The PARCS project

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

SECTION B

EXECUTIVE SUMMARIES

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

1: Scoping exercise of current activity in Scotland
EXECUTIVE SUMMARY

Background

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

PARCS Advisory Groups

1) PARCS Advisory Group consisted of representation from: Managed Clinical Networks' (MCN) managers, clinical leads: healthcare professionals (HCPs) and MCN Lead Clinician, Leisure Services, NHS Health Scotland**,** the three charities: Chest Heart & Stroke Scotland (CHSS), British Heart Foundation (BHF) Scotland and British Lung Foundation (BHF) Scotland, and an academic institution (professorial lead). This group advised throughout the lifespan of the project.

2) PARCS Advisory Sub Group – this consisted of similar representation with another key academic related to the national body in relation to instructor qualifications and training. This group reached consensus on the recommendations for a framework for delivery and instructor training which was endorsed by the wider PARCS Group.

3) Service User Advisory Group, representing all three conditions, cardiac, respiratory and stroke, and differing geographical regions. This group was consulted on issues from a service user perspective.

Scoping

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

Methods

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

Results

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

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

Conclusion

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

1) a framework for service delivery

2) local service delivery (incorporating key elements: a person centred, multimorbidity/LTC and partnership approach, single point of referral, peer and professional support, innovations and telehealth

3) resources to facilitate implementation

4) tackling inequalities

5) a standardised approach to specialist instructor training

6) a standardised approach to audit, evaluation/data collection, to maximise impact and resources

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

EXECUTIVE SUMMARY

(a) England and Northern Ireland

Background

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

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

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

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

Scoping

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

Key findings/issues

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

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

Conclusion

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

(b) Wales

Background

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

Scoping

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

Key findings

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

Conclusion

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

3. Qualitative evaluation report commissioned from Brightpurpose

EXECUTIVE SUMMARY

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

The key findings of the evaluation were as follows.

The current pathways

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

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

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

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

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

Understanding more about why people engage or not with exercise maintenance

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

Motivations – why do people participate in exercise maintenance?

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

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

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

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

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

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

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

Barriers – what stops people participating in exercise maintenance?

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

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

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

Why do people stop participating in exercise maintenance?

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

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

Improving provision to enable and maximise engagement

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

Further development of seamless pathways

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

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

Follow-up and safety nets

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

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

Harness the influence of healthcare professionals

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

The role of the third sector

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