it difficult to provide cost effective provision of services. Use of technology can however be an important factor in making exercise accessible, for example through providing online resources, specialist exercise DVDs, or use of Skype to participate from more remote areas.
The PARCS project reviewed delivery models for exercise maintenance and identified good practice for differing health, social and demographic circumstances. Contrasting health boards were identified for evaluation of service delivery – Ayrshire & Arran, Greater Glasgow & Clyde, and the Highlands. These demonstrated differing challenges; outside of the Inverness area, participants in the Highlands were not able to access exercise referral schemes; Ayrshire & Arran experienced significant waiting times for some rehabilitation programmes; in Greater Glasgow & Clyde, knowledge of services which were available was an issue.

Nonetheless, the broad approach described above, where community based exercise opportunities are provided, and incorporated within a pathway from rehabilitation to community, is applicable across contrasting areas of the country.

Volunteering

CHSS is one of the largest volunteer-involving organisations in Scotland and our volunteering programme is widely recognised across the third and public sector as being the programme to emulate. In the past year, across the Charity as a whole 1,600 volunteers undertook over 70 roles and contributed 155,000 hours of service, representing an economic benefit worth an estimated total of £1,600,000. We are the largest organisation in Scotland to hold the Investors in Volunteers status. Whilst not specific to sport, our comments below are common to all sectors working with volunteers.

1. **What are the barriers facing volunteers (either those wanting to volunteer for the first time or sustaining ongoing volunteering)?**

The volunteering landscape is changing. Demographic shifts, changes to people’s working lives, and technological changes, mean that the barriers facing volunteers are not the just about the perception of not being able to give their time. There is too much confusion about where to find out about volunteering in local areas. Additionally some demographic groups are still under-represented in volunteering, particularly disabled people, BME communities, and people from lower socio-economic communities.

2. **How might these barriers be overcome?**

Organisations that depend on volunteers need to understand the changing motivations and needs of volunteers, acknowledging and responding to competing pressures on their time against a changing backdrop of working, family and community life. Volunteering organisations need to ensure their offer to volunteers fits with people’s real lives and is responsive to their motivations and needs, to ensure that volunteering remains a core part of our society.

The profile of Employee Assisted Volunteering is too low in Scotland and under-resourced. The Scottish Government needs to champion this, and to lead as an exemplar of best practice through implementation of volunteer-friendly practices.

Volunteering should be accessible to all, regardless of backgrounds or perceived barriers. To increase the number of people realising the benefits of volunteering in Scotland, we need to change the paradigm. It needs to become a societal norm to volunteer, where opportunity or expectation is not limited by upbringing and social circumstance. This means there needs to be an entitlement to volunteer that gives equality of opportunity to all.
In particular we need to:

- Highlight that there are volunteering opportunities to suit all – micro, short and long term volunteering.
- Provide the support and structure to enable anyone, whatever their circumstances to find a quality volunteer experience
- Have an open-mind as to what any individual can contribute, and if there isn’t a suitable role, signpost them to other opportunities.
- Volunteers need to see the difference they are making - the direct contribution to the organisation, themselves and the wider community.

3. **What are the challenges in retaining volunteers beyond the short term?**

- Keeping the volunteer motivated past their initial motivation is vital. Organisations need to identify their changing motivations and respond to these.
- There need to be resources to support volunteers with extra support needs.
- The time commitment of regular volunteering is a challenge. Many of today’s volunteers are ‘portfolio’ volunteers – volunteering for multiple organisations to reach their individual motivations and not just staying with one organisation.
- Organisations need to create a quality volunteer experience resulting in more people continuing to volunteer – too many volunteers move on as they have not had a positive experience.

4. **What examples are there of good practice to encourage and maintain volunteers in community sport and are there lessons to learn from other sectors around attracting and retaining Volunteers in sport?**

Sports organisations need to interact better with the wider third sector to gain consensus about the key strategic pillars that will support the overall aims of increasing volunteer participation and retention - including a commitment to complement each other. The Sports Association for Scotland being a member of the Scottish Volunteering Forum is a good example of this practice.

5. **Can you provide examples of innovative joint working between clubs and public bodies that are utilising available sources of funding?**

There is great potential for clubs, local authorities and the third sector to collaborate better in providing opportunities for people living with long-term health conditions to be physically active and participate in sport. A combination of peer-support, trained professionals, and local community based clubs could together tackle many barriers to participation, and wider partnership opportunities may enable a wider range of funding opportunities to be accessed.