# Evaluation of the Macmillan Physical Activity Behaviour Change Care Pathway

## *Final report 2017*

Rachel Moreton
Alex Stutz
Sarah Robinson
Irshad Mulla
Mary Winter
Professor Jennifer Roberts
Dr Melvyn Hillsdon

Made possible with
WE ARE MACMILLAN. CANCER SUPPORT

CFE research

For more information about this report please contact Rachel Moreton:

CFE Research, Phoenix Yard, Upper Brown Street, Leicester,
LE1 5TE

T: 0116 229 3300 Rachel.Moreton@fe.org.uk
www.cfe.org.uk

CFE are research and consultancy specialists who focus on employment and skills. We have been providing our expert services to public and private sector clients for over twelve years. We re-invest our profits in order to fund innovative research projects and our ‘Policy Insight’ series.

# Acknowledgements

The authors would particularly like to thank the following evaluation steering-group members and Macmillan staff for their time, knowledge and expertise. Their contributions to the evaluation have been invaluable.

Macmillan physical activity specialist team:

Jo Foster
Sarah Worbey
Rhian Horlock
Kerryn Chamberlin
Justin Webb

Macmillan's evaluation team:

Sean Richardson-Jones
David Murray

Macmillan's expert advisory group

Dr Anna Campbell MBE, Edinburgh Napier University
Dr Nick Cavill, Oxford University

Macmillan's geographic teams

Diarmaid McAuley
Arry Cain
Margaret Greer

We would also like thank all the Move More Practitioners and other service staff, and all the stakeholders, healthcare professionals, volunteers and service users who gave up their time on numerous occasions to talk to the evaluation team and who allowed us to participate in their service activities. This evaluation would not have been possible without their assistance and contributions.

The authors would like to thank Sport England for funding this project through the Lottery supported Get Healthy, Get Active portfolio.

# CONTENTS

# SUMMARY

## Background

The Macmillan Physical Activity Behaviour Change Care Pathway (or the 'Move More' service as it is more commonly known) is an evidence-based service providing tailored, one-on-one behaviour change support to help people living with cancer (PLWC) to become more active or maintain a level of physical activity, depending on their stage of the cancer journey. It comprises five elements:

- raising awareness
- referral
- behaviour change intervention
- physical activity offer, and
- on-going behaviour change support.

The model is based on the NHS adult physical activity care pathway, Let's Get Moving.[1] It also draws on more recent learning from National Institute for Health and Care Excellence (NICE) public health guidance [PH49],[2] and Macmillan's own insight research.[3] It has been tailored for use in a cancer care environment.[4]

Macmillan's specialist physical activity team, worked collaboratively with Macmillan's geographic service development teams to co-create services with local NHS, government and leisure partners. Partners were enabled to take the overarching model and look at how they would apply it to their geography, population and health landscape. This has led to the development of a variety of implementation models.

---

[1] Department of Health (2012) Let's Get Moving – A physical activity care pathway. Commissioning Guidance. London: DoH https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216262/dh_133101.pdf

[2] NICE (2014) Behaviour change: individual approaches. Public health guideline [PH49] https://www.nice.org.uk/guidance/ph49

[3] Macmillan Cancer Support (20162016) What motivates people with cancer to get active? http://be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC16027-Physical-Activity-evidence-reviewREPORT-(A4)AWDIGITAL.pdf

[4] Campbell, A. Foster, J. Stevinson, C. Cavill, N. (2012) Interventions to promote physical activity for people living with and beyond cancer. Macmillan Cancer Support http://www.macmillan.org.uk/documents/aboutus/health_professionals/physicalactivityevidencebasedguidance.pdf

## This evaluation

In September 2014, Macmillan commissioned CFE Research to undertake, working in partnership with academics from the University of Sheffield and the University of Exeter, a longitudinal evaluation of the Physical Activity Behaviour Change Care Pathway.

The evaluation took a mixed-methods approach which comprised:

- qualitative interviews with staff, stakeholders and service users;
- ethnographic observations of services;
- analysis of quantitative data collected by services; and
- an economic analysis.

The evaluation was undertaken in two phases between September 2014 and July 2017.

The evaluation incorporated a formative process evaluation, an assessment of outcomes achieved and an economic analysis. An action learning approach has been taken and Macmillan's specialist team have worked with test sites to spread learning and develop interventions to improve efficacy during the pilot phase.

We are also, currently, undertaking a pilot study on the acceptability of accelerometers as an objective means of measuring physical activity levels in people affected by cancer. We expect this pilot study to report in late 2017.

## Key findings

### Raising awareness and generating referrals

Overall, services have successfully engaged with an ethnically diverse, if older, population of PLWC, although this overall result masks differences between services. Generally, women are more likely to engage with the programme. Services are engaging service users across different cancer stages and cancer types – broadly in line with the national picture.[5] Most service users are post-treatment, although a substantial proportion were undergoing treatment.

Most service users have been referred to the service by healthcare professionals (HCPs), most commonly by Clinical Nurse Specialists (32 per cent) – or they have been self-referred (26 per cent).

---

[5] http://www.cancerresearchuk.org/health-professional/cancer-statistics#heading-Zero

Services have found generating referrals harder and more time consuming than anticipated. Those services that are based in a healthcare setting (rather than in a community setting) find that they are better able to engage HCPs.

Establishing trust with healthcare professionals is the key to generating referrals. This is helped by the strength of the Macmillan brand. Meeting with potential referrers is effective, but engagement needs to be carried out on an on-going basis.

The extent to which services are embedded in the Recovery Package can have an impact on referral numbers. Where Health and Wellbeing events are run regularly and are well attended, they can be a successful route for generating referrals.

Practitioners use a wide range of other means, including online, social media and press outlets, in order to raise awareness of the service and help generate referrals.

## Behaviour change interventions

Behaviour change interventions are occurring in one of three ways – face-to-face, by telephone and in group settings. These interventions are usually delivered by a Move More Practitioner who has received motivational interviewing (MI) and level 4 Cancer Rehabilitation training. The MI training is valued by staff and where staff have not been trained, the interventions they deliver are weaker.

Service users found the interventions helpful and the experience a positive one. Practitioners were empathetic and supportive, but interventions do not always follow the evidence-based model that Macmillan have been working in partnership to test or effectively use MI techniques. There is a significant variation in the quality of interventions that were observed. Practitioners do not always carry out full MI but modify the extent to which they use MI, based on their perception of the individual's level of motivation and their stage of treatment. This goes against the principles and philosophy of MI and reflects a lack of understanding of true MI among practitioners.

Initial interventions delivered by telephone were the least likely to provide quality MI and resembled very brief advice. In models that used this approach, there is no behaviour change support provided prior to participation in the service.

Group interventions provide a valuable opportunity for mutual support and motivation.

## Physical activity provision

All services offer access to a wide range of physical activities. However, no services observed consistently offer access to all the activities that form part of Macmillan's minimum recommended offer. Some services that delivery activities directly place greater emphasis on promoting these. The physical activity offer is not always a personalised one.

There is no one-size-fits-all physical activity offer. An appropriate offer is one that takes into account local facilities and services and provides activities at a variety of times and locations that can be accessed by public transport, based on the needs of service users.

Services based in leisure settings benefit from easier access to a wider range of classes and facilities which can make the transition from free sessions to continued activity more straightforward than in a healthcare setting.

Signposting, if done correctly, can be an effective way of enabling a service user to access a wider range of physical activity and sporting opportunities than could be delivered directly. Signposting requires that there are good systems in place for providing on-going support to service users.

A key success factor in any delivery model is ensuring that instructors are knowledgeable concerning physical activities and the needs of PLWC. They also need to be approachable and able to develop good rapport with a range of service users as well as skilled in the principles of MI.

## On-going behaviour change support

A fundamental component of Macmillan's Physical Activity Behaviour Change Care Pathway is the inclusion of a formal behaviour change support offer to service users for a minimum of 12 months. Only one service (Lincolnshire) currently provides this.

All services provide opportunities for informal support where required, based around an 'open door' policy. Service users appreciate this offer and generally feel reassured that they can raise issues if they wish to. Not all service users want on-going support.

Support is often provided as part of activity sessions delivered by services. Once these end, opportunities for ongoing support generally diminish. As a result, both services and service users generally associate support with the delivery of physical activity and do not perceive the programme as lasting 12 months. Some services did not have the resources to deliver formal support to all for 12 months.

Without the formal ongoing support for at least 12 months there is a risk that service users will lapse back into inactivity.

### Outcomes

Most service users who responded to the longitudinal questionnaire have maintained or increased their levels of physical activity following engagement with the service.

In relation to those that have provided data at the start and follow-up points, we see small, but statistically significant, improvements in health and quality of life and other related measures such as reduced fatigue. Qualitative evidence also supports these improvements.

However, the sample may not be representative of the wider population of service users and is likely to be biased towards those most motivated to participate.

Without a control or other comparator group it is difficult to say with certainty whether the service has improved service users' health and mental wellbeing or whether this would have happened anyway. However, other evidence shows that while some health related behaviours such as diet and smoking improve after cancer diagnosis, physical activity levels reduce significantly.

Service users value and derive benefit from the specialist support and guidance provided by the service staff and the mutual support of other service users. They feel that they would not have been able to progress as quickly without the support of the service. Although most we spoke to were motivated and inclined to increase their physical activity levels, it seems likely that they would not have been able to do so successfully without the specialist support of the services.

### Economic assessment

Cost per additional minute of moderate or vigorous activity ranges from £1 to £6, depending on whether conservative or optimistic protocols are used. A very large range of cost per quality adjusted life year (QALY) estimates can be generated, depending on the assumptions made. If we assume the duration of the effects only last for 3 months, most estimates and the mean are above the NICE recommended threshold for the cost effectiveness of public health interventions (around £20,000 per QALY). If we assume the duration of effects last 12 months cost per QALY estimates range from £1,109 to £29,132; the most conservative estimate is above the threshold but all other estimates are below.

## Recommendations

### For Macmillan and future funders

If the Physical Activity Behaviour Change Care Pathway is to continue and be rolled-out more widely, the following should be taken into account.

## Referrals

As the Recovery Package is rolled out across the UK, services, Macmillan and decision-makers should work to ensure the Physical Activity Behaviour Change Care Pathway is embedded within it. In particular, the support with physical activity behaviour change should be a referral option as part of the Assessment and Care Planning using the Holistic Needs Assessment.

## Behaviour change interventions

MI training needs to be an on-going process which includes opportunities to practice, reflect and obtain updates and refresher training. In particular, more training and support is needed on how MI can be used with those already apparently motivated or predisposed towards physical activity.

Macmillan and future funders should consider exploring the opportunities, benefits and limitations of group-based approaches further. Where these are adopted, training should be provided to ensure they are of a good standard.

Macmillan should recommend that Practitioners consider using the Move More pack as part of conversations if appropriate. The pack should be offered to all service users.

## Physical activity offer

Where possible, Macmillan and future funders should continue to develop national level partnerships with sports and physical activity organisations and National Governing Bodies since this helps to open up opportunities, locally, for services.

Macmillan and future funders should emphasise to services that physical activity should be offered/signposted in line with the service users' needs and preferences. There is a benefit to reiterating to new services that there is no requirement to have a local directly delivered activity and, with the right support mechanisms in place, signposting can be an effective means of providing access to a wider range of activity.

## Ongoing Behaviour Change Support

Macmillan and future funders should ensure that future services prioritise the provision of a formal support offer for all service users who need it for a minimum of 12 months. This should be a personalised offer, appropriate to the service user and in line with the guidance in NICE public health guidelines [PH49].

There may be merit in Macmillan and future funders revising the specifications for new services to ensure that the nature of the programme and the follow-up requirement is clear. Services should be sufficiently resourced to provide ongoing support.

## Service management

Macmillan and future funders should continue to make the cancer and physical activity training package[6] for health care professionals available in a variety of formats and on a more frequent basis to local HCPs so that they are better able to and more inclined to deliver very brief advice on physical activity to their cancer patients.

Macmillan and future funders should continue to provide services with opportunities to network with each other and so to share best practice. These opportunities should be delivered in the form of a mixture of regional and national events and these should offer something for both new and well established services.

## Data collection and evaluation

Where a standardised dataset is to be used, in the future, data collection should be a condition of the funding. Questionnaires should be standard across all services, including common response scales, question orders and layouts.

If data collection is to remain a key part of the Physical Activity Behaviour Change Care Pathway, this needs to be appropriately resourced. Staffing models need to include dedicated and specialist time for supporting service users to complete the questionnaire, for chasing follow-up, and for entering, cleaning and analysing the data. Alternatively, Macmillan may wish to outsource data collection to an independent data collection agency.

Macmillan and future funders should consider whether there is scope for providing further guidance to services on the rationale behind the questionnaire, and on how they should communicate this rationale to service users.

Macmillan should ensure that all services understand that the questionnaire should be self-administered by service users. Services should be supported and encouraged to use the online version of the questionnaire, with service users completing the questionnaire on a tablet device if necessary.

Services should be supported and encouraged in making use of the data for planning, improving and sustaining their services as this is likely to lead to services valuing data collection more. Services that have effectively used the data should be enabled to share their approaches and their results with other services which have yet to exploit the data to provide themselves with ideas and inspiration. Services will require access to analytical expertise in order to effectively use the data.

---

[6] Understanding Physical Activity and Cancer http://learnzone.org.uk/macprofs/279

Robust data security policies and practices should be a pre-requisite for funded services in future.

The evidence for the Physical Activity Behaviour Change Care Pathway could be strengthened with more robust longitudinal data and a controlled trial or quasi-experimental evaluation with a comparison group.

## For services

### Referrals from professionals

Services should focus on building trust with key HCPs through on-going and face-to-face engagement. This should include engagement with Macmillan Information Centres. Services should use the Macmillan referral tactics tool as appropriate.

Services should continue to target GPs and, where possible, work with them to include the service as an option as part of the cancer care review.

Services should broker relationships with a range of potential sources of referrals including other charities, private health providers and other Macmillan services.

Services should explore ways to provide feedback on service-user progress to those who make referrals. This could be in the form of case studies of service users.

The referral process should be made as easy and efficient as possible. Access should be provided to an NHS email, where possible, to enable professionals to transfer referral details electronically.

Move More Practitioners should present at health and wellbeing events in order to promote the service to PABC and HCP. Offering short bursts of taster activity and getting current or former service users to attend as ambassadors for the service should be considered.

Services should promote the wider benefits of physical activity to potential service users and their families.

The language used to promote physical activity should be accessible, appealing and inclusive – to reflect a wide-as-possible concept of what physical activity involves.

Make self-referral easy with methods such as postcards or tear-off slips.

### Behaviour change interventions

If BC interventions are to be delivered by telephone, appointments should be made in advance and recipients should be aware of the purpose of the call and the estimated length of the call so that the service user is prepared and has the time for a meaningful conversation that lasts a minimum of 30 minutes. Practitioners need to be trained with the same level of competency and skills for telephone as for face-to-face interventions.

Practitioners should not undertake interventions unless they have completed training in motivational interviewing (MI).

Services should ensure that Practitioners devote the whole intervention to discussing behaviour change. Any requirements for data collection should be completed prior/post the intervention.

Healthcare based services in particular should consider whether greater flexibility in the location of interventions could be offered in order to ensure that the varying preferences of potential service users are met whilst maintaining sufficient levels of confidentiality and openness.

### Physical activity offer

Service users who express a desire to change behaviour should be encouraged to identify an activity that suits them. No matter what preference they have, Practitioners should do as much as possible to facilitate the service user's choice. All decision-making should be service user led.

Services should seek to facilitate access to as wide a range of physical activities as possible, including closed and open sessions and group and individual activities. Physical activity is often undertaken as activities of daily living and this should be valued, encouraged and supported. Services should review the profile of service users and consider how the activities available may need to be adjusted to ensure that they meet the diverse interests of users – for example, by ensuring that there are activities likely to appeal to men and cover a wide geographical area. Services should identify local activity providers first before deciding if there is a need for directly delivered activity to fill gaps.

Services that deliver activities directly need to ensure the intervention explores service users' physical activity preferences and interests and does not focus on promoting the particular activities that the service itself offers. The offer should include the negotiation of support activity between supervised sessions and the continuation of activity following the end of free sessions.

When signposting, all services need to consider the appropriateness of the activity for the particular PLWC. If required, Practitioners should work with external providers to ensure that they are appropriately trained and feel sufficiently supported to provide activities for PLWC.

Where activities are directly delivered, it is important that instructors provide personalised exercises for each service user and consider whether some need more advanced exercises.

Services should consider how they can build opportunities for social interaction into activities. Services should also consider how they might encourage the family and/or carers of PLWC to participate with them in physical activities.

### Ongoing Behaviour Change Support

Where possible, support should be provided by the same staff member at all stages, in order to ensure continuity of care. There may be benefits to front-loading this support in order to establish a relationship with the service user.

### Service management

We recommend that services separate the Move More Practitioner role from other, more administrative, tasks such as data entry and data collection.

Healthcare based services and those that mainly signpost service users may benefit from having more representatives of the leisure and/or community sectors on their steering group in order to ensure that they can link effectively with a wide range of activity providers. Community and leisure based services may wish to focus on recruiting members that are more likely to generate referrals.

### Data collection

Services should consider using the online version of the questionnaire. This could involve service users self-completing the survey on a tablet provided by the service – as part of the initial intervention or follow-up sessions.

Services should consider adopting a more strategic approach to reminding service users to complete follow-up questionnaires. This should include calling service users at different times and on different days in order to boost response rates.

# 01. Background to the Macmillan approach

*In this chapter, we describe the Macmillan Physical Activity Behaviour Change Care Pathway. We explain the policy drivers behind the Pathway, how it has developed over time and set out the key elements of the Pathway.*

The Macmillan Physical Activity Behaviour Change Care Pathway (or the 'Move More' service as it is more commonly known) is an evidence-based service providing tailored, one-on-one support to help people living with cancer (PLWC) to become more active. In September 2014, Macmillan commissioned CFE Research to undertake, working in partnership with academics from the University of Sheffield and the University of Exeter, a longitudinal evaluation of the Physical Activity Behaviour Change Care Pathway. This is the final report resulting from that evaluation. It begins with the background of the Macmillan approach and information on the different services included in the evaluation.

## Programme background

Improved cancer survival rates, a growing prevalence of unhealthy lifestyle behaviours, and a growing and ageing population, are contributing to increasing cancer prevalence. By 2040 it is estimated that a total of 5.3 million adults in the United Kingdom will be living with or beyond a cancer diagnosis, representing 6.2 per cent of the male and 8.5 per cent of the female population.[7]

Whilst survival rates are improving for many cancer types, they are not improving for all. For those who are living longer with and after cancer, they are not necessarily living well.[8] For example, one in four people struggle with the consequences of treatment including heart damage, depression and chronic fatigue.[9] One in two people living with cancer have two or more co-morbidities.[10] Enabling people to be physically active at all stages of their cancer journey can improve both clinical and quality of life outcomes.[11] [12]

---

[7] Maddams, J. Utley, M. Moller, H. Projections of cancer prevalence in the United Kingdom, 2010-2040. British Journal of Cancer 2012; 107:1195-1202

[8] Macmillan Cancer Support(2014) Routes from diagnosis

[9] Macmillan Cancer Support (2013) Cured – but at what cost?

[10] Macmillan Cancer Support (2012) The importance of physical activity for people living with and beyond cancer: A concise evidence review.

[11] Macmillan Cancer Support (2017) Physical activity and cancer: a concise evidence review

[12] Macmillan Cancer Support (2017) Physical activity and cancer: a summary of the evidence

The National Cancer Survivorship Initiative (NCSI)[13] recognised the importance of physical activity in cancer survivorship and its role in promoting and sustaining recovery and managing the consequences of treatment and co-morbidities. As part of the prototyping phase of NCSI the Bournemouth After Cancer Survivorship Programme (BACSUP) integrated behaviour support and tailored physical activity programmes for people living with and beyond cancer. As a result of this, in 2010, initially as part of the NCSI collaboration, Macmillan set up a physical activity programme to test how best to maximise the benefits of physical activity and support people who have had a cancer diagnosis to become and stay active at a population level.

Macmillan co-created a strategy, the ambition of which is to ensure everyone living with and beyond cancer is aware of the benefits of physical activity and enabled to choose to become and to stay active at a level that is right for them. Macmillan took an evidence-based, population level approach, underpinned by a socio-ecological model to achieving this. Core to this is understanding how the promotion of physical activity can be integrated into all stages of cancer care, as part of the recovery package core components.[14]

In order to achieve their ambition Macmillan has undertaken evidence reviews to understand the impact of physical activity and evidence for bringing about behaviour change for people who have had a cancer diagnosis, other long term conditions and the general population. They carried out insight research with key stakeholders who play a role in embedding the promotion of physical activity and providing support to people in making a sustained change, and reviewed the evidence of the most effective interventions to change behaviour in these key groups.

Cancer patients have been shown to demonstrate an enhanced motivation to change lifestyle behaviours, especially within the year after diagnosis.[15] Central to this is the evidence that a cancer diagnosis provides a ‘teachable moment’[16] when an individual is

---

13 Department of Health (2013) National Cancer Survivorship Initiative. Living with and beyond cancer: taking action to improve outcomes.

14 Macmillan Cancer Support (2013) The Recovery Package, sharing good practice

15 Coups, EJ. Ostroff, JS. A population-based estimate of the prevalence of behavioural risk factors among adult cancer survivors and non cancer controls. Preventive Medicine. 2005 Jun;40(6):702–11

[16] Rosenstock, I. M. (1974) Historical origins of the health belief model Health Education Monographs 1974:2 354-386

more inclined to change their behaviour.[17,18,19,20] These ‘teachable moments’ in which discussions about diet and physical activity (and other issues such as smoking cessation) are likely to be well received by the patient will not bring about a change in behaviour on their own. They need to be deliberately created as part of the patient consultation. This could be as part of a discussion about preventing or managing side effects or consequences of treatment, especially fatigue as part of an assessment and care plan. Core recovery package[21] interventions, such as an assessment and care plan, using the holistic needs assessment as a person centred tool, or a health and wellbeing event are excellent opportunities to raise the importance of moving more.

The National Institute of Health and Care Excellence (NICE) recommends that health, wellbeing and social care staff should be encouraged to deliver very brief advice (advice given in less than two minutes) to motivate people to make a lifestyle change.[22] A simple recommendation to be more physically active from a healthcare professional to a cancer patient, with onward referral to an appropriately qualified physical activity professional or group, or signposting to user-friendly self-help brochures, has been suggested to support changes in behaviour.[23]

Clinical nurse specialists and practice nurses are well placed to offer physical activity advice to cancer patients during their many interactions throughout treatment and observation, including recovery package assessment and care planning and health and wellbeing events.[24] 89 per cent of patients have a named clinical nurse specialist in charge of their care and practice nurses play a key role during follow-up.[25] Nurses often see the same patients many times and can build a strong relationship meaning patients may be more receptive to their advice.[26]

---

[17] Rabin, C. (2009) Promoting Lifestyle Change Among Cancer Survivors: When is the Teachable Moment? American Journal of Lifestyle Medicine 2009:3(5) 369–78

[18] McBride, C.M. and Emmons, K.M. (2003) Understanding the potential of teachable moments: the case of smoking cessation. Health education research 2003:18(2) 156-70

[19] Demark-Wahnefried, W. (2005) Riding the Crest of the Teachable Moment: Promoting Long-Term Health After the Diagnosis of Cancer. Journal of Clinical Oncology 2005:23(24):5814–30

[20] McBride, C.M. Puleo, E. Pollak, K.I. Clipp, E. C. Woolford, S. Emmons, K. M. (2008) Understanding the role of cancer worry in creating a “teachable moment” for multiple risk factor reduction. Social Science & Medicine 2008:66(3) 790–800

[21] Macmillan Cancer Support (2013) The Recovery Package, sharing good practice

[22] NICE (2014) Behaviour change individual approaches. NICE public health guidance 49. London: NICE

[23] Rock, C.L. Doyle, C. Demark-Wahnefried, W. Meyerhardt, J. Courneya, K.S. Schwartz, A.L. et al. (2012) Nutrition and physical activity guidelines for cancer survivors. CA: A Cancer Journal for Clinicians. 2012:62(4) 242–74

[24] Murphy, J. Girot, E. (2013) Improving Cancer survival with lifestyle advice. Nursing Times 2013:109(29) 22–3

[25] NHS (2014) National cancer patient experience survey - national report. Leeds: NHS

[26] Karvinen, K.H. McGourty, S. Parent, T. Walker, P. R. (2012) Physical activity promotion among oncology nurses. Cancer Nursing 2012:35(3) E41–8

There is evidence that most cancer survivors are keen to receive information or advice about exercise at some point during the cancer experience.[27][28] It is important that this counselling is delivered by a qualified health professional, and is individually tailored to each patient. Many patients would prefer to meet in person to receive exercise counselling, with information ideally provided by an exercise specialist associated with a cancer centre, indicating a strong desire for trustworthy and professional information.[29]

Evidence suggests that only 5 per cent of cancer survivors meet all healthy lifestyle recommendations: being physically active, maintaining a healthy weight, eating a healthy diet, and not smoking.[30] Specifically, the latest available data on the prevalence of healthy lifestyle behaviours for people living with and beyond cancer tells us that:

- 79 per cent of people do not eat five pieces of fruit or vegetable a day (a proxy indicator of healthy eating) [31]
- 27 per cent of people are classified as obese[31]
- 21 per cent of people smoke[31]
- 16 per cent of people drink alcohol above recommended levels [31]
- 77 per cent of people are not physically active to recommended levels.[32]

There is a lack of clear evidence on trends. However, the evidence suggests the prevalence of unhealthy behaviours in people living with cancer is similar to that seen in the non-cancer population: healthy eating, weight, smoking and alcohol consumption are slightly better in cancer survivors, whilst physical activity participation is lower. Macmillan's

---

[27] Rock, C.L. Doyle, C. Demark-Wahnefried, W. Meyerhardt, J. Courneya, K.S. Schwartz, A.L. et al. (2012) Nutrition and physical activity guidelines for cancer survivors. CA: A Cancer Journal for Clinicians. 2012 Apr 26;62 (4):242–74.

[28] Kenfield, S.A. Stampfer, M.J. Giovannucci, E. Chan, J.M. (2011) Physical Activity and Survival After Prostate Cancer Diagnosis in the Health Professionals Follow-Up Study. Journal of Clinical Oncology. 2011 Feb 17;29 (6):726–32.

[29] RichmanM E.L. Kenfield, S.A. Stampfer, M.J. Paciorek, A. Carroll, P.R. Chan, J.M. (2011) Physical Activity after Diagnosis and Risk of Prostate Cancer Progression: Data from the Cancer of the Prostate Strategic Urologic Research Endeavor. Cancer Research. 2011 May 31;71(11):3889–95.

[30] Blanchard, C.M. Courneya, K.S. Stein, K. (2008) Cancer Survivors Adherence to Lifestyle Behaviour Recommendations and Associations With Health-Related Quality of Life: Results From the American Cancer Society SCS-II. Journal of Clinical Oncology. 2008 Apr 29;26(13):2198–204204

[31] Wang, Z. McLoone, P. Morrison, D.S. (2014) Diet, exercise, obesity, smoking and alcohol consumption in cancer survivors and the general population: a comparative study of 16 282 individuals. British Journal of Cancer. Nature Publishing Group; 2014 Nov 27;112(3):572–5.

[32] NHS (2012) Quality of Life of Cancer Survivors in England - Report on a pilot survey using Patient Reported Outcome Measures (PROMS). London: Crown Copyright.

review of the evidence[33] found that physical activity levels reduce significantly during and after cancer treatment, and do not increase again.[34,35]

Based on this evidence and insight Macmillan's model starts with the recovery package, encouraging those who are delivering holistic needs assessments as part of assessment and care planning, cancer care reviews and health and well-being events to advocate physical activity. Macmillan have put in place accredited training for healthcare professionals to increase their confidence in advocating physical activity to all of their cancer patients,[36, 37] supported by regularly updated concise evidence reviews.[38,39]

There are a number of methods and frameworks that can be utilised to support individuals changing their behaviour but the key feature throughout all of them is that it they are person centred. The individual should be enabled to progress at their own pace and make decisions.

Macmillan's insight research[40] has shown that people living with and beyond cancer want support in becoming more active and want this to be tailored to their needs, whilst being active agents in choosing the right approach for them. NICE Guidance PH49 recommends that behaviour change support is provided for at least a year to bring about long term behaviour change, the regularity and format of support to be based on the individual need and preferences of the individual.[41] As with the general population, people living with cancer need to be supported to *sustainably* change their behaviour, this is particularly important if they are trying to become active due to increased physical and psychological challenges they may face after their diagnosis.

Macmillan's insight research into the barriers and motivators of people living with and beyond cancer in becoming and staying active[42] shows that in terms of physical activities,

---

[33] Macmillan Cancer Support (2012) Interventions to promote physical activity for people living with cancer. Evidence Based Guidance. London: Macmillan Cancer Support.

34 Blanchard, C.M. Denniston, M.M. Baker, F. et al. (2003) Do adults change their lifestyle behaviours after a cancer diagnosis? Am J Health Behaviour. 2003. 27(3):246–56. 38

35 Irwin, M. Mctiernan, A. Bernstein, L. Gilliland, F. Baumgartner, R. Baumgartner, K. Ballard Barbash, R. (2004) Physical activity levels among breast cancer survivors. Medicine and Science in Sports and Exercise. 2004. 36: 1484–1491.

36 Webb, J. Foster, J. Poulter, E. (2015) Increasing the frequency of physical activity very brief advice for cancer patients. Development of an intervention using the behaviour change wheel, 1–12. http://doi.org/10.1016/j.puhe.2015.12.009

37 Webb, J. Hall, J. Hall, K. and Fabunmi-Alade, R. (2016). Increasing the frequency of physical activity very brief advice by nurses to cancer patients. A mixed methods feasibility study of a training intervention, 1–13. http://doi.org/10.1016/j.puhe

38Macmillan Cancer Support (2017) Physical activity and cancer: a concise evidence review

39 Macmillan Cancer Support (2017) Physical activity and cancer: a summary of the evidence

40 NCSI (2013) Living with and beyond cancer: taking action to improve outcomes NCSI. http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf

41 NICE (2014) Behaviour change individual approaches. NICE public health guidance 49. London: NICE.

42 Macmillan Cancer Support (2016) What motivates people with cancer to get active.

some people would like a group based activities, some individual, some want cancer specific, others not.

As a result, Macmillan has worked with clinicians, service users, local decision-makers, service providers and academics to develop an intervention based on the best available evidence from the general population, including learning from the adult physical activity care pathway and NICE PH49.The intervention is delivered as an integrated care pathway that initiates in healthcare and is followed by a multi-stage, behaviour-change based intervention, usually based in the community.

The intervention has been tested across the UK, whereby localities have been able to take an overarching model and apply to their local health landscape and population/geography. This has resulted in a number of models, which are summarised within this report.

The first test sites initiated in 2010 as part of the NCSI, then additional sites were developed following an awareness raising campaign in 2011. In 2013 Macmillan successfully gained match funding from Sport England as part of their Get Healthy, Get Into Sport funding stream (now Get Healthy, Get Active). Through this funding, Macmillan worked with six areas across England: Dorset, Berkshire, Luton, Shropshire, Manchester and Sheffield. In 2014 the evaluation was commissioned, focusing initially on these six areas (phase one sites in Table 1.1). As this time Macmillan made physical activity a core priority. A large number of test sites were developed across the UK by service development teams working with Macmillan's central specialist physical activity/behaviour change team. Over the next two years this programme of work continued to spread, with additional specialist resource for each of the nations allowing the work to be tailored for each geographical area.

In 2015 the evaluation was expanded to review the variety of models in use and a further eight sites were included (phase two sites in Table 1.1). This was combined with an action learning approach that brought together all of the test sites at regular intervals to share best practice and allow the central Macmillan team to understand what the issues were and co-create solutions . For example developing a variety of behaviour change interventions to support delivery including a training interventions for health care professionals, direct mail from hospitals to patients. Combined with local innovations such as peer support, league tables of health care referrers.

| **Phase one sites** | **Start date** |
|---|---|
| Berkshire | Jan 2014 |
| Dorset | Jan 2014 |
| Luton | Jan 2012 |
| Manchester | Nov 2014 |
| Sheffield | Apr 2015 |
| Shropshire | Jan 2012 |
| **Phase two sites** | |
| Aberdeen | Dec 2014 |
| Antrim and Newtownabbey | Oct 2016 |
| Ards and North Down | July 2016 |
| Edinburgh | Apr 2015 |
| Guys and St Thomas' Hospital Trust (GSTT) (London) | Jan 2015 |
| Hertfordshire | Jan 2015 |
| Lincolnshire | Feb 2015 |
| Velindre (Cardiff) | Jan 2015 |

Table 1.1: Phase 1 and 2 evaluation sites and their start dates (based on service user start dates)

## The Macmillan Physical Activity Behaviour Change Care Pathway Model

Macmillan's Physical Activity Behaviour Change Care Pathway model is based on the NHS physical activity care pathway, Let's Get Moving.[43] This in turn is based on NICE public health guidance.[44] The NHS pathway has been tailored for use in a cancer environment. The Macmillan model of care was further adapted, drawing on more recent information from the use of the NICE public health guidance[45] and on Macmillan's own insight research.

---

[43] Department of Health (2009) Let's Get Moving, commissioning guidance, a physical activity care pathway https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216262/dh_133101.pdf

[44] https://www.nice.org.uk/guidance/published?type=ph&title=physical%20activity

[45] https://www.nice.org.uk/guidance/ph49

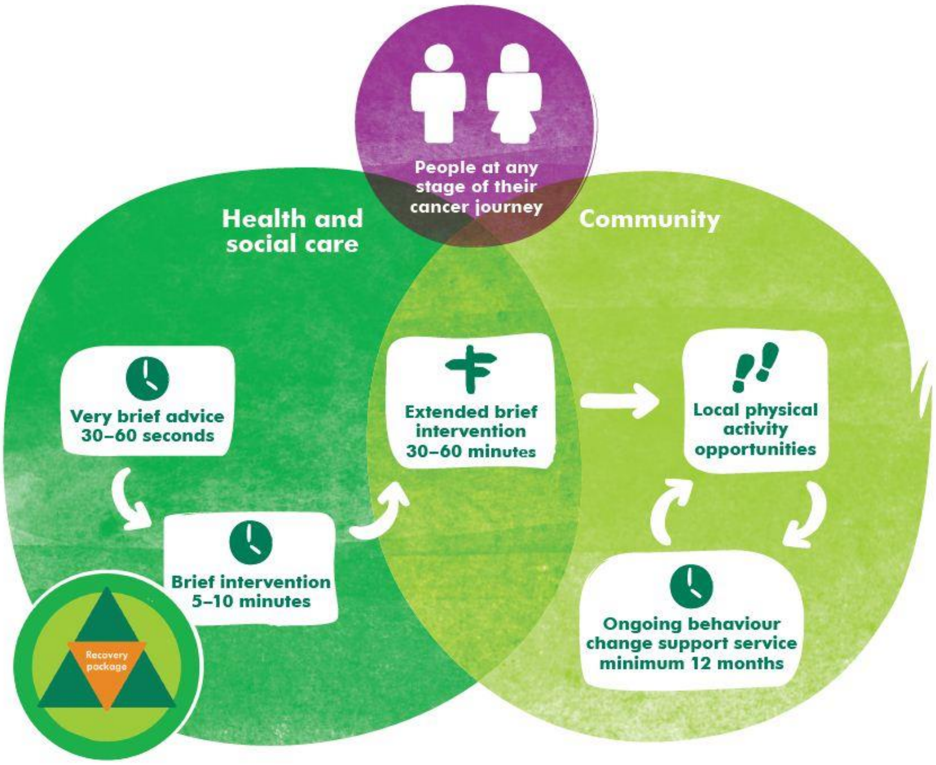


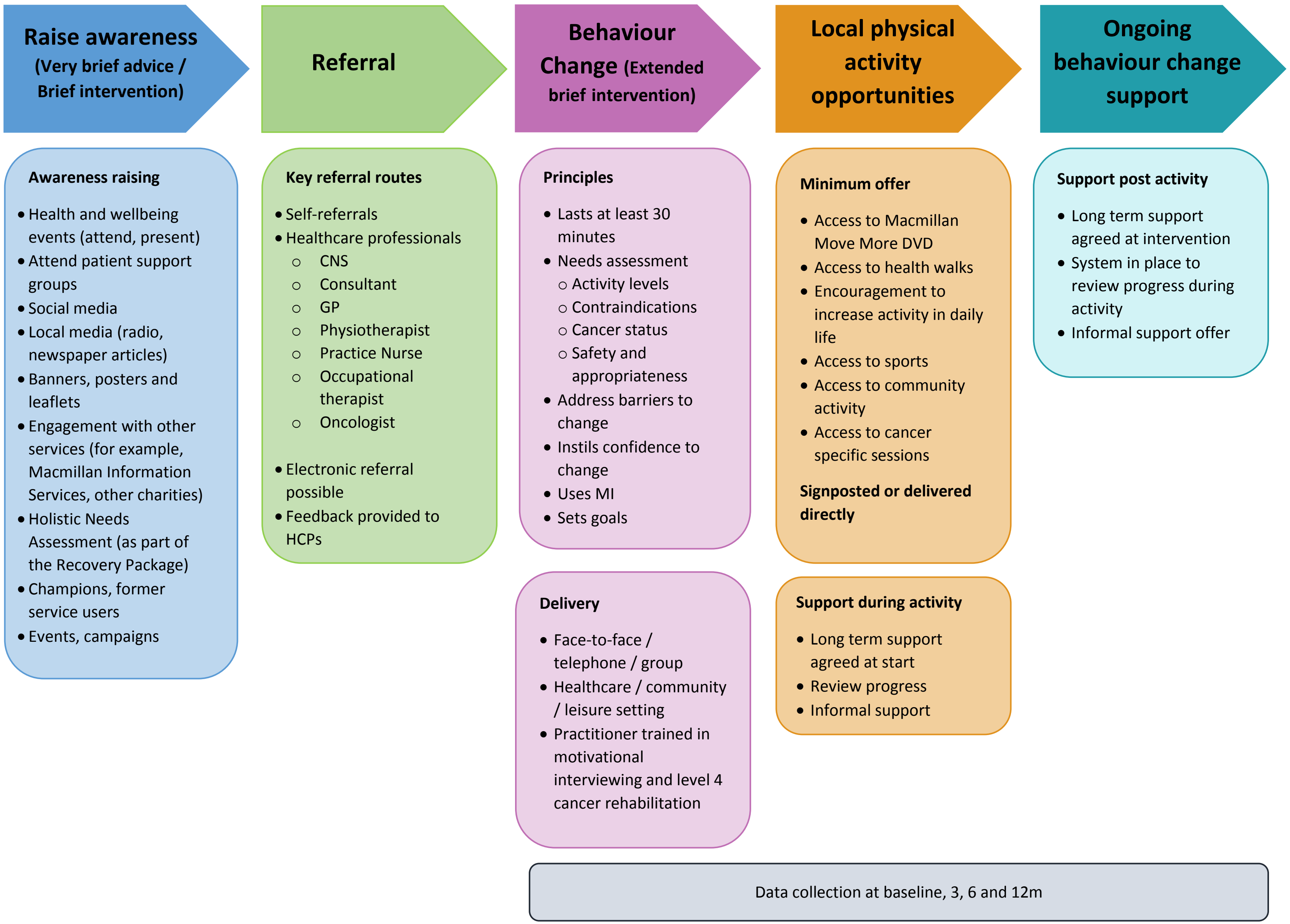
**Figure 1.1: The Macmillan Physical Activity Behaviour Change Care Pathway**

Figure 1.2, overleaf, provides a more detailed overview of the five stages of the Physical Activity Behaviour Change Care Pathway and the different elements that could or should make up each stage. There is an expectation that services adhere to the key principles of the Pathway and also be aligned to local priorities and the physical activities available locally. The services included in our evaluation delivered aspects of the Physical Activity Behaviour Change Care Pathway differently; for example, they offered different settings, different types of physical activities and different methods of conducting the behaviour change intervention (face to face and/or by telephone). This has allowed us to explore which approaches are more, and which less, successful. In Appendix 1, we provide Pathway summaries for each of the 14 services included in the evaluation. These show the different ways the services configured and delivered the Pathway, in practice.

The following are the key components of the Physical Activity Behaviour Change Care Pathway:

- the service is embedded in the Recovery Package;
- behaviour change intervention and long term person-centred support;
- the physical activity offer; and
- Data collection.

Each of these is explored in turn in the following section.



**Raise awareness (Very brief advice / Brief intervention)**

**Awareness raising**

- Health and wellbeing events (attend, present)
- Attend patient support groups
- Social media
- Local media (radio, newspaper articles)
- Banners, posters and leaflets
- Engagement with other services (for example, Macmillan Information Services, other charities)
- Holistic Needs Assessment (as part of the Recovery Package)
- Champions, former service users
- Events, campaigns

**Referral**

**Key referral routes**

- Self-referrals
- Healthcare professionals
    - CNS
    - Consultant
    - GP
    - Physiotherapist
    - Practice Nurse
    - Occupational therapist
    - Oncologist

- Electronic referral possible
- Feedback provided to HCPs

**Behaviour Change** (Extended brief intervention)

**Principles**

- Lasts at least 30 minutes
- Needs assessment
    - Activity levels
    - Contraindications
    - Cancer status
    - Safety and appropriateness
- Address barriers to change
- Instils confidence to change
- Uses MI
- Sets goals

**Delivery**

- Face-to-face / telephone / group
- Healthcare / community / leisure setting
- Practitioner trained in motivational interviewing and level 4 cancer rehabilitation

**Local physical activity opportunities**

**Minimum offer**

- Access to Macmillan Move More DVD
- Access to health walks
- Encouragement to increase activity in daily life
- Access to sports
- Access to community activity
- Access to cancer specific sessions

**Signposted or delivered directly**

**Support during activity**

- Long term support agreed at start
- Review progress
- Informal support

**Ongoing behaviour change support**

**Support post activity**

- Long term support agreed at intervention
- System in place to review progress during activity
- Informal support offer

Data collection at baseline, 3, 6 and 12m

Figure 1.2: Overview of the key components of the Macmillan Physical Activity Behaviour Change Care Pathway

## The service is embedded in the Recovery Package

Services should be embedded into the local delivery of the Recovery Package. Service teams should build good relationships with cancer care teams and professionals should access the *Understanding physical activity and cancer* training[46].

As the diagram below illustrates, the Recovery Package is a series of key interventions which, when delivered together, can improve outcomes for people living with and beyond cancer.

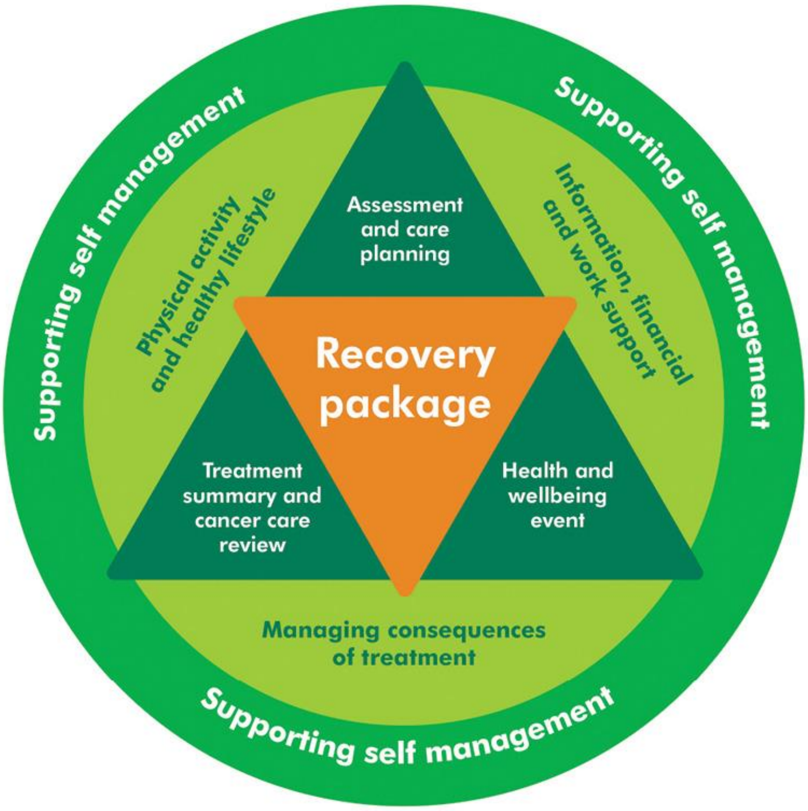


Figure 1.3: The Recovery Package[47]

The Recovery Package is made up of:

- an Assessment and care plan using Holistic Needs Assessment (HNA)
- a Treatment Summary
- a Cancer Care Review, and
- a Health and Wellbeing event.

---

[46] http://learnzone.org.uk/courses/course.php?id=297

[47] https://www.macmillan.org.uk/_images/recovery-package-sharing-good-practice_tcm9-299778.pdf

### Holistic Needs Assessment (HNA)

The HNA identifies the needs of the person living with cancer (PLWC) and ensures that they are met. It is a questionnaire that is completed by the PLWC which allows them to highlight the most important issues to them at the time, including those concerned with physical activity. This then informs the development of the care and support plan produced by the healthcare professional. To ensure that the changing needs of the PLWC are met, a HNA should be undertaken at each different stage of a patient's treatment journey. The HNA is also available in an electronic format (EHNA) where a referral for physical activity can be indicated by a tick box.

### Treatment summaries

A Treatment Summary is a document that describes the treatment, its potential side effects, and the signs and symptoms of recurrence. The Summary is designed to inform GPs and other primary care professionals of actions that need to be taken and to provide an up-to-date and clear understanding of the patient's treatment. The PLWC also should receive a copy in order to help improve their understanding of their treatment.

### Cancer Care Review

This is a discussion between a patient and their GP or practice nurse about their cancer journey. It should help the PLWC to understand what information and support is available to them in their local area. This review should occur within six months of them receiving notification of a diagnosis.

### Health and Wellbeing events

Health and Wellbeing events are designed to help PLWC and their families to access the support that they may need during and after cancer treatment. They typically provide information and support on a range of issues including: diet and exercise, treatment side effects, benefits and financial support and the local services available. These events may be tumour specific or generic (covering all tumour sites) or delivered as an appointment.

Across England, Wales, Scotland and Northern Ireland, responsibilities for, and policies concerning, health differ. All the nations, to some degree, highlight the importance of embedding elements of the Recovery Package within the cancer care pathway. The Recovery Package is currently being rolled out across the UK, and the extent to which the four elements are available varies. As a result, not all of the services in the evaluation are able to access these opportunities. Below, we provide further information about the variations in the Recovery Package between countries.

## England

The Recovery Package has been recognised in key national strategy documents, including the NHS England Five Year Forward View[48] and the Cancer Taskforce Strategy[49]; the latter outlines a commitment to ensure that 'every person with cancer has access to the elements of the Recovery Package by 2020'.

## Wales

In November 2016 the Wales Cancer Network, working with the Welsh Government, published a Cancer Delivery Plan for the NHS – to 2020. This includes a key action: the Wales Cancer Network is to lead on the consistent application, across Wales, of elements of the Recovery Package as appropriate to identified needs. Local health boards are expected to assign a named key worker to assess and record the clinical and non-clinical needs, of people who are diagnosed with cancer, which should be included in a care plan. These should include regular assessments of the consequences of treatment as well as other needs.

## Scotland

In Scotland, the NHS Scotland quality strategy underpins the development of the NHS in Scotland.[50] Published in 2010, this strategy sets out three ambitions related to quality, of which two, 'People are able to live well at home or in the community' and 'Everyone has a positive experience of healthcare' are relevant to HNA and care planning. The Transforming Care After Treatment (TCAT) programme is being delivered by the Scottish Government in partnership with Macmillan.[51] Assessment and care planning are a major part of this programme.

In 2014 Macmillan launched the Improving the Cancer Journey service. This service offers PLWC financial, emotional and practical support. Every newly diagnosed cancer patient is offered a visit from a link worker who finds out about the kind of support they need before helping them access it. The service brings health, social care, charities and other organisations together and builds support around the person with cancer and their family.

## Northern Ireland

Here, the Department of Health, Social Services and Public Safety established a set of Service Frameworks in 2011 which set out standards for care to be used by patients and their wider families in relation to prevention, diagnosis, treatment, rehabilitation and

---

[48] https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

[49] http://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

[50] http://scotland.gov.uk/publications/2010/05/10102307/0

[51] http://www.gov.scot/Topics/Health/Services/Cancer/TCAT

care.[52] Several standards include performance indicators regarding Holistic Needs Assessment and care planning.

## Behaviour change intervention and longer-term support

The behaviour change intervention is designed to increase the service user's level of physical activity. The initial intervention should last for a minimum of 30 minutes and be delivered by a practitioner who has completed their level 4 cancer rehabilitation training and a course in behaviour change (such as Macmillan's two day course on motivational interviewing). The practitioner should take a person-centred approach, and work in tandem with the service user in order to decide on the design and delivery of appropriate support. The intervention should incorporate an assessment of needs (looking at previous activity levels and the appropriateness of activities to the service users' cancer type and treatment history), and a discussion of behaviour change support. The latter should cover the service user's motivations, confidence and barriers to achieving and maintaining behaviour change. Practitioners should help individuals to set goals and plan how these goals will be met. The practitioner could use the Macmillan Move More guide to shape the conversation.

As part of the initial intervention, plans for longer-term support should be agreed. On-going support should be provided at a time, location and in a format appropriate to the service user. Regular reviews should be undertaken to check progress against goals, suitability of activities chosen, cancer status and to provide information and/or signposting to wider Macmillan services such as financial advice and psychological support, if required.

### Activity choice

Service users should be able to choose from a range of activities to facilitate them finding something in line with their likes and needs. As a minimum, service users should be able to choose from the following:

- Macmillan Move More DVD
- health walks
- sports
- community activities (such as Zumba, gentle exercise etc.)
- cancer/long term condition specific sessions where appropriate,, and
- encouragement to increase activity in daily life (carrying shopping, walking to and from work etc.).

---

[52] https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/service-framework-for-cancer-prevention-treament-and-care-full-document.pdf

### Data collection

In order to monitor progress and evidence the effectiveness of the programme, service users should be invited to complete a questionnaire before their initial intervention, and at 3, 6 and 12 months thereafter. The questionnaire collects the minimum data set as described on page 30. The questionnaires should be provided in hard-copy and electronic format and should be self-completed by service users. Macmillan have made a short film available to inform service users of the importance of completing the questionnaire.

## This report

In Chapter 2, we set out our evaluation methodology in detail. This description includes an explanation of our approach, its limitations and a detailed exploration of some of the challenges involved with collecting the data.

The next four Chapters explore each of the key steps of the Physical Activity Behaviour Change Care Pathway. Chapter 3 looks at how services have raised awareness and generated referrals and includes a profile of service users. Chapter 4 focuses on the behaviour change interventions and Chapter 5 on the physical activities which services provide access to. Chapter 6 concerns on-going behaviour change support. For each of these Chapters we take a similar approach, first setting out how Macmillan envisage the relevant stage of the Pathway should be delivered and then going on to assess to what extent the services adhere to this.

Chapter 7 covers service management issues, including how services are staffed and the role of steering groups and case management systems.

The outcomes and the impact of the services are investigated in Chapter 8. This Chapter draws on both qualitative and quantitative data. Chapter 9 provides an economic assessment of the service.

Chapter 10 draws together the conclusions and recommendations from across the report.

We analyse and present findings first at the overall level and then, for each topic, we look at several key sub-groups as appropriate – national models, delivery models and setting. The sub-groups are explained in further detail in the following Chapter.

# 02. Evaluation methods

*In this chapter we set out the overall evaluation methodology. We discuss the qualitative and quantitative approaches adopted and set out the limitations of the evaluation. We also include a detailed exploration of some of the data collection challenges.*

## Aims and objectives

In September 2014, Macmillan commissioned CFE Research to undertake, working in partnership with academics from the University of Sheffield and the University of Exeter, a longitudinal evaluation of the Physical Activity Behaviour Change Care Pathway. The evaluation explored processes combining formative and summative elements. The evaluation also provides indicative evidence of impact. The evaluation aimed to:

- Understand how the Pathway has been implemented, describe the processes in place and assess the extent to which delivery is in line with the ideal model set out in Chapter 1.
- Explore the efficacy of the interventions and the elements that are working well and less well.
- Consider the scalability of the Pathway, identify the optimum processes for best practice delivery and which aspects need to be emphasised or modified should the Pathway be rolled-out more widely.
- Assess the impact of the Pathway on service users and their families.

## Methods

The evaluation took a mixed-methods approach which comprised:

- qualitative interviews with staff, stakeholders and service users
- ethnographic observations of services
- analysis of quantitative data collected by services,, and
- an economic analysis of the services.

The evaluation was undertaken in two phases, between September 2014 and July 2017.

We are also undertaking a pilot study on the acceptability of accelerometers as an objective means of measuring physical activity levels in people affected by cancer. We expect this study to report in late 2017.

Further details concerning each element of the method are provided below.

## Interviews with staff and stakeholders

We completed 168 interviews with service delivery staff and stakeholders over the course of the evaluation. Table 2.1 below provides a breakdown of the total number of interviews undertaken – by role type.

| Stakeholder type | Roles interviewed | Total number of interviews |
|---|---|---|
| Services | Move More Practitioners[53] | 34 |
| | Support staff[54] | 26 |
| Healthcare professionals | CNS/Nurse<br>Psychologist<br>General Practitioner<br>Physiotherapist | 47 |
| Employed by Macmillan | Development manager<br>Information manager<br>National programme staff | 20 |
| Local stakeholders | Public Health<br>Sports/Fitness professionals<br>University staff<br>Local Commissioner<br>Clinical Commissioning Group<br>Hospital Cancer staff<br>Grant/Contract holder<br>Cancer forum representative<br>Ambassador<br>Volunteer[55] | 44 |

**Table 2.1: Total number of interviews undertaken – by role type**

We conducted in-depth, semi-structured interviews with up to eight staff and stakeholders from each of the 14 projects. For phase one services, we interviewed the Move More practitioner on three occasions across the lifetime of the evaluation (sampling points 1, 2 and 3). For phase two services, we interviewed the Move More Practitioner on two occasions (sampling points 2 and 3). At the third sampling point, we also identified up to three key stakeholders from each service whom we re-interviewed in order to gain further

---

[53] See the Glossary for a definition of Move More practitioner and Chapter 7 for more about the role

[54] Support staff roles are also explored further in Chapter 7.

[55] Move More sites in Scotland only

insights into the service. Figure 2.1 below gives an overview of which types of stakeholders were interviewed and when.

| Sampling point 1 (June 2015) | Sampling point 2 (Oct 2016) | Sampling point 3 (May 2017) |
|---|---|---|
| • Phase one practitioners<br>• Phase one stakeholders | • Phase one practitioners<br>• Phase two practitioners<br>• Phase two stakeholders | • Phase one & two practitioners<br>• Phase one & two stakeholders |

Figure 2.1: Interviews by type across the three sampling points

Stakeholders were selected in consultation with the services and Macmillan in order to ensure that they were representative of the services and able to provide a broad understanding of the services. Move More Practitioners were interviewed face to face as part of the visits to each service site. Other stakeholders were interviewed either in person where possible, as part of the visit, or by telephone.

## Interviews with service users

Service users were selected by Move More Practitioners – who provided contact details of 12 current or former service users. We asked Practitioners to provide a representative sample of different service users who had engaged with the service. However, the extent to which this was achieved is unknown. After conducting an initial baseline interview, phase one service users were then re-contacted on two further occasions. Phase two service users were re-contacted on one further occasion.

As is common in longitudinal studies, the sample size reduced over time. In most instances this was due to researchers being unable to contact service users, although in some instances individuals did not wish to continue participating in the evaluation. As Table 2.2 below shows, we engaged with 140 service users at least once during the evaluation (an average of 10 service users per site), 101 service users at least twice (an average of 7 service users per site) and 26 service users three times (an average of 4 service users per site). In total we conducted 267 service user interviews.

|  | Service | Sampling point 1 interviews (140) June 2015 | Sampling point 2 interviews (101) Oct 2016 | Sampling point 3 interviews (26) May 2017 |
|---|---|---|---|---|
|  | **TOTAL** | **140** | **101** | **26** |
| Phase one sites | Berkshire | 12 | 10 | 7 |
|  | Dorset | 7 | 4 | 2 |
|  | Luton | 12 | 10 | 6 |
|  | Manchester | 12 | 8 | 4 |
|  | Sheffield | 10 | 9 | 4 |
|  | Shropshire | 10 | 6 | 3 |
| Phase two sites | Aberdeen | 11 | 9 |  |
|  | Antrim & Newtownabbey | 7 | 5 |  |
|  | Ards and North Down | 9 | 6 |  |
|  | Edinburgh | 10 | 5 |  |
|  | GSTT | 12 | 7 |  |
|  | Hertfordshire | 7 | 5 |  |
|  | Lincolnshire | 11 | 10 |  |
|  | Velindre | 10 | 7 |  |

Table 2.2: Service user interviews completed at each sampling point

Most interviews were conducted by telephone. For stakeholder and service user interviews, an interview guide was developed in consultation with Macmillan. For stakeholders, this covered the service structure, staffing, mechanisms for delivery, perceptions of success and impact and learning. For service users, this covered current activity and previous activity levels, support received and the impact of participation in the Move More programme. The interviews were semi-structured to allow for the flexibility to explore issues raised by interviewees, but the common framework ensured that the key topics were always covered.

Interviews were transcribed in full and reviewed by members of the evaluation team to identify emerging themes. NVivo and Excel software was used to summarise the qualitative data against key research questions and the topics from the interview guide. The team held a number of workshop sessions at which further emerging themes were ascertained. Interview data was further analysed and summarised against these themes to understand the extent to which identified views were prevalent across the sampled interviewees. Key verbatim quotes were selected to illustrate particular points or demonstrate typical views.

The evaluation also draws on monitoring reports prepared by Macmillan for Sport England and local evaluation reports from some of the phase one projects.

## Ethnographic visits

We undertook up to three ethnographic visits with each of the services. Phase one services were visited three times during the evaluation, and the phase two services were visited twice; this was in line with the sampling point timetable provided on page 27. Each visit involved observations of physical activity sessions and interviews with Move More Practitioners, other service staff and stakeholders and informal conversations with service users. We shadowed service staff in order to understand the behaviour change techniques adopted at each service.

During the visits we observed a total of 33 initial behaviour change interventions, with at least two interventions observed for each service. The observations were assessed using the Behaviour Change Counselling Index (BECCI[56]), a tool designed to assess the frequency of use of behaviour change counselling methods. This tool is made up of 11 statements and has been tested for use in a consultation setting. Each statement has a Likert scale attached which is intended to reflect the degree to which observers believe the action was carried out, ranging from 0 (not at all) to 4 (a great extent). We followed a mean substitution approach for any items marked ‘not-applicable’. From the scores we calculated an overall average score.

Dr Melvyn Hillsdon from the University of Exeter provided training to the CFE evaluation team on the correct implementation of the BECCI tool. This training involved learning about the definitions of the terms included in the tool and coding simulated interventions, both as a team and separately.

We had limited opportunities to observe follow up interventions. Services were reminded of the importance of facilitating observations of follow-up interventions as part of service visits. However, Move More Practitioners found it difficult to schedule follow-up sessions for the times of our visits. In some instances, where interventions (initial or follow-up) had been arranged these were cancelled or re-scheduled at the last minute because, for example, service users were unwell or had undergone a change of circumstances. The difficulty in observing follow-up sessions is related to our finding that in many cases follow-up is informal and ad hoc. As a result, we were only able to observe five follow up conversations in five services (one each in Aberdeen, Edinburgh, Lincolnshire, Luton and GSTT) and are therefore unable to comment on the quality and quantity of follow up interventions in the other services.

## Analysis of quantitative data

Macmillan developed the Cancer Physical Activity Standard Evaluation Framework (CaPASEF) in tandem with a team of expert advisors[57] in January 2013.[58] This development was based on information derived from the use of Public Health England’s

---

[56] Lane, C., Huws-Thomas, M., Hood, K., Rollnick, S., Edwards, K. And Robling, M. (2005). Measuring adaptations of motivational interviewing: the development and validation of the behaviour change counselling index (BECCI). Patient Education and Counselling, volume 56 (2): 166-173

[57] Expert advisors included Dr Anna Campbell MBE, senior lecturer at Edinburgh Napier University and Dr Nick Cavill, Director of Cavill Associated Ltd

[58] Available here: http://www.macmillan.org.uk/Documents/AboutUs/Health_professionals/Physicalactivity/Cancer-Physical-Activity-Standard-Evaluation-Framework.docx last accessed February 2015

physical activity standard evaluation framework[59] and uses validated measures. After consultation with Macmillan and the evaluation steering group about how the CaPASEF could be applied to our evaluation, a minimum dataset specific to this evaluation was agreed. The purpose of this provision was to ensure that the best available data, comparable across sites, was collected for demonstrating the impact of the behaviour change interventions and of engaging in physical activity more broadly. The minimum dataset was tested by a service user advisory group which was made up of seven service users from the service sites.

The data was collected from service users by questionnaires at baseline and 3, 6 and 12 months after the initial intervention. The dataset includes the following information:

### Demographic information

This includes gender; ethnicity; age; cancer type and treatment stage; housing tenure; and educational attainment (the latter two being proxy indicators of socio-economic background).

### Health Related Quality of Life (EQ-5D)[60]

The EQ-5D is a standardised measure of health status. It comprises five dimensions of health: mobility; ability to self-care; ability to undertake usual activities; pain and discomfort; and anxiety and depression. A set of population based preference weights are available which enables the construction of an index of Health Related Quality of Life (HRQoL) from the EQ-5D health state outcome data[61]. This index is measures on a continuous scale from zero to one (the latter representing full health). Higher scores represent better health. The EQ-5D index is the instrument recommended by NICE for generating quality of life weights for Quality Adjusted Life Years (QALY). Our analysis estimated the average change in the continuous EQ-5D index.

### Fatigue[62]

Fatigue levels are measured by the Functional Assessment of Chronic Illness Therapy (FACIT-Fatigue scale) questionnaire. The FACIT measure is a collection of health-related quality of life questionnaires targeted for the management of chronic illness. The FACIT score (based on answers to 13 questions) ranges from 0 to 52, where higher scores represent more fatigue. In the analyses presented, the FACIT score is treated as a continuous scale, and we estimate the average change in the score. Given that a high

---

[59] http://webarchive.nationalarchives.gov.uk/20170110172214/

[60] https://euroqol.org/

[61] Dolan P. Modelling valuations for EuroQol health states. Med Care 1997;11:1095–1108.

[62] http://www.facit.org/

FACIT score is an indication of a decrease in health status, the FACIT score is reverse coded for ease of interpretation – so a higher score represents less fatigue.

### Self-efficacy[63]

This measure was included in order to correlate change, and examine whether there was a relationship between high/low self-efficacy and levels of activity. This was measured using the General Self-Efficacy (GSE) scale. The GSE is a ten item psychometric scale that is designed to assess optimistic self-beliefs which help in coping with a variety of difficult demands in life. In contrast to other scales designed to assess optimism, this one explicitly refers to personal agency, that is, to the belief that one's actions are responsible for successful outcomes. The GSE has ten questions, the results for each measured on a scale of one to four, so the overall scale ranges from ten to 40 where a higher score represents better self-efficacy. We treat this as a continuous scale and estimate the average change in the GSE score.

### Levels of physical activity and sport

The key measure of physical activity used here is the Scottish Physical Activity Questionnaire (SPAQ).[64] The SPAQ provides data on the number of minutes of 'moderate and vigorous' exercise per week. The SPAQ was developed and validated by NHS Health Scotland in partnership with the University of Edinburgh as a tool for use in physical activity interventions. The questionnaire requires information on a service user's level of physical activity over the previous week, taking into account leisure time physical activity and physical activity at work.

As is typical with self-report tools, responses to the SPAQ tend to produce high estimates of the number of minutes of exercise per week undertaken and a skewed distribution, with some of the higher values suggesting unrealistic responses. We excluded responses at each sampling point of more than 1400 minutes per week.

Sports participation, specifically, is measured by two questions similar in format to questions included in the International Physical Activity Questionnaire (IPAQ). Service users are asked how many days during the last week they took part in any sport, with sport being defined as competitive or non-competitive sporting activity, including sessions of deliberate exercise such as running or jogging. They were then asked to state the amount of time they *usually* spent doing sport on *one* of those days.

From the sports participation questions, it is possible to derive both the total number of individuals who undertook at least 30 minutes of sport on one or more days in the last

---

[63] http://userpage.fu-berlin.de/health/selfscal.htm

[64] http://www.healthscotland.com/documents/6255.aspx

week (the 1x30 indicator) and the total minutes of sport in which individuals participated in the last week.

Prior to analysis, the sports participation data was cleaned as follows:

- Those who answered the number of days but did not provide data on the time they spent participating in sport were excluded.
- Those who provided a total number of minutes per week ≥ 1,000 minutes were excluded.
- Those who provided information on the number of hours per day and the number of minutes, where the number of minutes ≥ 60 (for example, 4 hours and 60 minutes, or 4 hours and 80 minutes) were excluded.
- Those who provided information in both the hours and the minutes column had their data cleaned so that only one figure was left (for example, 2 hours and 120 minutes cleaned to show just 120 minutes).

Two further questions were included on levels of physical activity between the ages of 20 and 24 and in the five years leading up to the service user's cancer diagnosis.

### Analytical approach

In order to understand the outcomes achieved by service users we take a 'completers only' approach to analysing the outcomes data. This approach only looks at the results for those service users who 'completed' the programme. While the Physical Activity Behaviour Change Care Pathway does not have a clear completion point, for the purposes of this report we look at completion in terms the three follow-up data collection points. Completers are therefore defined as someone who has as provided useable questionnaires data at 3, at 6 and at 12 months. While this is not perfect – not everyone who remains engaged with the Pathway completes such follow-up questionnaires, it is, however, the only indication we have available.

This 'completers approach' is different from the approach taken for the economic analysis (the intention to treat analysis described in the section on economic analysis below). The completers approach is the best one in terms of determining the extent to which the behaviour and health related quality of life of service users who have provided data have changed and how this varies across different types of service user and service delivery. It should be noted, it also generates the most optimistic results. The economic analysis, in contrast, focuses more on understanding the efficiency and costs of achieving outcomes.

The completers only outcomes analysis looks at the average change in outcomes, from baseline to each of the data collection points (3, 6 and 12 months) – only, of course, for those participants who provide data at these points. The downside here is that the sample may not be representative of the entire population of service users. The completers may be more motivated than average service users to fully participate in the intervention, and if so, this will lead to an overestimate of outcomes. Also, and in particular, different levels of success, across different services, in collecting data mean that the results over-represent outcomes from the more successful, in these terms, services. Lincolnshire in particular prioritises on-going support to service users and has maintained very good response rates across all questions and sampling points. In some instances, data from Lincolnshire accounts for nearly half of all responses. Consequently, the results are skewed towards those of Lincolnshire.

## Economic analysis

The primary aim of the economic analysis was to calculate the cost per improvement in the four outcome measures as described above:

- the primary outcome:
    - self-reported physical activity (SPAQ)
- and the three secondary outcomes:
    - fatigue (FACIT)
    - health related quality of life (EQ-5D)
    - self-efficacy (GSE)

EQ5D is also used to calculate quality adjusted life years (QALYs).

The economic analysis calculates the change in cost and the changes in outcome from baseline to 3 month follow-up. The average change in cost divided by the average change in outcome is a measure of the cost effectiveness of the Physical Activity Behaviour Change Care Pathway. The analysis also provides estimates of cost per quality adjusted life year (QALY) based on the effects of the programme lasting for 3 months and 12 months. We adopt a pragmatic approach to the economic analysis and wherever possible a range of estimates are provided which make more or less conservative assumptions.

### Outcomes

For all four outcomes, we have baseline data and data at the 3 month follow-up. The analysis estimates the average change in each outcome over this period and tests whether or not this change was statistically significant. Average change per service user can be calculated in a number of ways.

The most conservative calculation is based on an ‘intention to treat’ (ITT) analysis, which assesses outcomes for all service users who enrolled on the programme. The least conservative analysis uses data for ‘completers only’: i.e., those service users who completed 3 months of programme. It is not straightforward to define completion for this intervention since it is not a time limited programme with a defined end point. The Macmillan model for the Physical Activity Behaviour Change Care Pathway states that a minimum of 12 months of on-going support is to be provided. However, there is no expectation that every service user will remain so for the full 12 months. Not all services are at the same stage in their operating cycle. The length of time that services have been established varies between 12 and 47 months (and services in Northern Ireland have only been receiving referrals for between 8 and 10 months); this has implications for the number of services users recruited (to each service) and the number providing follow-up data at 3, 6 and 12 months.[65] This makes using 12 month follow-ups impractical for some services. 3 months has generally been used as this is where the data is strongest, although we have also looked at changes in health-related quality of life (EQ-5D) at 6 months and 12 months for those projects where sufficient data is available.

ITT analysis assesses outcomes for all service users who enrolled on the programme (i.e. provide baseline data), regardless of whether they dropped out at any stage. An implication of this approach is that for service users who are present at baseline, but not follow up, the change in outcome at follow-up is assumed to be zero (i.e. no change from baseline); this lowers the estimate of the average change. ITT analysis is the recommended approach here because it is a good approximation to a ‘real world’ treatment pathway in physical activity programmes, where drop-out and non-adherence are common. In the economic analysis Chapter we present the average change in outcome using both the ITT and the completers only approach. This provides a range of estimates for the effectiveness of the interventions.

### Costs

The perspective of the cost analysis is that of the provider. This requires an estimate of the total cost (TC) of delivering the Physical Activity Behaviour- Change Care Pathway; that is, the change in costs from baseline (before intervention) to follow-up. The relevant costs include all the direct costs of delivery, including any in-kind contributions such as volunteer staff time and free venues provided for activities. These data have been collected from each service using a costing template, and they represent the actual costs of delivery over a specific period of time as reported to us by the services. It is important to note here that two services (Berkshire and Cardiff) have been excluded from all cost analysis because the cost data provided by these services was not comparable to the data for the other services. In Berkshire’s case, the costs provided by the previous service lead were not recognised by the current lead and it has not been possible for that service to provide alternative cost information. For Cardiff, the cost information is incomplete and not in a useable format.

Services sometimes found it challenging to provide information on the full costs of delivery. This was particularly the case where the service was embedded within another service, meaning that some staff members spent part of their time on other projects. In

---

[65] In particular the two services in Northern Ireland have only been established for 12 months, whereas all other services have been established for at least 24 months.

these cases, services were asked to estimate the time usually dedicated to the Move More programme and to apportion staff costs accordingly. Some services estimated overhead costs differently to others. For example, Guys standard approach to costing internal overheads for services (use of rooms within the hospital, heat, light etc.) is to add on 15 per cent on-costs to the core salary cost of service delivery.

The cost analysis reports different categories of expenditure, including set-up and running costs, in-kind contributions and staff costs. Set-up costs are the one-off costs of setting up the service, which should not require repeat expenditure; they generally include:

- recruitment;
- initial training;
- equipment for sports and physical activity;
- marketing and media, including website development (although costs of materials provided centrally by Macmillan are not included);
- launch events;
- staff uniforms; and
- IT equipment for staff.

In contrast to set-up costs, running costs are incurred on a continuous basis for as long as the service operates; these include:[66]

- staff salaries;
- staff travel and expenses;
- admin and telephones;
- marketing and media;
- on-going training, learning and professional supervision for staff;
- delivery of activities provided as part of the programme (including venue hire, sessional instructors, refreshments and other resources);
- occasional events; and
- costs of supporting volunteers e.g. training, expenses;

---

[66] Running costs do not include costs of activities that are not provided directly by the programme but that the programme signposts to. Local evaluation costs have been incurred by some projects, but these have been excluded as they do not represent a cost of delivering the intervention.

In-kind costs are resources that the service has not directly incurred monetary costs for. These can include:

- donations of materials and equipment for delivering activities;
- donation of venues for physical activity sessions and behaviour change interventions;
- cost of providing free or discounted memberships or classes; and
- cost of hosting the service – e.g. desk and meeting space for staff and steering groups, management/admin support.

### Quality adjusted life years (QALYs)

QALYs are single measures of health that combine quality of life and quantity of life. The EQ-5D index health state descriptive system is recommended by NICE as a standard way to measure health and generate the quality of life weighting for QALYs. A tariff derived from a population sample provides an index value for health related Quality of Life (QoL) ranging on a scale from 0 to 1[67]; for example, 10 years in a health state valued at 0.8 gives 8 QALYs.

QALY calculation requires estimates of the changes in both quality of life and quantity of life for the service user cohort, and an estimate of the duration of the treatment effect: i.e., how long the change in quality of life lasts. We estimate changes in quality of life using the EQ-5D index. In order to estimate changes in length of life we would need epidemiological or trial data that links physical activity participation to mortality effects in this population (people with cancer diagnoses). We are not aware of any such data; hence, in the absence of this information, we make the (conservative) assumption that the intervention affects only quality of life and not quantity. The QALY calculation is then the change in quality of life multiplied by the duration effect.

The most conservative assumption for duration is that the treatment effect lasts only for the length of the intervention, and that quality of life returns to the baseline level when treatment ends. This seems a particularly conservative approach in the context of the 3 month perspective taken. There is no epidemiological/cohort data that provides information on how quality of life for people with cancer is affected in the long-term by this type of intervention. However, a number of other sources of information are available, although these do provide very mixed results on the longer term effects. As a result of the mixed evidence on longer-term effects we provide a range of estimates from the effect

---

[67] Dolan P. (1997) Modelling valuations for EuroQol health states. *Med Care* 1997:11 1095–1108

lasting 3 months to 12 months. In the economic analysis Chapter we discuss how changing this assumption will affect the results.

## Sub-group analysis

The analysis of outcomes and the economic analysis both consider how results vary by different sub-groups of services. We use the following groupings of services for these purposes.

### National approaches

All services vary, but there are some clear differences between approaches between some of the UK nations. In Northern Ireland, both of the services included, offer of up to five free taster sessions initially to the service user, including closed circuits activity. In Scotland, all Move More services offer a series of 12 free sessions of one of four physical activities (circuits, gentle movement, walking and gardening). In England and Wales, the services offer a broad mix of activities: some offer access to a set number of free activities, some focus on signposting to activities and others offer a mixture of the two approaches.

| Nation | Service |
|---|---|
| Northern Ireland | Antrim and Newtownabbey<br>Ards and North Down |
| Scotland | Aberdeen<br>Edinburgh |
| England and Wales | Berkshire<br>Dorset<br>GSTT<br>Hertfordshire<br>Lincolnshire<br>Luton<br>Manchester<br>Sheffield<br>Shropshire<br>Velindre (Wales) |

Table 2.3: National model breakdown of services

### Physical activity offer

Services tend to use one of two main delivery methods. Eleven services across the UK offer a mixture of direct delivery, such as circuit classes, and signposting to other community based activities. Three services predominantly signpost to activities delivered locally, and these services provide very few, if any, activities directly.

| Delivery model | Service |
|---|---|
| Direct delivery and signposting | Aberdeen<br>Antrim & Newtownabbey<br>Ards & North Down<br>Berkshire<br>Dorset<br>Edinburgh<br>GSTT<br>Hertfordshire<br>Luton<br>Manchester<br>Velindre (Wales) |
| Signposting[68] | Lincolnshire<br>Sheffield<br>Shropshire |

Table 2.4: Delivery model service breakdown

## Healthcare and community settings

Services fall broadly into one of two settings. Healthcare based services are led by healthcare providers such as an NHS Trust or a Cancer Centre. The community setting group includes services led by organisations such as local authorities, county sports partnerships, sports and leisure trusts and a university (see table 2.5 below). While the community based group is diverse, these services share the common feature that they are *not* healthcare based. Where appropriate in our qualitative analysis, we have differentiated between community services that are led by leisure providers and those led by other community organisations.

---

[68] Some signposting services do also have a very limited direct delivery offer – however, at these services, signposting is the most common pathway for service users

| Setting | Service | Lead organisation |
|---|---|---|
| Healthcare | Berkshire | Berkshire NHS Foundation Trust |
| | GSTT | Guys' and St Thomas' Hospital Trust |
| | Shropshire | Shropshire Community Health NHS Trust |
| | Velindre | Velindre Cancer Centre |
| Community | Aberdeen | Sport Aberdeen |
| | Antrim & Newtownabbey | Antrim and Newtownabbey Borough Council |
| | Ards and North Down | Serco |
| | Dorset | Active Dorset and Bournemouth University |
| | Edinburgh | Edinburgh Leisure |
| | Hertfordshire | YMCA |
| | Lincolnshire | Active Lincolnshire |
| | Luton | Active Luton - Sports and Leisure Trust |
| | Manchester | Manchester Community Giants |
| | Sheffield | Sheffield Hallam University |

**Table 2.5: Service setting breakdown**

## Limitations of quantitative and economic analysis

The following caveats should be borne in mind when considering the analyses of quantitative outcomes data, including the economic analysis.

- The process evaluation was formative and the services have adjusted and developed what they do as the evaluation has progressed. Furthermore, services have interpreted and delivered aspects of the Physical Activity Behaviour Change Care Pathway differently. Where we have compared service costs and results and undertaken analysis by sub-group, the variation between individual services should be borne in mind.
- The uncontrolled before and after study design which was adopted to evaluate the Physical Activity Behaviour Change Care Pathway is not a strong method for attributing cause and effect. In particular, other factors could have affected the observed outcomes which are not accounted for in this study.
- It is not straightforward to define completion for this intervention as it is not a time limited programme with a defined end point. If this were a clinical trial ideally this would be 12 months. For the perspective of the economic analysis, start and completion are defined via the provision of outcome information; a starter is someone who provides baseline outcome data, and a 3 month completer is someone who provides data at the 3 months follow-up. We acknowledge that survey completion is not necessarily the same as programme completion, but this is the best indicator available.

- As is common in longitudinal evaluations, levels of non-response to follow-up questionnaires are high. For example 2,464 people provide useable SPAQ responses at the start of the programme, and only 44 per cent of these provided responses 3 months later. It is not clear to what extent this is due to service users leaving the programme or simply to them not completing the questionnaire.
- As a result of this, sample sizes at month 6 and month 12 are relatively small in some cases, and this limits our ability to consider project-by-project variation and carry out some sub-group analyses and also to disaggregate by service user characteristics. In general, in what follows, we do not carry out statistical analysis on cell sizes that are smaller than 30 participants because extrapolating from these small sample sizes can be very misleading.

In addition, the following caveats should be borne in mind when considering the economic analyses and results.

- The 3 month perspective adopted is relatively short term. The assumption that the effect of the treatment only lasts for the length of the intervention seems particularly conservative in the context of our 3 month approach. In the absence of information on the mortality effects of physical activity for people with cancer, and mixed evidence on the duration effect for this intervention, we provide a range of estimates of the quality of life years (QALYs) generated based on the effects lasting for 3 months and 12 months.
- The analysis only considers the direct costs of delivery for this intervention. It does not consider the costs to the service users (for example, travel costs) or any implications for NHS resource use (for example, any resulting effects on GP and hospital visits).

Some of the challenges in collecting the data and the resulting limitations are explored further in the section on data collection challenges below.

## Service specific limitations

### Berkshire

Berkshire was one of the first areas to participate in the design, implementation, and evaluation of Macmillan's Behaviour Change Care Pathway approach. The service was launched in Windsor in 2013 and expanded across the whole of the county in 2014. The expansion of the programme was jointly funded by Macmillan and Sport England as part of the Get Healthy, Get in to Sport funding (now Get Healthy, Get Active).

The service has undergone a number of staff changes since its inception. The Service Lead left in November 2015 and the Physical Activity lead for the Service left in February 2016. The Physical Activity Lead was replaced at a lower grade in July 2016; however, this lead also left – in September 2016. This situation has led to a hiatus in service delivery of the Physical Activity Behaviour Change Care Pathway of approximately 10 months.

The service has since recruited two Move More Practitioners and will be re-launched in summer 2017, aligned to the Macmillan Physical Activity Behaviour Change Care Pathway.

In addition, the service will move from a healthcare setting to a community one, hosted by the CSP, although it remains part of a larger Berkshire wide cancer rehabilitation programme that is embedded in the Recovery Package.

As regards Berkshire in particular, the data collection required for this evaluation was not always completed at follow-up sampling points and service user data is incomplete. The service has provided no monitoring data since April 2016. Financial information provided by the previous service team cannot be confirmed as accurate by the current service lead. In consultation with Macmillan, we agreed not to include the Berkshire service in the quantitative and economic analysis. The evaluation does draw on learning and insights from qualitative fieldwork with stakeholders, service users and ethnographic visits in relation to this service.

### Northern Ireland services

Both Northern Ireland services included in the evaluation (Ards and North Down, and Antrim and Newtownabbey) began engaging service users later than other services (July 2016 and October 2016 respectively). Consequently, at the time of conducting the analysis for this report no service users had been engaged for the full 12 months. This limits our ability to carry out longer-term analysis of outcomes in Northern Ireland. These services have also had less time than others to get established, although they have benefited from learning from elsewhere.

## Objective measure pilot

To assess changes in physical activity levels, self-report measures of physical activity are currently being used, but these are somewhat limited as physical activity behaviour is very difficult to recall and report accurately from the point of view of the service users themselves and can also be subject to bias. As such it is possible that the effectiveness of the programme may be underrepresented due to recall difficulties, or even exaggerated due to over-reporting of physical activity. The solution is to use objective measures of physical activity, called accelerometers, which are worn on the body (for example, like a wrist watch) and collect accurate and detailed information on habitual physical activity over a number of consecutive days. Unlike pedometers they measure intensity as well as frequency of activity. Accelerometers are also able to detect small changes in physical activity (which may be missed by self-report measures) and could potentially allow a more widespread evaluation of the Macmillan Physical Activity Behaviour Change Care Pathway in the future. However in order to inform a more widespread evaluation, the feasibility of using accelerometers for collecting physical activity data from people affected by cancer needs to be established. It is also necessary to determine whether the use of accelerometers to assess physical activity is acceptable to people affected by cancer.

Macmillan has commissioned CFE Research, working in partnership with the University Of Exeter, to assess whether it would be feasible to use accelerometers[69] to evaluate the effectiveness of the Physical Activity Behaviour Change Care Pathway. The pilot will allow us to report estimates of the volume of physical activity, and time per day spent: in a sedentary situation; and in light, moderate and vigorous physical activity. The trial will also explore how the objective measure compares to self-reported activity levels based on service user's completion of the minimum dataset. We have been working with two services (Lincolnshire and Luton) to provide service users with accelerometers at two sampling points (baseline and six months) to test the efficacy of the approach and the quality of the data collected. NHS ethical approval was received, and staff from both sites received training from the University of Exeter.

Participating service users are required to wear a GENEActiv™ accelerometer for two periods of seven consecutive days. These devices are worn on the non-dominant wrist like a wrist watch. They provide no feedback to the wearer. Data captured from the devices will allow us to understand users' levels and patterns of physical activity at both time points as well as differences in these patterns between sampling points one and two. To date, 58 participants have used the accelerometers and returned these to Exeter, and this data has been successfully uploaded. Each participant also completed a short questionnaire about the acceptability of wearing the device.

The results from the objective-measure pilot will be reported separately in late 2017.

## Data collection challenges

As at the end of May 2017 we have received baseline survey data on 4,733 individuals across 14 services. Table 2.6 overleaf shows the number of completed survey sections for each sample point and service. Note that services began collecting data on service users at different points in time (see table 2.6 on page 43 for details); hence, the varying number of service users. The table also shows response rates. The figures calculated only include those service users who have provided an answer for each section/statement of the relevant question at the start *and* at the relevant follow-up- sampling point – this gives an indication of the samples available for conducting analyses of change over time. In the case of the SPAQ, only those service users have been included for whom a total SPAQ score can be calculated. As is common with longitudinal research designs, the levels of survey attrition are high - as follow-up timescales increase there are fewer observations available for analysis. However, as the table demonstrates, response rates, in general, are lower than expected at baseline; here, we would expect to see considerably higher response rates across the 14 sites. The two Scotland services appear to underperform against the other

---

[69] Accelerometers are portable movement sensitive devices that can be used to measure physical activity. Unlike pedometers they measure intensity as well as frequency.

services at baseline with the highest completion rate being only 37 per cent (Aberdeen, SPAQ). This may be attributable to the fact that initial engagement with service users is carried out over the telephone and the survey is often distributed after this. In other services, the service users are encouraged to bring the completed questionnaire to the initial (face-to-face) intervention

It is worth noting that the two newest services (both in Northern Ireland) have achieved among the highest proportion of responses (albeit from a smaller base) at baseline. This may indicate that the Move More Practitioners have benefitted from learning from earlier services and/or have now placed a higher priority on ensuring service users complete the questionnaire.

As can be seen, response rates vary considerably across the services and across different elements of the minimum data set. For example, completion rates at baseline for FACIT range from 14 per cent (Shropshire) to 95 per cent (Sheffield). At the 12 month sampling point, the completion rates for EQ5D vary from 0 per cent (Luton) to 62 per cent (Lincolnshire). Despite the SPAQ challenges reported later in this chapter, completion rates tend to be highest for the SPAQ, as compared with the other measures. In this section we explore some of the challenges in data collection and how this activity could be strengthened in future.

|  |  | Beneficiaries records |  |  |  | FACIT/Fatigue |  |  |  | EQ5D/Quality of Life |  |  |  | General Self-Efficacy |  |  |  | SPAQ |  |  |  |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
|  |  | Start | 3m | 6m | 12m | Start | 3m | 6m | 12m | Start | 3m | 6m | 12m | Start | 3m | 6m | 12m | Start | 3m | 6m | 12m |
| **Aberdeen** | **Count** | 293 | 257 | 232 | 191 | 98 | 30 | 14 | 11 | 103 | 31 | 16 | 11 | 58 | 14 | 10 | 4 | 107 | 38 | 17 | 11 |
|  | **Percentage** |  |  |  |  | 33% | 12% | 6% | 6% | 35% | 12% | 7% | 6% | 5% | 4% | 4% | 2% | 37% | 15% | 7% | 6% |
| **Antrim & Newtownabbey** | **Count** | 84 | 76 | 30 | 2 | 73 | 24 | 0 | 0 | 75 | 28 | 0 | 0 | 67 | 26 | 0 | 0 | 75 | 26 | 0 | 0 |
|  | **Percentage** |  |  |  |  | 87% | 32% | 0% | 0% | 89% | 37% | 0% | 0% | 80% | 34% | 0% | 0% | 89% | 34% | 0% | 0% |
| **Ards & North Down** | **Count** | 137 | 103 | 80 | 17 | 114 | 38 | 15 | 0 | 126 | 44 | 16 | 0 | 124 | 40 | 17 | 0 | 136 | 48 | 18 | 0 |
|  | **Percentage** |  |  |  |  | 83% | 37% | 19% | 0% | 92% | 43% | 20% | 0% | 91% | 39% | 21% | 0% | 99% | 47% | 23% | 0% |
| **Berkshire** | **Count** | 250 | 247 | 247 | 207 | 141 | 32 | 8 | 3 | 210 | 42 | 8 | 4 | 22 | 0 | 0 | 0 | 213 | 44 | 12 | 0 |
|  | **Percentage** |  |  |  |  | 56% | 13% | 3% | 1% | 84% | 17% | 3% | 2% | 9% | 0% | 0% | 0% | 85% | 18% | 5% | 0% |
| **Cardiff** | **Count** | 322 | 287 | 252 | 178 | 173 | 113 | 28 | 6 | 111 | 64 | 31 | 3 | 124 | 77 | 29 | 6 | 146 | 84 | 45 | 8 |
|  | **Percentage** |  |  |  |  | 54% | 39% | 11% | 3% | 34% | 22% | 12% | 2% | 39% | 27% | 12% | 3% | 45% | 29% | 18% | 4% |
| **Dorset** | **Count** | 392 | 391 | 377 | 331 | 153 | 74 | 29 | 3 | 182 | 95 | 36 | 3 | 105 | 40 | 21 | 2 | 159 | 97 | 33 | 3 |
|  | **Percentage** |  |  |  |  | 39% | 19% | 8% | 1% | 46% | 24% | 10% | 1% | 27% | 10% | 6% | 1% | 41% | 25% | 9% | 1% |
| **Edinburgh** | **Count** | 289 | 249 | 212 | 134 | 87 | 26 | 26 | 17 | 101 | 30 | 28 | 19 | 97 | 31 | 25 | 20 | 94 | 43 | 31 | 19 |
|  | **Percentage** |  |  |  |  | 30% | 10% | 12% | 13% | 35% | 12% | 13% | 14% | 34% | 12% | 12% | 15% | 33% | 17% | 15% | 14% |
| **Guys** | **Count** | 716 | 698 | 661 | 518 | 315 | 142 | 73 | 61 | 0 | 0 | 0 | 0 | 192 | 107 | 27 | 13 | 417 | 284 | 130 | 105 |
|  | **Percentage** |  |  |  |  | 44% | 20% | 11% | 12% | 0% | 0% | 0% | 0% | 27% | 15% | 4% | 3% | 58% | 41% | 20% | 20% |
| **Hertfordshire** | **Count** | 518 | 418 | 353 | 202 | 269 | 36 | 32 | 16 | 278 | 39 | 34 | 19 | 249 | 31 | 30 | 17 | 260 | 43 | 37 | 31 |
|  | **Percentage** |  |  |  |  | 52% | 9% | 9% | 8% | 54% | 9% | 10% | 9% | 48% | 7% | 8% | 8% | 50% | 10% | 10% | 15% |
| **Lincolnshire** | **Count** | 316 | 263 | 232 | 177 | 292 | 207 | 162 | 108 | 291 | 206 | 162 | 109 | 174 | 104 | 70 | 20 | 305 | 206 | 163 | 108 |
|  | **Percentage** |  |  |  |  | 92% | 79% | 70% | 61% | 92% | 78% | 70% | 62% | 55% | 40% | 30% | 11% | 97% | 78% | 70% | 61% |
| **Luton** | **Count** | 607 | 568 | 541 | 469 | 175 | 25 | 3 | 0 | 292 | 72 | 11 | 0 | 139 | 24 | 3 | 0 | 283 | 73 | 11 | 1 |
|  | **Percentage** |  |  |  |  | 29% | 4% | 1% | 0% | 48% | 13% | 2% | 0% | 23% | 4% | 1% | 0% | 47% | 13% | 2% | 0% |
| **Manchester** | **Count** | 295 | 264 | 203 | 181 | 202 | 61 | 44 | 22 | 222 | 70 | 48 | 24 | 199 | 46 | 39 | 17 | 208 | 70 | 48 | 19 |
|  | **Percentage** |  |  |  |  | 96% | 28% | 5% | 12% | 75% | 27% | 24% | 13% | 67% | 17% | 19% | 9% | 71% | 27% | 24% | 10% |
| **Sheffield** | **Count** | 176 | 156 | 131 | 93 | 168 | 68 | 38 | 16 | 175 | 74 | 41 | 17 | 171 | 74 | 41 | 17 | 176 | 75 | 41 | 17 |
|  | **Percentage** |  |  |  |  | 95% | 44% | 29% | 17% | 99% | 47% | 31% | 18% | 97% | 47% | 31% | 18% | 100% | 48% | 31% | 18% |
| **Shropshire** | **Count** | 368 | 357 | 346 | 306 | 52 | 38 | 30 | 3 | 166 | 56 | 37 | 3 | 50 | 36 | 28 | 2 | 182 | 58 | 38 | 3 |
|  | **Percentage** |  |  |  |  | 14% | 11% | 9% | 1% | 45% | 16% | 11% | 1% | 14% | 10% | 8% | 1% | 49% | 16% | 11% | 1% |
| **Total** |  | **4763** | **4334** | **3897** | **3006** | **2312** | **914** | **502** | **266** | **2332** | **851** | **468** | **212** | **1771** | **650** | **340** | **118** | **2761** | **1189** | **624** | **325** |

**Table 2.6: Response numbers and rates for core outcome measures by service and sampling point.**

## Understanding the purpose of the questionnaire

To address poor response rates, CFE ran a workshop in April 2016 for service co-ordinators, explaining the purpose and importance of the questionnaire and how the data would be used for the national evaluation. Macmillan has worked with services on a one to one basis in order to try to understand why data collection has been poor and has provided substantial support to services – this has included the production of guidance briefings, a short film clip aimed at PLWC and the sharing of lessons learnt at cluster meetings and knowledge exchange events. CFE Research has also worked with Macmillan to provide regular support to all services with data collection and reporting.

Service users that could remember completing the questionnaire felt it was important to complete it because Macmillan is a charity that they respect and one that they have already engaged with. However, it should be noted that most service users could not recall completing the questionnaire. Those who could remember had some understanding of the questionnaire's purpose, although this was not always correct. Service users felt it was important to complete the questionnaire to give the instructor a general idea of their level of activity and health so that their progress could be tracked, although this is not how the data is generally used by services:

> *Well, I thought it would be, because I thought that he would then tailor everything to our needs, but it was just, 'Fill the form in,' and then the form got filed- I don't think he actually read it.*
>
> — **Service user, Guys and St Thomas's**

The feedback from service users suggests that there may be scope for providing further guidance to services on the rationale behind the questionnaire and how they can communicate this to service users.

## Appropriateness of the questions

The selection of the questions included in the minimum dataset are standardised, validated measures; they were selected in consultation with Macmillan's Expert Advisory Group and tested by the service user advisory group. The questions should therefore, be fit for purpose. Prior to the evaluation, some elements of the CaPASEF were optional (FACIT and GSE). At the start of the evaluation, their inclusion in the questionnaire was made compulsory. However, it took some services longer than others to include these questions. This has undoubtedly affected the response rates, particularly at baseline.

**Service users generally reported that the questionnaire was fairly straightforward to complete, albeit that with the inclusion of the SPAQ it takes a considerable amount of time.** It should be noted that service users were attempting to recall completing the questionnaire some months after they had done so, and a great many were not able to recall the questionnaire in detail.

A few of the Move More Practitioners reported that some service users had questioned the relevance of the questions relating to home ownership and education level. This view was widely expressed earlier in the evaluation and addressed during the CFE workshop. While we found no evidence that service users objected to these questions through qualitative interviews with service users, the low relative response rates to these questions (see Figure 2.2) suggests that issues remain. Practitioners were more likely to raise this as an issue if they administered the questionnaire themselves (rather than when the questionnaire was self-completed by service users). For example, one Practitioner (in Manchester) waits until he has established a rapport with the service user before asking the educational attainment question as he has found that many service users became very defensive otherwise. If the interviewer believes that a question is sensitive this can affect responses.[70] Potentially sensitive questions are best administered through self-completion rather than by an interviewer.[71] They are also better placed towards the end of a questionnaire, rather than at the start as in the minimum dataset questionnaire.

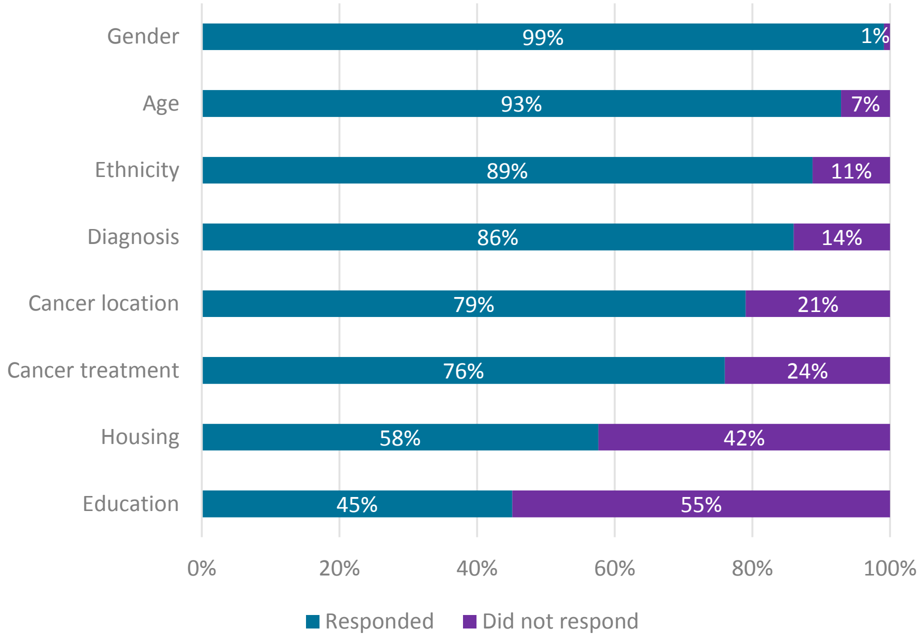


Figure 2.2: Response rates to the demographic questions in the questionnaire

Move More Practitioners felt that the SPAQ, in particular, was challenging to complete and was the section of the questionnaire most likely to be returned incorrectly. This was corroborated by some service users who reported that they felt daunted by it or found it complicated. However, of all the outcome questions, SPAQ had the highest percentage of useable responses at each stage. The objective measure pilot will explore the feasibility of

---

[70] Singer, E. and Kohnke-Aguiree, L. (1979) Interview Expectation Effects: A Replication and Extension, *Public Opinion Quarterly*, 43(2), 245-260

[71] Barton, A. (1958) Asking the Embarrassing Question, *Public Opinion Quarterly,* 22(1), 67-68

the accelerometer as an alternative way of measuring changes in physical activity in robust evaluation studies.

The GSE measures have notably lower response rates than some of the other questions. Also, the wording of the self-efficacy questions, in some instances, was said to be confusing or off-putting. It was widely reported by Practitioners that service users perceive many of the statements to be negative. In particular, Q19, which asks respondents how true they find the statement: 'If someone opposes me, I can find the means and ways to get what I want' was viewed in this way. For example, in one instance observed, the statement was initially interpreted as: 'have I become more manipulative as a result of my cancer?' There is merit in considering the use of an alternative physical activity-specific measure of efficacy. The Patient Activation Measure has been suggested; however, this is not a measure of self-efficacy but a score relating to how ready patients are to manage their care. While it includes aspects of efficacy it is not limited to this. .

Guys and St Thomas' NHS Foundation Trust (GSTT) used an alternative 5-point scale for the EQ5D measure rather than the specified 3-point scale, so we are unable to aggregate their EQ5D data with that from other services. Where a minimum dataset is to be used in future, this should specify that common response scales are used to ensure data can be aggregated across services.

## Data collection methods

All questionnaires are designed and validated for self-completion to ensure as far as possible that responses are honest and not influenced by others. Macmillan's preferred method of data collection is that this activity is kept separate from the behaviour change and support interventions. Practitioner-led completion when delivered simultaneously with behaviour change is incompatible with the principles of motivational interviewing. It is not necessary to know the patient's current levels of physical activity in order to engage in a conversation about it. Assessment of patient behaviour at the start of a behaviour change conversation nearly always results in defensiveness and encourages Practitioners to jump to offering strategies for change too early.

Table 2.7 below illustrates the method of data collection used by each service.

| | **Baseline** | **Follow up** | | | | |
|---|---|---|---|---|---|---|
| | **Self-completion** | **3/6/12 months** | **Method of self-completion** | **Follow up by phone** | **Follow up by letter** | **Staff member inputting data** |
| **Aberdeen** | Yes | ✓ | Post | Yes 3 times | No | Practitioner & service assistant |
| **Antrim & Newtownabbey** | Yes | ✓ | Post | Yes | No | Practitioner |
| **Ards & North Down** | Yes | ✓ | Post | Yes | No | Practitioner |
| **Dorset** | Yes | ✓ | Post | Yes | No | Practitioner |
| **Edinburgh** | Yes | ✓ | Post | Yes 3 times [72] | No | Service officer |
| **GSTT** | Yes | ✓ | Post (After follow up call) | Yes 3 times | Letter | Practitioner |
| **Hertfordshire** | No | ✓ | Email, post and service led f2f | Yes at least 2 times[73] | Email | Practitioner |
| **Lincolnshire** | No | ✓ | Service lead f2f | Yes | Yes | Practitioner |
| **Luton** | Mix | ✓ | Post & service lead face to face | Yes 3 times | No | Practitioner |
| **Manchester** | No | ✓ | Service led f2f, post, telephone | Yes 3 times | Survey resent | Practitioner |
| **Sheffield** | Yes | ✓ | Post | Yes 3 times | Email | Practitioner |
| **Shropshire** | Yes | ✓ | Post | Yes up to 3 times | No | Practitioner |
| **Velindre** | Yes | ✓ | Post | Yes 3 times | 2 letters sent | Service support asst & Data admin officer |

Table 2.7: Method of data collection at baseline and follow up – by service

As the table illustrates, the majority of services (nine) ask service users to self-complete the initial questionnaire at baseline. Some services opt to post the baseline questionnaire to service users who are then expected to bring the completed questionnaire to the behaviour change session; others ask the service user to complete the questionnaire prior to the start of the session. In a minority of instances we observed, because of individual commitments or time pressures, service users completed and returned the questionnaire after the behaviour change session.

In three services (Manchester, Lincolnshire and Hertfordshire), and at Luton as observed in some instances, the completion of the baseline questionnaire takes place during the initial behaviour change intervention. In these cases, the Move More practitioner is most likely to administer the survey (rather than have the service user self-complete), asking each question to the service users. There is no clear pattern in terms of completion levels at follow up points between those services that facilitate self-completion and those at which completion is practitioner led. From the sessions observed, we found that in these latter

---

[72] If the follow up point is whilst the service user is still attending activities the volunteer assisting in the activity will prompt them to complete the survey

[73] Recent introduction since new service lead has been in position.

cases the quality and accuracy varied considerably. In the worst examples, we encountered instances where Practitioners were leading service users in their answers, using their own judgement in interpreting the responses and misinterpreting what the scales meant. Move More Practitioners from these three services also felt that the statements that make up the self-efficacy questions are repetitive. For those services following the self-completion model this appeared to be less of an issue. The minimum dataset questionnaire should continue to be self-completed by service users. This should be emphasised with services. However, it is appropriate for staff to provide support and encouragement.

### Follow-up data collection

All Move More Practitioners highlighted the challenge of data collection at the 3, 6 and 12 month follow up points. Most acknowledged the natural attrition rates that longitudinal data collection often suffers and highlighted the challenges of getting hold of service users.

Follow up questionnaires are mostly distributed in hard-copy format in the post, and service users are provided with a stamped addressed envelope with which to return it. Hertfordshire, Luton and Manchester indicated that they also deliver face to face data collection sessions with service users at follow-up where this is preferred. Practitioners indicated that they attempt to contact the service user to ensure completion up to three times; however, most admitted that this may vary depending on the practitioner's other commitments **Follow up calls tend to take place when convenient to the service rather than at specific times/days.** Practitioners are often constrained by their working hours/days in terms of when they are able to contact service users. **There were very few instances where interviewees said that they had attempted to make these telephone calls in the evening, for example, or on Saturdays, when there may be a better chance of contacting the service users concerned**. Services should give more consideration to the planning of calls made to chase completion of follow-up questionnaires and to the likely availability of service users.

**Longitudinal data collection is likely to be hampered by the fact that almost all the services generally provide only limited and reactive behaviour change support over 12 months**; the only contact post activity is at data collection points or if service users continue to attend activities on an on-going basis. Some Practitioners felt that in many cases service users get what they need from the service relatively quickly so may be less likely to see the value / purpose of follow-up questionnaires 12 months later. That Lincolnshire has the highest follow-up response rates is undoubtedly linked to the fact that they provide far more formal follow-up support and are therefore better placed to ensure data continues to be collected.

### Resources

**Data collection can be seen by Practitioners as a time consuming task and one that has a lower priority for services than that of engaging with service users.** In at least one instance, it was viewed as a barrier to service delivery due to the frequency with which it has to be carried out. One service felt that to be sustainable after Macmillan funding ends, data collection would need to be considerably scaled back to ensure that their delivery model remains financially viable. The process, in particular, of updating the database with the data can be time consuming. Manually entering data from paper surveys increases the chances of user input errors. Some services have brought in additional administrative support to assist with data entry and this is said to have helped free up practitioner time and reduce backlogs of questionnaires to be inputted. Collecting data from service users with tablets allows services to upload rather enter the data when back in the office, which saves considerable time.

If data collection is to remain a key part of the Physical Activity Behaviour Change Care Pathway, this needs to be appropriately resourced. Staffing models need to include dedicated and specialist time for supporting service users to complete the questionnaire, for chasing follow-up and for entering, cleaning and analysing the data. Alternatively, Macmillan may wish to outsource data collection to an independent data collection agency.

### Data collection format

The majority of services use paper based questionnaires – only Manchester and Lincolnshire currently use the online version to collect baseline information. Some Practitioners felt that the online version may not be an appropriate mechanisms for their client group who are generally older and perceived to be less 'Internet savvy' – we have not tested out this assumption. Manchester and Lincolnshire complete the questionnaire with service users on a tablet device as part of the behaviour change intervention. However this does takes time and may detract from the intervention itself.

Lincolnshire and Hertfordshire are starting to use the online version for follow-up questionnaires and feel that this may help them to increase the response rates, although it is too early for them to have an overall sense of the quality of the responses received.

Supporting the use of online questionnaires would reduce the burden imposed by data collection. An online questionnaire is also beneficial in that it can be designed to make the questions visually appealing and easier to complete and can validate answers in real time to improve the quality of data collected.

We recommend services explore ways of making the online questionnaire as accessible as possible to service users. This could involve service users self-completing the survey on a tablet provided by services as part of initial interventions or as part of follow-up sessions where these are delivered face to face.

### Using the data

Most services use the data to meet the national evaluation requirements. Some have used it locally to evaluate the demographic profile of service users and create targeted marketing campaigns in response. Others have successfully used the data to make cases to CCGs and other funders in order to sustain their service. Sheffield (who have comparatively good response rates at baseline and 3 months in particular) have already obtained an additional year's funding from Macmillan as a result of this and are currently providing data in relation to their bid to be considered as part of the city's recovery package offer for cancer patients – from 2018. As a university, Sheffield have also used the data as part of conference presentations. Some services, particularly those operating in a commercial environment, recognised the potential benefits that the data could provide. However, a considerable number of services viewed the data collection simply as part of the national evaluation rather than as an intrinsic and useful part of their service.

Services should be supported, encouraged and educated on how to make use of the data for planning, improving and sustaining their services, as this is likely to lead to services valuing data collection more. Services that have effectively used the data should share their approaches and their results with others that have yet to exploit it, in order to provide ideas and inspiration. Services will require access to analytical expertise in order to effectively use the data.

# 03. Raising awareness and generating referrals

*In this Chapter we explore how services have publicised the service in order to generate referrals from HCPs and PLWC. We include information on the different sources of referrals and highlight the most effective ways of engaging HCPs. We set out the demographic characteristics and cancer statuses of service users.*

## Key points

- Services are engaging with almost twice as many females as males. The services are engaging an older profile of service users; cancer is more prevalent among older people. The overall proportion of non-white British service users is in line with the national population.
- The services are also successfully engaging with service users who are experiencing a variety of cancer stages. Cancer types are broadly in line with the national picture.
- Most service users are referred by CNSs (32 per cent) or by self-referral (26 per cent).
- Establishing trust with HCPs is key to generating referrals. Meeting with potential referrers is effective but engagement needs to be carried out on an on-going basis.
- It is important that HCPs advocate the benefits of engaging in physical activity as this leads to referrals.
- Where feedback on service users has been provided to HCPs they have found this valuable and it has helped to establish confidence in the service.
- Providing the option of electronic referrals is key to making the referral process as easy as possible.
- Services have had limited success in generating referrals from GPs.
- Services that are embedded in a healthcare setting are more likely to find generating referrals from HCPs easier than those in other settings.
- Health and Wellbeing events are a successful way of recruiting PLWC into a service and engaging with HCPs.
- Developing relationships with Macmillan information centres is also useful for generating two-way referrals and for making links with key HCPs.
- Services, with the support of Macmillan, have successfully used a range of awareness raising techniques to generate self-referrals.

## Raising awareness and generating referrals

Raising awareness of the programme among potential service users and HCPs is essential for generating referrals to the services. Services should use a range of methods to raise awareness of the service locally, and Macmillan provides marketing materials and support in relation to this. A key mechanism for raising awareness of the service is the HNA undertaken during the assessment of care and planning as part of the Recovery Package. Figure 3.1 below outlines the key elements in raising awareness and the different potential referral routes. This Chapter first explores how services are raising awareness of the Pathway: through marketing; through Health and Wellbeing events; and through Macmillan Information Centres. We then go on to look at where referrals are coming from. Our focus is particularly on generating referrals from HCPs and the approaches that have proved effective in this regard, including the use of electronic referrals and the efficacy of providing feedback on service user progress. The Chapter concludes with an overview of the profile of service users.

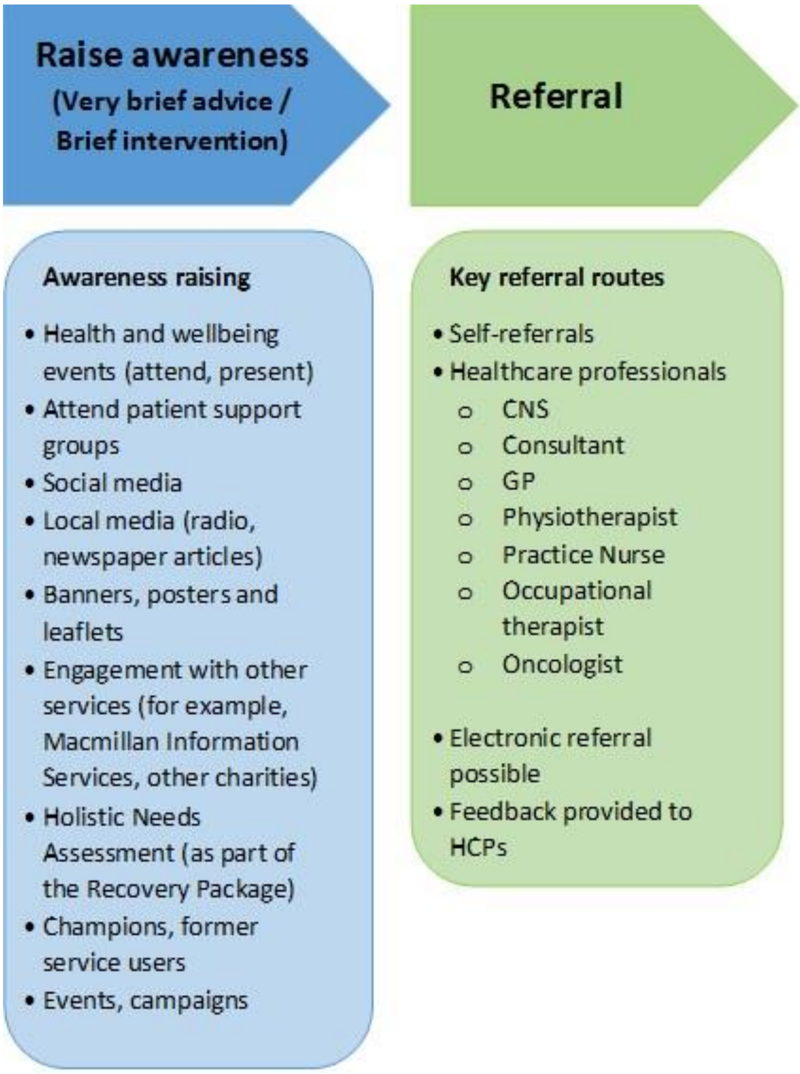


**Figure 3.1: Overview of the Physical Activity Behaviour Change Care Pathway elements which raise awareness and generate referrals**

# How services raise awareness of the programme

## Marketing and promotion

In line with the Macmillan model outlined above, services use a wide variety of methods to promote their service and encourage referrals. Table 3.1 gives an overview of these.

| | Website | Social and traditional media | Newsletter | Promotional materials | Health and Wellbeing events |
|---|---|---|---|---|---|
| **Aberdeen** | Yes via Aberdeen Leisure website | Twitter | e-newsletter to service users | Flyers, Banners | Yes |
| **Antrim and Newtownabbey** | Own | Film on YouTube | Council newsletter | Flyers, Banners | Yes |
| **Ards and North Down** | Yes via Council website | Council Facebook, press articles | Council newsletter | Flyers, Banners | Yes |
| **Dorset** | Own | Twitter | e-newsletter to service users | Flyers, Banners | Yes |
| **Edinburgh** | Yes via Edinburgh Leisure | Via Edinburgh Leisure | No | Flyers, Banners | No |
| **GSTT** | Own | Yes (GSTT) | Yes (GSTT) | Flyers, Banners | Yes |
| **Hertfordshire** | Own | Twitter, local magazine | No | Flyers, Banners, GP screens | Yes |
| **Lincolnshire** | Own | Press editorials | No | Flyers, Banners, | Yes |
| **Luton** | Own | Facebook, Twitter, local radio | Newsletter for PLWC | Flyers, Banners, GP screens | Yes |
| **Manchester** | Own | Twitter, Instagram, YouTube | Newsletter to service users | Flyers, Banners | Yes |
| **Sheffield** | Own | Twitter | Newsletter to HCPs | Flyers, Banners | Yes |
| **Shropshire** | Own | No | Newsletter for CNSs[74] | Flyers, Banners | Yes |
| **Velindre (Cardiff)** | Own | Twitter | No | Flyers, Banners | Yes |

Table 3.1: Overview of methods used to promote the service

---

[74] Only produced two issues.

All make extensive use of printed materials, including flyers, leaflets, posters and banners to promote the service. These are typically available at a range of locations, including healthcare settings, GP surgeries, Macmillan Information Centres, other cancer centres – for example Maggie's Centres – as well as a range of community settings. Most services also undertake some form of online promotion, either through a bespoke service website or through their host organisation's website. Most services, though not all, also use some form of social media to promote their service. Where services have promoted themselves through local print media (e.g., through coverage of launch events or editorials) they reported a resulting spike in enquiries. In addition, Macmillan, centrally, provides a comprehensive suite of promotional materials, including online materials, which is available to services and to potential service users.

**Services have undertaken a wide range of promotional activities** and some services have been particularly proactive in promoting to PLWC and a wider audience including HCPs. For example, in Berkshire, service staff have presented at events (such as the Oxford Academic Health Science Network), produced a promotional video and secured coverage in various journals, including the European Medical Journal. Like some other services, the Berkshire service was also successful in gaining recognition through award schemes. The service won a Nursing Times award for cancer nursing in 2016, was shortlisted for the Macmillan Excellence Award and was a County Sports Partnership Innovation Award Finalist. Some services, for example Manchester, Shropshire, Lincolnshire and Luton, have established links with fundraising events, and many have established links with local organisations in order to promote the programme.

Macmillan have developed a marketing toolkit to help services meet the Macmillan branding requirements. During the evaluation, Macmillan provided substantial additional support to ensure that services were aligned with national branding. Services were asked to review their materials in collaboration with colleagues from Macmillan. The majority felt that the support they received from Macmillan was excellent.

In Shropshire, the need to redesign marketing materials presented the service lead with the opportunity to include a tear-off self-referral form, which has made the referral process there more straightforward. Similar, simple self-referral mechanisms are working well for other services. For example, Ards and North Down (where 47 per cent of referrals are self-referrals) uses postcards very effectively.

**The language used to promote activities is important in terms of making them appealing and ensuring that potential service users are not put off**. For example, the term 'circuits' may conjure up ideas of strenuous exercises for very fit people, when the reality in this context is very different. The Macmillan toolkit draws on learning from the Macmillan insight and physical activity teams on the effective use of language. This has been effectively put into practice by services. For example, Antrim and Newtownabbey advertise their Nordic walking classes as 'Simply Strolling'. The language used in

Manchester's promotional materials was changed to highlight the wider and more low-key benefits of physical activity.

The importance of inclusive language applies not only to printed materials, but also to the way staff talk to potential service users about physical activity and the service.

> *I think the big thing when you start to talk to patients about physical activity and getting fit, they immediately think that involves putting the Lycra on and going to the gym. What we talk to the patients about is, 'Have you got a dog? Do you walk the dog around the park?' It may be something as simple for some patients as walking to fetch the daily paper. It doesn't have to be running around a gym.*
>
> — **Healthcare professional, Sheffield**

### A trusted brand

**Both Practitioners and stakeholders feel the Macmillan brand has a positive impact on the generation of both referrals and self-referrals**. It is seen as a trusted brand and one which is viewed positively across the 14 services. In a very small number of instances stakeholders indicated that the Macmillan name is associated by some with end-of-life care rather than with concerns such as physical activity:

> *It infers trust but people don't associate us with being active. A lot of people view Macmillan as end-of-life, still. They still think, 'I don't need Macmillan, my cancer's gone.'*
>
> — **Stakeholder, Manchester**

## Health and Wellbeing events

**Services are increasingly using Health and Wellbeing events as a successful way of recruiting PLWC into their service. Events at which the practitioner gives a presentations and/or short taster session are particularly effective**. All except one service has attended events. GSTT staff reported a link between higher numbers of referrals/self-referrals of people with particular tumour sites and the fact that the service was promoted at Health and Wellbeing events relating to these. In Luton, one Health and Wellbeing event generated 19 referrals.

Health and Wellbeing events are part of the recovery package, usually run by local NHS Trusts and are designed to provide information to PABC on the support available during and after cancer treatment. They typically include information on a range of topics including: explanations of treatment processes, financial support, diet and lifestyle and other key healthcare messages. Events vary considerably in length, format and frequency across the country. The sessions observed by CFE comprised a series of short presentations to PABC. They included a presentation from the practitioner explaining the value of physical activity and providing more information on the service.

In some cases, for example, that of Antrim and Newtownabbey and Dorset, the practitioner has also run taster exercise sessions as part of Health and Wellbeing events. This energises the audience and helps potential service users and healthcare professionals to understand what the circuit classes will be like and it allays any fears that they may be too strenuous. Increasingly, services see the value of bringing along a service user to speak at these events. This is a very powerful way to present the benefits of the programme to PABC and professionals.

> *We'd rather use the voice of a person or a patient to tell the story and to promote the service because it's much more powerful someone saying, 'This has impacted my life in this way,' than it is for us to say, 'You should do this because we think it's good.' Yes, I think there's definitely a role for patients and service users advocating, definitely.*
>
> — **Stakeholder, Hertfordshire**

In at least one area (Shropshire), the events, organised by the Shrewsbury and Telford Hospital NHS Trust, are also used as an opportunity to complete an Assessment and Care Plan using the HNA. Where PLWC indicate that they are interested in physical activity this allows the practitioner to approach people immediately.

**Health and Wellbeing events also provide service staff with a useful opportunity to engage with HCPs presenting at the event**. This has helped services to establish stronger links and potentially increase the numbers of referrals. The events give professionals the opportunity to see the service staff in action and assess how they relate to patients.

> *The health and wellbeing events, definitely, without a doubt, is the one that's got us out there. Into a wider range of people in terms of, they can pretty much assess who you are, and what you're doing, from your ten-minute, twenty-minute talk. How are the patients, are the audience, receiving what you're saying?*
>
> — **Service staff member, Manchester**

A few of the services (Velindre, Lincolnshire and Hertfordshire) have found the events less useful as a source for referrals. This can be due to the frequency of events – for example, there was only one event in the last year in Lincolnshire compared to approximately 25 events in the last 18 months in Manchester. In other instances, the events were felt to have low levels of attendance or the wrong format (a market place format) in which there was no opportunity to present to PABC and thus to generate a substantial numbers of referrals.

## Macmillan Information Centres

**Macmillan Information Centres can be important in generating referrals and engaging with professionals.** In many instances, Information Centres are based either within or very close to hospital grounds. Centre staff have strong relationships with key HCPs, engage regularly with them and often attend cancer specific meetings with healthcare staff. Move More Practitioners have found working closely with Macmillan information professionals helpful in opening up referral routes. For example, in Manchester, the Centre was instrumental in brokering introductions to relevant professionals and providing information about cancer related provision that was required at the initiation of the service. Similarly, in Sheffield and Antrim and Newtownabbey, the relationship between the project staff and the Information Centres has opened doors to the improvement of referral opportunities. Information Centre staff are also often involved in the set-up of Health and Wellbeing events and can prove helpful in facilitating access to these for Move More services.

> *The info centres are a really strong relationship for the service. They're the first thing you see when you walk into most major hospitals. We have a close relationship with the Centres because they have a good relationship with the CNSs […] Because [Information Centre managers] sit on a lot of the cancer meetings, they will feed back to us or disseminate information […] to those teams.*
>
> — **Stakeholder, Hertfordshire**

Macmillan Information Centres can also support self-referrals. The Centres are important sources of information for PABC. Promoting the service with the centres and ensuring that the staff are aware of the benefits of the service has often contributed considerably to referral rates.

**A good relationship between the Macmillan Information Centre and the service offers additional benefits for service users**; services can signpost to a wide range of additional information and support via the Centres, including to counselling, complementary therapies and support in returning to work.

> *…there was one lady a few months ago, she wasn't quite sure what she wanted. She was talking about her weight issues and stuff so I sat down with her to have a chat but there was more going on […] so I can obviously refer her to the counsellors.  We've also got the Macmillan physiotherapists and dieticians that I can refer to as well.*
>
> — **Service staff, Shropshire**

In Shropshire, the service is co-located with the Information Centre. This can help to generate self-referrals through 'passing traffic'. In other cases, Information Centres are used as locations to which referral forms and questionnaires can be sent and from which these can be collected. This is particularly important for those services without an electronic referral form (see page 63).

## Where do referrals come from

Figure 3.2 illustrates the wide range of sources of referrals to the programme. **Most service users are referred by CNSs (32 per cent) or by self-referral (26 per**

**cent)**. Self-referrals include people who have contacted the service after seeing promotional material, such as banners or newspaper articles. Some of those accessing the service via health and wellbeing events will also be self-referrals.

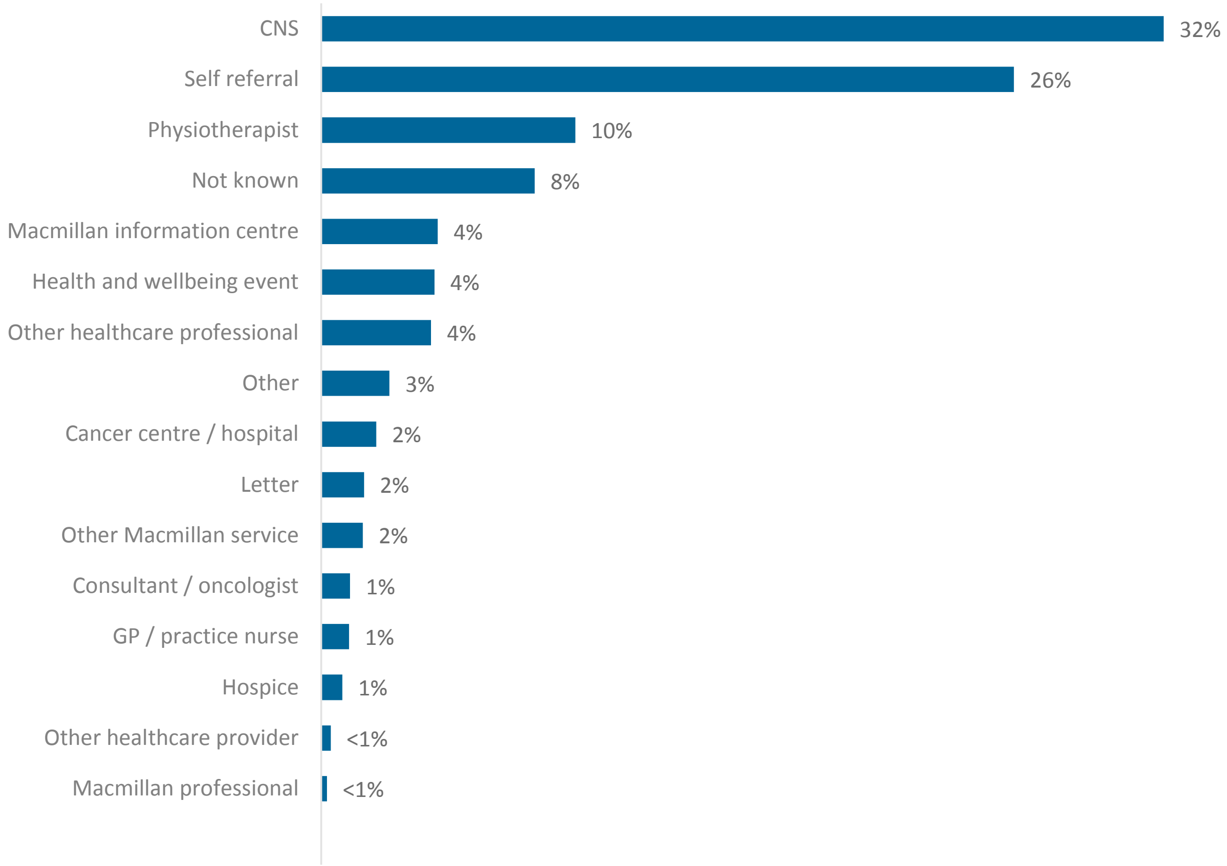


**Figure 3.2: Referral agency (n=4,763)**

Table 3.2 below provides further information relating to each service on key referral sources. It also outlines the methods used to engage healthcare professionals, whether electronic referrals are possible and if and how feedback is provided to those who refer service users.

| | **Service setting** | **Main referral sources** | **Electronic referrals available** | **Methods for engaging HCP** | **Feedback provided to referrers** |
|---|---|---|---|---|---|
| **Aberdeen** | Community | CNS (42%)<br>Self-referral (33%) | Yes | One to one,<br>Tumour-specific staff meetings | Yes via email after activities |
| **Antrim and Newtownabbey** | Community | Self-referral (38%)<br>Health & Wellbeing events (23%)<br>Physiotherapists (21%) | No | One to one,<br>Staff meetings<br>Existing relationships, | Informal |
| **Ards and North Down** | Community | Self-referral (47%)<br>Information centre (30%) | No | One to one,<br>Tumour-specific staff meetings | Informal |
| **Dorset** | Community | Self-referral (63%)<br>CNS (15%) | No | Tumour-specific staff meetings | Ad hoc |
| **Edinburgh** | Community | Self-referral (49%)<br>CNS (9%) | Yes | One to one,<br>Tumour-specific staff meetings | Informal and ad hoc |
| **GSTT** | Healthcare | Physiotherapists (38%)<br>Health & Wellbeing events (23%)<br>CNS (21%) | Yes | Embedded in cancer site-specific teams,<br>Co-location of services | Informal |
| **Hertfordshire** | Community | Self-referral (38%)<br>CNS (22%) | Yes | One to one,<br>Tumour-specific staff meetings,<br>Outreach | Informal and ad hoc |
| **Lincolnshire** | Community | CNS (% not known)<br>Physiotherapists (% n/k)<br>Occupational therapists (% n/k) | No | One to one,<br>Tumour-specific staff meetings | Ad hoc |
| **Luton** | Community | CNS (53%)<br>Self-referral (19%) | Yes – email | Tumour-specific staff meetings | Yes individually by email |
| **Manchester** | Community | Self-referral (36%)<br>CNS (34%) | | One to one,<br>Tumour-specific staff meetings | Informal |
| **Sheffield** | Community | CNS (32%)<br>Self-referral (27%)<br>Information centre (26%) | Yes[75] | One to one,<br>Tumour-specific staff meetings, shadowing CNS | Limited to confirming attendance on programme |
| **Shropshire** | Healthcare | CNS (80%)<br>Psychologist (5%) | Yes | One to one,<br>Attending clinics,<br>co-location of services | Referral rates from different cancer team (league table) |
| **Velindre (Cardiff)** | Healthcare | CNS (41%)<br>Self-referrals (28%) | Yes | One to one,<br>Co-location of services | Yes – including quotations |

Table 3.2: Overview of key referral sources and methods for engaging healthcare professionals

---

[75] Introduced in May 2017

## Referrals from healthcare professionals

A variety of health care professionals refer – including physiotherapists, oncologists, radiographers, psychologists and dieticians – although most referrals come from CNSs who specialise in a specific tumour site. The specialisms of CNSs who refer vary from service to service, although the more common tumour sites (breast, prostate and lung) are well represented.

> *I think the key thing is getting the ownership of the specialist nurses because they're the ones who act as that vital case manager for people. The chance for specialist nurses to then refer on, that, I think, has been crucial.*
>
> — **Macmillan Development Manager**

**Securing the buy-in of healthcare professionals is crucial to service success and an important activity. However, Services have generally found getting referrals from healthcare professionals to be harder and more time consuming than expected**. Service leads report that it can take considerable resources to generate referrals and that the process of engagement needs to be on-going.

A minority of service leads talked about occasionally encountering perceptions that physical activity is just 'sport and Spandex', and the challenge is getting people to understand that the service is about improving the health of service users. Professionals who refer people to the service understand the value of physical activity generally and specifically for PLWC. No healthcare professionals to whom we spoke repeated the perception that 'rest is best', although several felt that this view may still be found among older professionals, particularly consultants and surgeons. It is notable that, overall, only 1 per cent of referrals have come from consultants and oncologists.

**Establishing trust with healthcare professionals is key to generating referrals – they need to know that service users will be taken care of and will receive the right level of activity for them**. Developing this trust can take time. As a result, those services that build on pre-existing projects or where the practitioner has a history of working in the sector are likely to find it easier to generate referrals. For example, the Antrim and Newtownabbey Move More practitioner previously delivered the exercise on referral programme and is well known and trusted among healthcare professionals.

**Meeting with potential referrers to discuss the service is effective in generating referrals**. Most services indicated that attending tumour group-specific team meetings was an effective way of promoting their programme. Presenting at these meetings allows Practitioners to promote the programme to multiple HCPs. They also provide a valuable opportunity to feedback on how service users are progressing.

> *If there are any problems with any patients, [the practitioner will] come directly back to us and tell us. […] So each time we have a steering group meeting, [the practitioner provides] feedback on the programme. So, how many people have been referred, how many sessions they've delivered.*
>
> — **Healthcare professional, Luton**

**Regular face-to-face contact with HCPs helps to raise and maintain awareness of the service** – this is important for differentiating the service from the plethora of other initiatives that professionals receive information on. There is often a high turnover of staff so engagement has to be carried out on an on-going basis. It is not enough to raise awareness with HCPs once. However, it is not always possible to meet with HCPs as frequently as desired.

> *…two months down the line [referrals] start to drop off again. The engagement isn't held. We would happily go into a CNS meeting every two or three months, but unfortunately, it's not that simple. They can't quite fit us in that often. So, we normally get to a CNS meeting at each hospital, I would say, at least once a year.*
>
> — **Move More Practitioner, England**

Many services reported that they are now spending less time promoting their service to 'new' healthcare professionals and are more likely to be relying on existing referrers and cultivating these relationships.

In a small number of instances, the geographical boundaries of the programme can affect the willingness of hospital staff to refer. If a service is limited to taking referrals from a subsection of the hospital's catchment area, healthcare professionals are less likely to refer patients, since they are required to discriminate among their patients.

### Providing feedback to healthcare professionals

Some services provide feedback on service users to those who referred them. The nature of this varied considerably from informal conversations on the ward or at events to detailed feedback forms. See table 3.2 for further information. **Where feedback is provided, HCPs have found this valuable and it has helped to establish confidence in the service**. There does not appear to be one approach that has worked more effectively than another. We describe a number of different approaches services have taken below.

In GSTT and Velindre, feedback includes the results of the service user's cardiorespiratory fitness tests, undertaken pre- and post- activity. Other services, for example Hertfordshire, produce case studies of clients that are also used to promote the service to other healthcare professionals.

In Shropshire, the service lead completes an outcome sheet to be sent to HCPs, showing attendance data. This keeps referrers up to date on the progress of the service user and serves as a prompt for the referrer to give further ‘nudges’ to the patient.

> *…so we’ve done a little outcome sheet that we’ve devised that just gets scanned in here and sent off through the NHS email. So, the CNSs know that the patient’s been seen or even if the patient’s at least been contacted and what the outcome [is], are they booked in, or have they chosen not to attend…*
>
> **— Service staff member, Shropshire**

## Electronic referrals

Healthcare professionals are extremely busy. **Providing the option of electronic referrals is key to making the referral process as easy as possible**. It is encouraging to see that over half of services are now able to receive referrals electronically either because they are part of the NHS infrastructure or because they have access to an NHS email address. This is viewed positively by HCPs and service leads and is the most frequently mentioned tool that improves the referral processes.

> *Originally, [the service] had an Active Luton email address, but there was a big change back in early 2016 […] Luton and Dunstable Hospital got them an NHS email address, and actually it’s so much easier for them to do electronic referrals.*
>
> **— Stakeholder, Luton**

> *I think the biggest barrier [to] getting people involved was the referral process because it involved flow charts and forms and emails and things like that. The big step change for us was once it became an electronic referral like everything else.*
>
> **— Stakeholder, Velindre**

Having access to an NHS email address is often on the wish list of those services without one. In Lincolnshire for example, staff perceive that they receive fewer referrals because of the additional effort involved in completing and posting a paper referral form.

> *You’re not allowed to send personal details through the internet, unless you’re sending it to a secure email address. It has to be an NHS email address, and we don’t have an NHS email address because we’re not in the NHS, so it’s causing a bit of a problem in terms of getting referrals to us, because they have to post them instead.*
>
> **— Service staff member, Lincolnshire**

## Engaging with primary care

It has been seen that, throughout the evaluation, **services have had very limited success in generating referrals through GPs. Only 1 per cent of referrals to the services came from GPs or practice nurses**. The most GP referrals received by a service is 12, in Hertfordshire. All services have made a number of attempts at engaging GPs but some have not continued, choosing instead to prioritise other sources of referrals. For an example of the former situation, the Antrim and Newtownabbey Move More practitioner presented at a GP conference; the GPs there were supportive (and mostly unaware of the programme). Two services participated in a direct mail-out pilot to GP practices. However, the numbers of referrals from GPs remained very low in these services. Several services argue that PLWC are unlikely to have regular contact with GPs – this tends to occur at pre-diagnosis stage or further down the treatment pathway. Those in active treatment spend considerably more time in contact with secondary care. Other services felt that GPs by their very nature are generalists who see a 'conveyor belt of patients' with a variety of symptoms and as such are less likely to remember details of a service that would be of benefit to only a very small number of their patients.

Move More Practitioners indicated that they focused their efforts on engaging with practice managers who are often receptive to the service and happy to display marketing materials in the surgery; this may lead to self-referrals.

Macmillan's ambition is that services become embedded in the Recovery Package. As part of the package, GPs are expected to carry out a cancer care review within six months of receiving notification of a diagnosis. We found no instances in which services had worked with GPs to include the service as an option as part of the cancer care review. Hertfordshire are currently working on embedding the service into the GP referral pathway. Sheffield are looking to establish a pathway with a Macmillan funded GP so that every person who goes through the cancer care review will automatically be referred to the project.

## Generating referrals in healthcare and community settings

**Services which are embedded in a healthcare setting are more likely to find generating referrals from healthcare professionals easier than those in other settings**. In these services (GSTT, Shropshire, Velindre) there is a perception that establishing relationships with HCPs is much more straightforward. Staff are likely to be based in the same location as HCPs and often at the same location as other Macmillan services such as Information Centres and counselling services. Services are therefore more accessible and visible to HCPs. In some instances, HCPs report that they view the service as a positive 'exit route' for patients, post treatment. In areas where the service is delivered by members of the physiotherapy team (GSTT and Velindre) the service staff have successfully encouraged their colleagues to refer patients, so increasing the volume of referrals.

There is also the opportunity for generating 'walk-ins' - potential service users show an interest in signing up after seeing the sessions in action. For GSTT, moving to the new Cancer Centre (the entry point for all cancer patients from the area) has increased the exposure of staff and PLWC to the programme and thus boosted referrals. HCPs now have much better information about the service.

> *We're a lot more proactive about what we do in terms of getting people to engage with exercise now than we were – and more confident than we used to be, just because we're so exposed to the information [the service] gives*
>
> — **Healthcare professional, GSTT**

The benefit, for HCPs, is that they can see the service being delivered and consequently often have working relationships with the service's staff; this increases their confidence and trust in the service and has improved their rate of referral of their patients. In GSTT, where direct delivery of activities occur, these are delivered in the same healthcare setting in which service users' access treatment. Healthcare environments can help PLWCs feel less intimidated by physical activity, as it occurs somewhere they know and in which they feel safe. They are also able to quickly and easily access healthcare support if they need it.

**Community based services with no prior relationships with HCPs can require considerable resource inputs, particularly during the set-up phase of the service, to develop these**. Gaining access to the appropriate HCPs at the strategic decision making level is considerably harder for these services than it is for healthcare based services. It takes longer to establish a trusting relationship with HCPs and in some instances it takes more time to convince likely referrers of the merits of the programme.

> *I don't have a main contact within NHS. I haven't found a main contact within the NHS who can promote this and really make this a part of their treatment pathway. You know, the CNSs are all very nice but their focus is clinical. I need someone who's more strategic.*
>
> — **Move More Practitioner, Scotland**

While there is no 'silver bullet' as regards developing relationships with HCPs, Macmillan has created a referral tactics tool which highlights different approaches which may be taken.

Many services talked about the value of using clinical champions or other members of the steering group to broker initial relationships. This is covered in more detail in Chapter 7 on Service Management.

Services often operate over a number of different hospitals or NHS trusts and potentially can receive referrals from all of these. In these instances it can be challenging to have to broker relationships across multiple organisations. This process is easier for those services that are already embedded in a healthcare service as they can use their existing relationships to help broker relationships across other locations. Community based services, particularly in Scotland, often reported that they had to start from scratch with each agency and required substantial extra effort to establish relationships.

Healthcare based services have the advantage of being able to access patient health updates and notes from HCPs and the NHS system. This can help inform both referrals and the delivery of behaviour change. Service staff are also able to provide expedient feedback to HCPs more easily than those in a community setting.

## Wider sources of referrals

Many services have generated referrals from a range of organisations from across the private and charitable sectors. In Aberdeen for example, the service has established a strong working relationship with CLAN Cancer Support and Maggie's Aberdeen (both charities). These relationships have allowed the service to engage with participants and volunteers, which has led to an increase in referrals. Luton have established referral routes with Virgin Care, a private healthcare provider of services to the NHS. Some services have also established referral routes through links with Macmillan's HOPE (Help Overcome Problems Effectively) course, which is available across the UK. This is a six week course open to PLWC, designed to help participants develop confidence in the management of their condition. Word of mouth is also viewed as an important route for generating self-referrals.

Services also present at cancer support groups. These are typically (though not always) tumour site specific and attendance varies considerably across the services. Engagement with support groups depends on local relationships, the degree to which the service is embedded in a healthcare setting (this appears to increase the number of groups staff have access to) as well as the resources available in the service to carry out this type of promotion.

> *We're very lucky in that there are lot of support groups. So, we went and did presentations night after night to the support groups […] There's 45 [PLWC] going to the head and neck meeting next week, let's go and set up a table and tell them what [the service is] all about.*
>
> — **Service staff member, Berkshire**

Dorset and Luton participated in a pilot letter campaign. Letters were sent from hospitals to PLWC to promote the service. This has accounted for 2 per cent (77) of total referrals.

Some of the services have distributed leaflets and posters via the Macmillan mobile information and support service, a service that targets harder to reach communities. However, most services felt that these undertakings were sporadic and, while useful for dissemination, they offered limited opportunities to engage with service users and/or have a physical presence.

## Who is using the service

In total, we have received data on 4,734 service users. Overall, **services are engaging with almost twice as many females as males** (63 per cent compared with 36 per cent respectively). Some services have been more successful in engaging with a gender balanced cohort of servicer users (for example, Aberdeen, Manchester, GSTT and Shropshire). It is not clear why this is so. Table 3.3 provides the service user gender split for each service below.

| | % Male | % Female |
|---|---|---|
| Aberdeen | 51 | 49 |
| Antrim and Newtownabbey | 29 | 71 |
| Ards and North Down | 28 | 73 |
| Dorset | 16 | 84 |
| Edinburgh | 24 | 76 |
| GSTT | 47 | 53 |
| Hertfordshire | 30 | 70 |
| Lincolnshire | 43 | 57 |
| Luton | 28 | 72 |
| Manchester | 51 | 49 |
| Sheffield | 38 | 63 |
| Shropshire | 46 | 54 |
| Velindre (Cardiff) | 32 | 68 |

**Table 3.3: Proportion of male and female participants by service**

Figure 3.3 below shows the age and gender profile of service users. **The services are engaging an older profile of people. The average age of service users is 59 years**. This is perhaps unsurprising as cancer disproportionally affects older people, with half of all cases in the UK each year diagnosed in people aged 70 or over;[76] 24 per cent of service users were over 70 years.

Manchester is notable in having a younger age profile than the other services. Over a quarter (27 per cent) of Manchester's service users are under 45 years old. This is in keeping with the fact Manchester is generally a young city, with 73 per cent of the population under 45.[77] In contrast, Shropshire, Aberdeen and Lincolnshire engaged a higher than average proportion of service users over 75 (18, 17 and 21 per cent respectively).

---

[76] http://www.cancerresearchuk.org/about-cancer/causes-of-cancer/age-and-cancer-0?_ga=2.120172872.1557722557.1501661739-1658069389.1501661739

[77] In comparison 58 per cent of the UK population overall is under 45 years. Source: 2011 Census https://www.nomisweb.co.uk

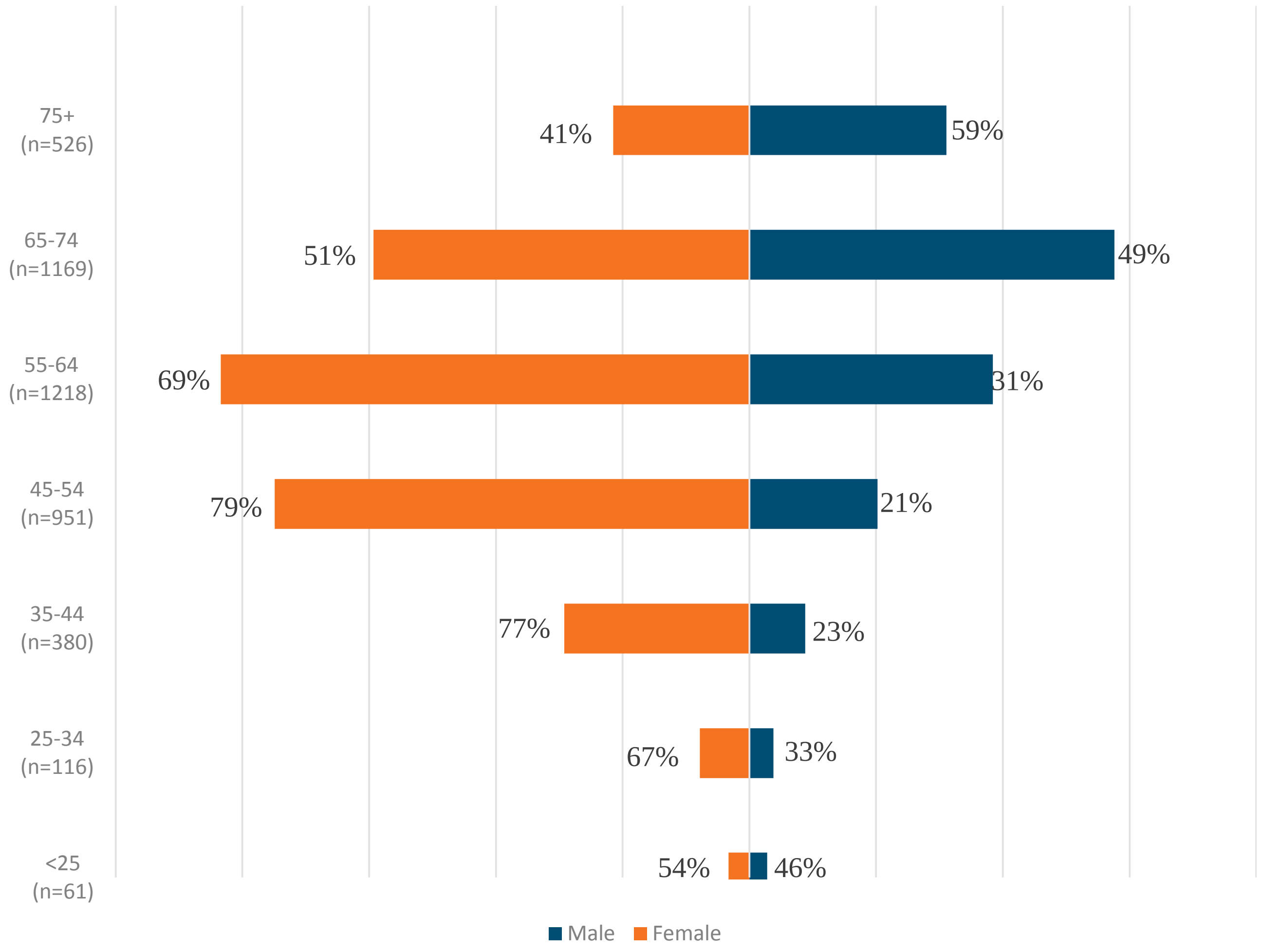


Figure 3.3: Age profile and gender of service users

**17 per cent of service users classify themselves as disabled. This is in line with the proportion in the population as a whole (18 per cent).**[78]

Overall, of those who stated their ethnicity, most described themselves as white British (85 per cent).[79] This is in line with the UK population where 87 per cent describe themselves as white British.[80] **Overall, the service is successfully engaging an ethnically diverse profile of service users**.

---

[78] Office for National Statistics (2013) *Disability in England and Wales : 2011 and comparison with 2001* ONS Available online at http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/disabilityinenglandandwales/2013-01-30 Last accessed 7th June 2016

[79] This excludes data from Scotland where there were problems with the recording of service user ethnicity.

[80] Source: 2011 Census https://www.nomisweb.co.uk

The overall figures hide variations between services. GSTT and Manchester, in particular, have high proportions of non-white British service users (41 per cent and 26 per cent respectively). This is particularly notable for GSTT, as the wider population for the areas covered is just 35 per cent non-white British. Other areas with ethnically diverse populations have been less successful in engaging non-white British service users. For example, 16 per cent of Sheffield's population identifies as an ethnicity other than white British. However, the majority of service users (96 per cent) identified as white British. Similarly, Luton has 19 per cent non-white British service users, whereas the figure for the wider population is 45 per cent.

Reasons given by some services for the low rates of referral of non-white British PLWC centred either on problems gaining access to the groups due to perceived cultural barriers or more practical difficulties such as language difficulties.

> *I went to speak about cancer awareness to a Bengali ladies group and I was relying on two ladies that spoke Bengali to translate for me, they didn't necessarily have expertise within public health… Handing out leaflets wouldn't have necessarily helped because they are elderly ladies, not all of them have a high level of literacy*
>
> — **Stakeholder, Luton**

The questions about level of education and on housing ownership (the financial proxy questions) had higher levels of non-response (see figure 2.2 in the previous Chapter). Of those that responded to these questions, we can see that they are typically home owners, and have higher levels of education (figures 3.4 and 3.5). This may indicate that the service is less successful in engaging with lower socio-economic groups. There is evidence that those from lower socio-economic groups are less likely to be physically active during leisure time.[81]

---

[81] Trost SG, Owen N, Bauman AE, Sallis JF, Brown W. Correlates of adults' participation in physical activity: Review and update. Med. Sci. Sports Exerc. 2002;34(12):1996-2001. doi:10.1249/01. MSS.0000038974.76900.92.

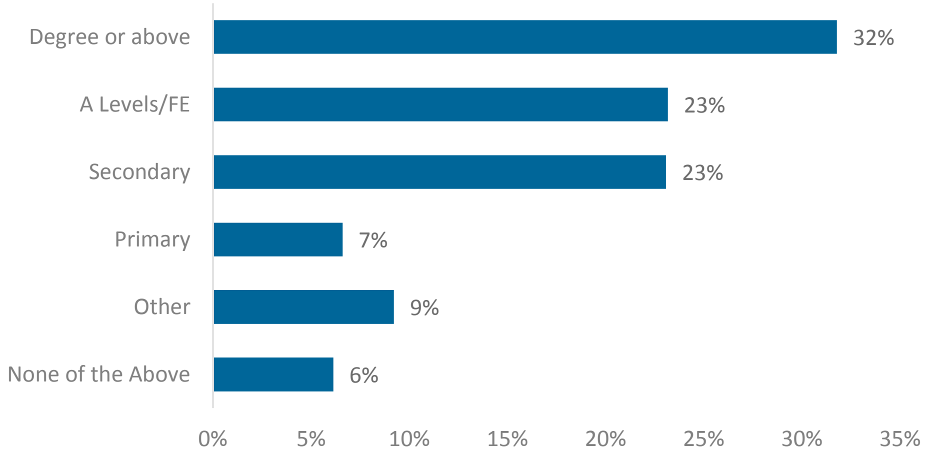


Figure 3.4: Level of highest qualification of service users (n=2,136)

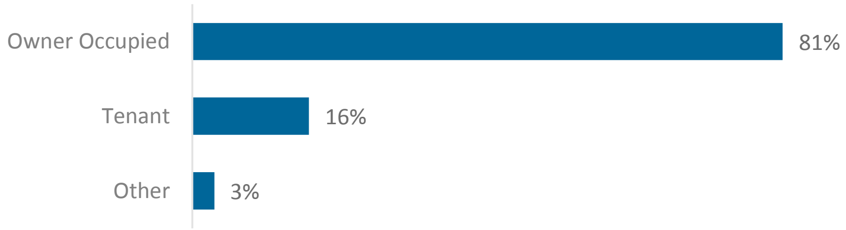


Figure 3.5: Housing tenure of service users (n=2,728)

Breast cancer remains the most common cancer type experienced by service users, accounting for 36 per cent of those that answered this question. This is followed by prostate cancer (14 per cent). We can see from figure 3.6 that both lung and colorectal cancers also appear frequently (10 per cent each).

**Service user cancer types are broadly line with the national picture** (see figure 3.7). The four most common cancers, generally, are the same as the most common types amongst service users (breast, prostate, lung and bowel) and (discounting ‘other types’) eight of the ten most common cancer types nationally are represented in the ten most common service user cancer types. There is an over-representation of service users with breast cancer compared to the national picture (35 per cent of service users compared to 15 per cent nationally). None of the Velindre service users indicated they have/had breast cancer and for this service there is an over-representation of service users with lung cancer – this may be due to a data capture error. Both Manchester and Shropshire have a large proportion of missing data on cancer type (69 and 63 per cent respectively), and Luton is missing 22 per cent of respondent data for this measure.

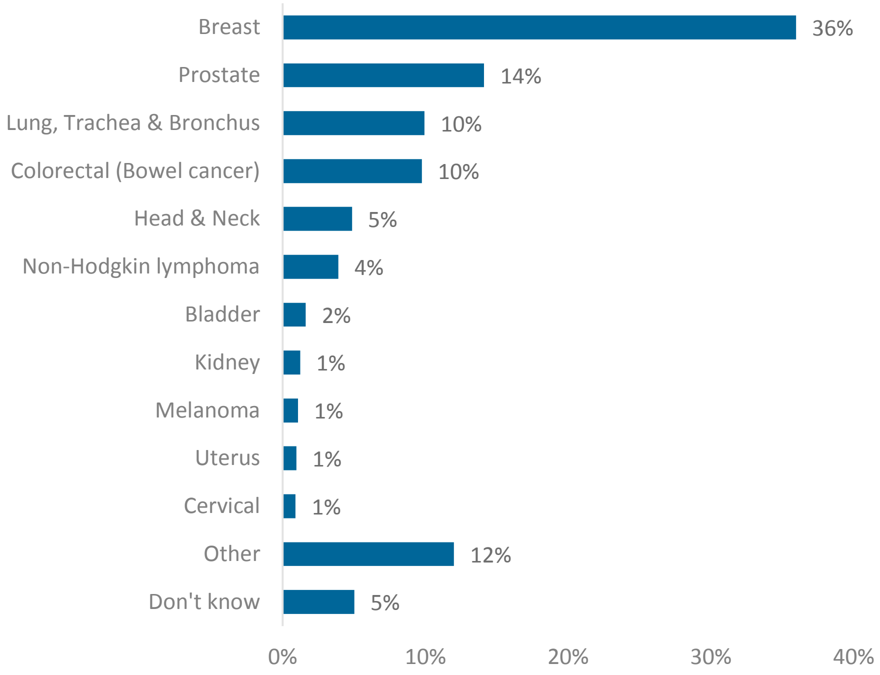


Figure 3.6: Cancer type of service users (n=4,074)

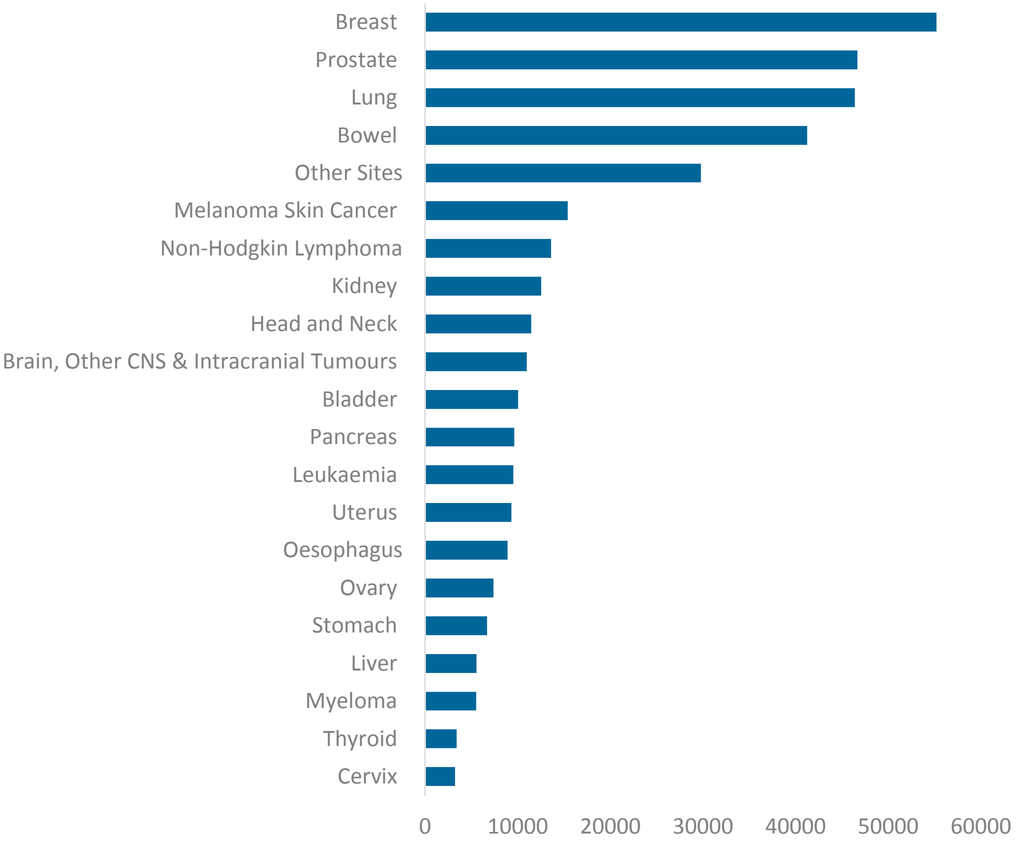


Figure 3.7: Cancer incidence by type across the UK in 2014[82]

---

[82] Cancer Research UK http://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/common-cancers-compared#collapseZero

**The services are also successfully engaging with service users experiencing a variety of cancer stages.** In particular, 320 service users with advanced or metastatic cancer (9 per cent of those who answered the question) have engaged with the service. Service users were most likely to report that they were in remission or cancer-free (31 per cent of those who provided data); 19 per cent indicated that their cancer was stable, and a further 13 per cent reported that their cancer was localised and had not spread.

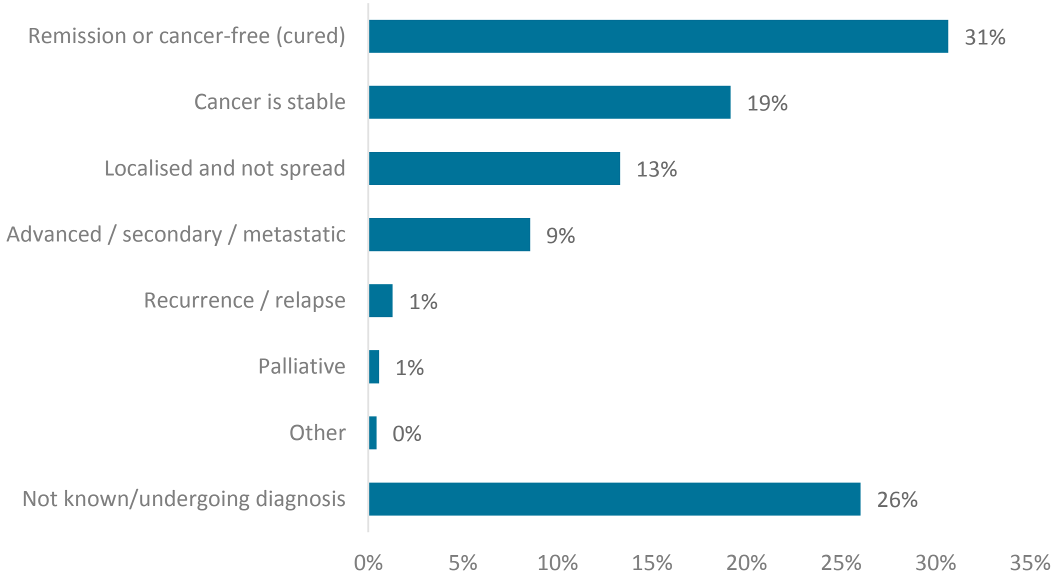


**Figure 3.8: Cancer location of service users (n=3,742)**

Very few people indicated that they were receiving palliative treatment. Some Move More Practitioners stated that it can be hard to persuade individuals who are undertaking end-of-life care that physical activity should be a priority for them:

> *I had a chap who was palliative, he came from a very physically active background, he did tai chi, and walking. Went to go to see him, and it was an incredibly hostile environment…He had a lot of things that he wanted to do, he was estimated six to nine months, and physical activity just was not one of them*
>
> — **Service staff, Lincolnshire**

Some Practitioners felt the need to adjust their approach to motivational interviewing (MI) for palliative referrals.

> *It is a different approach, and the goals and the aims are totally different, and it might not be, you're aiming for the government's recommendation […] but it's around more quality of life, and survival and personal goals, which is still the core concept of MI.*
>
> — **Service staff, GSTT**

However, this suggests a misunderstanding about the role of MI. At the start of an MI conversation service users should be actively engaged in setting the agenda and the focus of the discussion, rather than the practitioner deciding the aim. The conversation should be client led, and outcomes should not be pre-determined.

Almost half of service users indicated that they were post treatment (48 per cent) compared with 25 per cent indicating that they were currently undergoing treatment.

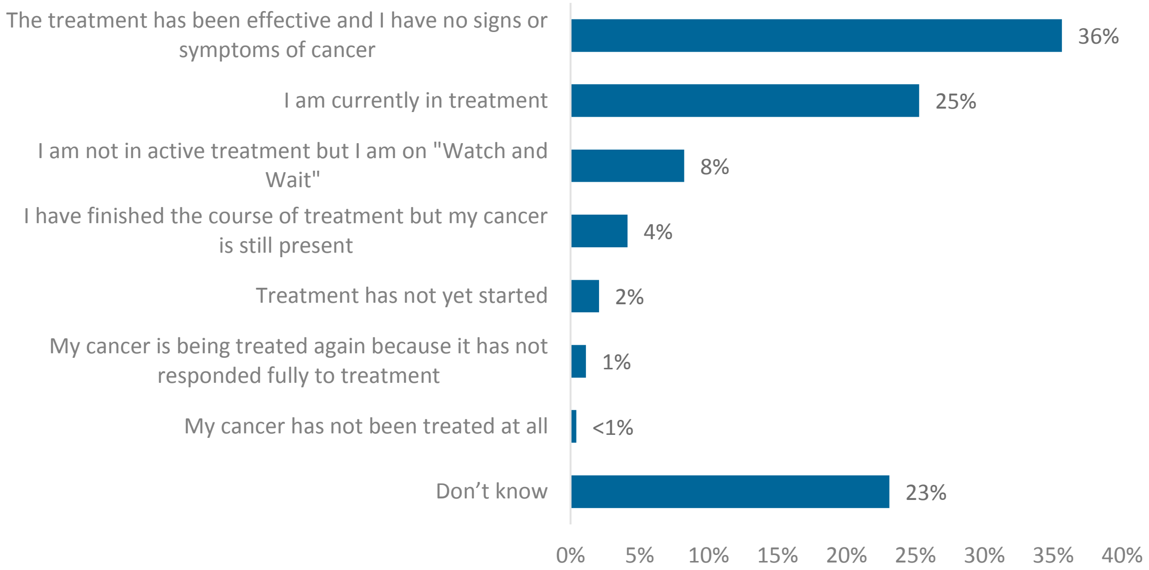


**Figure 3.9 Service user cancer treatment (n=3,603)**

Only three per cent were at the pre-treatment stage. This is interesting as increasingly we found HCPs discussing the merits of patients undertaking physical activity before undergoing treatment. This is particularly the case for those cancers that involve more intrusive surgery. For example, in Shropshire, the project is beginning to work with a pre-habilitation lung team and will offer 8-10 sessions of 'prehab' in the gym to build up the service users' fitness to undergo surgery. In Sheffield, a similar scheme is about to be undertaken with the local upper gastro-intestinal team where HCPs have found that the advice given previously, of 'enjoy yourself and eat whatever you can', has led to patients gaining weight and becoming less fit; thus making their surgeries more complicated and difficult. It is too soon to evaluate the success or otherwise of these schemes.

## Conclusions

Services use a wide range of methods, including online media, social networking and the press, to raise awareness of the programme and to help generate referrals. Macmillan have provided support in the form of expertise, learning and a comprehensive suite of materials. Services have welcomed the support offered and made good use of it, in particular to ensure that the language used by services is inclusive and not off-putting to potential service users.

The extent to which services are embedded in the recovery package can have an impact on referral numbers. Where Health and Wellbeing events are run regularly and are well attended, they can be a successful channel by which to promote the programme, generate referrals from PLWC and engage with HCPs. Where services have had most success, they have presented at the events. Offering short taster exercise sessions can be helpful as well as fun. Getting current service users to speak at events also provides a powerful way of communicating the benefits of the service.

Developing positive relationship with the staff working in the Macmillan Information Centres is likely to be fruitful for services. Centre staff have good links with key HCPs and can thus broker introductions and provide information about the local cancer care landscape. As important sources of information for PABC, the Centres provide opportunities for self-referrals. Services can also signpost service users to complementary support and advice via the Centres.

Referrals come from either self-referrals or a variety of HCPs – although the largest proportion come via CNSs. Services have found engaging HCPs more challenging than expected. They have also found that attending tumour-specific staff meetings is an effective way of engaging a range of HCPs and raising awareness of the programme. This kind of relationship building needs to take place on an on-going basis to ensure the service remains high on the agenda and is not lost amongst the plethora of other initiatives that exist. Those services that are based in a healthcare setting (rather than in a community setting) find that they are better able to engage HCPs.

Overall, the services have successfully engaged with an ethnically diverse, if older, population of PLWC, although this masks differences between services. Overall, women are more likely to engage with the programme. Services are engaging service users across different cancer stages and cancer types, broadly in line with the national picture. Most service users are post-treatment but services have also successfully engaged a substantial proportion of service users who are in-treatment too. Very few palliative patients are referred to the programme.

## Recommendations

### Macmillan / future funders

As the Recovery Package is rolled out across the UK, services Macmillan and UK wide decision makers should work to ensure that the Physical Activity Behaviour Change Care

Pathway is embedded within it. In particular, support with physical activity from the services should be a referral option as part of the HNA[83].

## Services

The referral process should be made as easy and efficient as possible for professionals and self-referrals. Access should be provided to an NHS email wherever possible in order to enable professionals to transfer referral details electronically. For potential service users, quick and easy completion methods should be offered, such as postcards or tear-off slips.

Services should focus on building trust with key HCPs through on-going and face-to-face engagement. This should include engagement with Macmillan Information Centres. Services should use the Macmillan referral tactics tool as appropriate.

Move More Practitioners should present at Health and Wellbeing events to promote the service to PABC and HCPs. Offering short bursts of taster activity and getting current or former service users to attend as ambassadors for the service should be considered.

Services should broker relationships with a range of potential sources of referrals including other charities, private health providers, and other Macmillan services.

Services should continue to target GPs and, where possible, work with them to include the service as an option as part of the cancer care review.

There should be efforts made to ensure that the language used to promote physical activity is accessible, appealing and inclusive, to reflect a wide-as-possible concept of what physical activity involves.

Services should explore ways to provide feedback on service user progress to those who provide referrals. This could be in the form of case studies of service users.

Responsibility for creating relationships with and referrals from HCPs and partner organisations should be shared by senior staff, service champions and steering group members as well as Practitioners. Steering groups should include suitably senior members who can help to remove blockages to progress and effectively advocate for the service.

---

[83] Each nation within the UK refers to the Recovery Package slightly differently and has different plans for roll out. See page 22 in Chapter 1 for further information.

# 04. Behaviour change interventions

*This Chapter explores the different approaches services have taken to delivering behaviour change interventions and assesses their effectiveness.*

## Key points

- The majority of sessions delivered face to face lasted over 30 minutes.
- Interventions are usually delivered by a Move More Practitioner who has received MI and Level 4 Cancer Rehabilitation training
- The average (mean) BECCI score is 22.8 (out of a possible total of 44). This indicates that the Practitioners we observed were generally delivering MI consistent behaviour change interventions '*to some extent*'.
- Practitioners were empathic, patient and encouraged the individual to talk about their situation; this helped to instil the confidence to change.
- Service users generally found the initial intervention positive and helpful.
- Services modify the extent to which they use MI, based on their perception of the individual's level of motivation and stage of treatment. Services users who are perceived to be more ready to change their behaviour may not receive the most MI consistent consultation.
- Additional training and on-going support is needed to enable Practitioners to deliver MI in a variety of circumstances and should include how best to support those who are perceived to be more motivated to make a change.
- Services that deliver interventions face-to-face (England and Wales, and Northern Ireland) receive higher BECCI scores than those that use telephone based approaches (Scotland).
- It is questionable whether the physical activity offer is always a truly personalised one.

## The Macmillan behaviour change approach

At the heart of the service is a programme of support which includes a behaviour change intervention – which are described in PH49 as extended brief interventions. These consultations, led by Practitioners, are designed to explore the benefits of increasing physical activity and to enhance the service users' confidence in overcoming barriers to do so. The practitioner employs motivational interviewing techniques (MI) to help individuals explore and address their potential ambivalence about behaviour change.

Effective MI should include elements of spirit (for example empathy and compassion) and technique (for example reflective listening). The approach is based on the belief that a service user's motivation to change is more likely to improve through negotiation rather than through coercion or persuasion. A strong principle is that is the process should be service user led; the service user should be able to articulate the benefits and costs involved through a collaborative relationship with the practitioner.

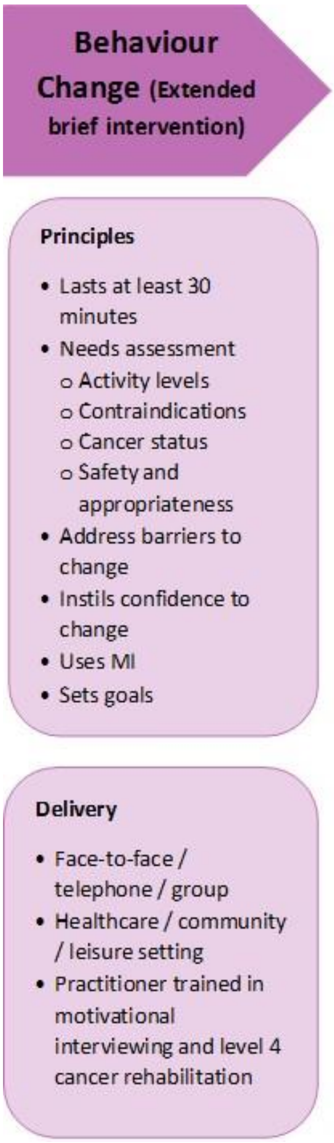
Key components of the behaviour change model, as suggested by Macmillan are:

The individual has an initial intervention that lasts a minimum of 30 minutes (but is usually longer). This intervention should cover:

- Behaviour change support
    - Practitioner to consider using the Move More guide to help shape the conversation. The pack is intended to be used as a shared decision-making tool as well as something service users can take away with them.
    - Practitioner explores possible futures in terms of changing behaviour.
    - Instilling the confidence to change
    - Exploring the importance of physical activity to the individual
    - Practitioner supports individual to set short and long term goals.
    - A physical activity suitable to the individual is identified (co-created plan).
    - Plans for long term support, encompassing regularity and type of contact, and how to overcome barriers are agreed.
- Needs assessment
    - Previous activity levels prior to diagnosis
    - Contraindications to physical activity
    - Stage of cancer/type/treatment history etc.
    - Comorbidities
    - Safety considerations
    - Self-efficacy
    - Appropriateness of physical activity chosen by individual

Macmillan recommends that the practitioner delivering the intervention should have completed their level 4 cancer rehabilitation training, and should have completed a course in behaviour change (for example,  the two day MI course run by Macmillan). This is so that Practitioners understand and are skilled at implementing behaviour change as well as the cancer specific contraindications, safety considerations and limitations for PLWC.

Services included in the evaluation delivered the behaviour change interventions face-to-face, by telephone (Edinburgh, Aberdeen and GSTT) or in one case (Dorset) in a group setting. The intervention may be delivered in a healthcare, leisure or community setting. The key principles and the different delivery mechanisms associated with this element of the Physical Activity Behaviour Change Care Pathway are illustrated in figure 4.1 below.



**Behaviour Change (Extended brief intervention)**

**Principles**

- Lasts at least 30 minutes
- Needs assessment
    - Activity levels
    - Contraindications
    - Cancer status
    - Safety and appropriateness
- Address barriers to change
- Instils confidence to change
- Uses MI
- Sets goals

**Delivery**

- Face-to-face / telephone / group
- Healthcare / community / leisure setting
- Practitioner trained in motivational interviewing and level 4 cancer rehabilitation

Figure 4.1: The key Macmillan principles and delivery mechanisms for behaviour change interventions

# How services meet principles of behaviour change

## Length of session

In total, 33 behaviour change sessions were observed by the evaluation team, including six carried out over the telephone. The length of these sessions varied considerably, ranging from ten minutes (Scotland) to 75 minutes (Shropshire). **The majority of sessions which were delivered face to face lasted over 30 minutes**.

The sessions were often used for collecting additional information. This included Practitioners working with the service users to complete the minimum dataset or other questionnaires including the Physical Activity Readiness Questionnaire[84]. In some instances this either limited the amount of time available for motivational interviewing to less than the recommended minimum of 30 minutes or came at an inappropriate time during the MI discussion, leading to a more disjointed session.

## Use of the Move More pack

We observed few instances where the Move More pack was used as a tool to structure the intervention session. However, the pack is often referred to – most commonly either in terms of the Move More activity DVD as a potential exercise tool or the diary sections as a motivational tool for recording activity levels. The pack's contents' relevance may depend on the service user's concerns and levels of motivation. For example, in one service we observed an intervention where the Move More pack was central to the conversation and was enthusiastically received by the service user. In another intervention, conducted by the same practitioner, the service user was clearly distressed and concerned about her ability to care for her pet. In this example, focusing on the pack in the same way was not felt to be appropriate by the Practitioner. We suggest that Practitioners should not always be expected to make use of the pack to structure the conversation, although it should be offered to all service users.

## Quality of MI

The behaviour change interventions we observed were assessed using the Behaviour Change Counselling Index (BECCI[85]) – a tool designed to assess the quality of behaviour change counselling. This tool is constructed around 11 statements and has been tested for use in a consultation setting (although not all statements are relevant to all situations). Each statement is associated with a Likert scale which reflects the degree to which observers believe that the action indicated by the statement has been carried out, ranging

---

[84] PAR-Q is a pre-screening tool used by some services. This has been a local decision and is not one that is endorsed by Macmillan.

[85] Lane, C., Huws-Thomas, M., Hood, K., Rollnick, S., Edwards, K. And Robling, M. (2005). Measuring adaptations of motivational interviewing: the development and validation of the behaviour change counselling index (BECCI). *Patient Education and Counselling*, volume 56 (2): 166-173

from 0 (not at all) to 4 (a great extent). We followed a mean substitution approach for any items marked 'not-applicable'. From the scores we calculate an overall average score.

Table 4.1 below shows the average scores for each of the 11 statements, and the overall score. **The average (mean) score overall is 22.8 (out of a possible total of 44). This indicates that the Practitioners we observed were generally delivering an effective behaviour change intervention '*to some extent*'**. Practitioners scored lowest (an average of 1.7) for the statement *Practitioner and patient exchange ideas about patient behaviour change.*

| **Description of item** | **Average across all observations (n=33)** |
|---|---|
| Practitioner invites patients to talk about BC | 2.1 |
| Practitioner demonstrates sensitivity to talking about other issues | 2.4 |
| Practitioner encourages patient to talk about current behaviour | 2.4 |
| Practitioner encourages patient to talk about change | 2.1 |
| Practitioner asks questions to elicit how patient thinks & feels | 1.9 |
| Practitioner uses empathic listening statements when patient talks | 2.2 |
| Practitioner uses summarises to bring together what patients says | 1.9 |
| Practitioner acknowledges challenges about BC that patient faces | 2.0 |
| Practitioner provides information it is sensitive to patient concerns | 1.8 |
| Practitioner activity conveys respect for patient choice | 2.2 |
| Practitioner & patient exchange ideas about patient BC | 1.7 |
| **Practitioner BECCI score** | **22.8** |

Table 4.1: Average BECCI scores for the 11 statements and overall

**If we discount the particularly low Scotland scores (see page 86) the average improves to 25.3. However, this still shows behaviour change interventions are only somewhat MI consistent**.

Instances in which the practitioner used effective questioning strategies to understand how the individual thinks and feels about a topic were limited – this is represented in the low average BECCI score of 2. Practitioners tended to use closed questions rather than open ended questions such as ‘how would you like things to be different’. This, on occasion, limited the opportunities for service users to express their thoughts about the topic. Few Practitioners encouraged the individual to share strategies that could potentially help them change their behaviour. Where strategies were suggested this tended to be done by the practitioner.

Practitioners in some services sometimes simply went through the motions of asking set questions, rather than refining and shaping the conversation based on the responses, suggesting that the spirit of MI was absent. This was particularly noticeable when individuals were asked to describe a typical day. This is potentially a useful and positive way to begin a discussion; however, individuals did not always answer in a particularly informative way and the practitioner often did not follow up effectively on such an answer in order to elicit the information required so that what followed was truly personalised.

There was little evidence of Practitioners making summary statements during interventions. This is important in MI as it allows the practitioner to ensure that they have an accurate understanding of the needs of the individual whilst also encouraging the service user to correct any inaccurate assumptions.

### Instilling confidence

**In the best interventions we observed, Practitioners were empathic, patient centred and encouraged the individual to talk about their situation, which helped to instil the confidence to change**. This is a key aspect of successful motivational interviewing and one that is essential in reducing resistance to change. Demonstrating empathy has a major impact on an individual’s willingness and ability to change and to talk about their current situation.

Service users report that the manner in which project staff explained the benefits of staying physically active motivated them to join the programme and that they valued the initial process.

> *I found him really lovely and very friendly.  Really nice with his kind of manner in speaking to me.  So I contacted him and we met for a coffee and he made me feel at ease straight away. He just spoke to me about what I was doing currently and suggested things that I could possibly do to help myself*
>
> — **Service User, Sheffield**

## Overall assessment of MI

**Despite considerable investment from Macmillan in an evidence based training package for Practitioners, there is considerable variation in the quality of interventions that we observed and (except for services in Scotland – see page 86 for further detail) improvements were hard to detect over the course of the evaluation**.

The overall averages mask variations between projects and between individual observations. Figure 4.2 shows the individual BECCI scores for each observation carried out at each service. The variation in scores for many projects reflects our finding that Practitioners modify how they use MI on a case by case basis. The figure also highlights the fact that our scores are based on a small number of observations, which may not necessarily be reflective of typical practice.

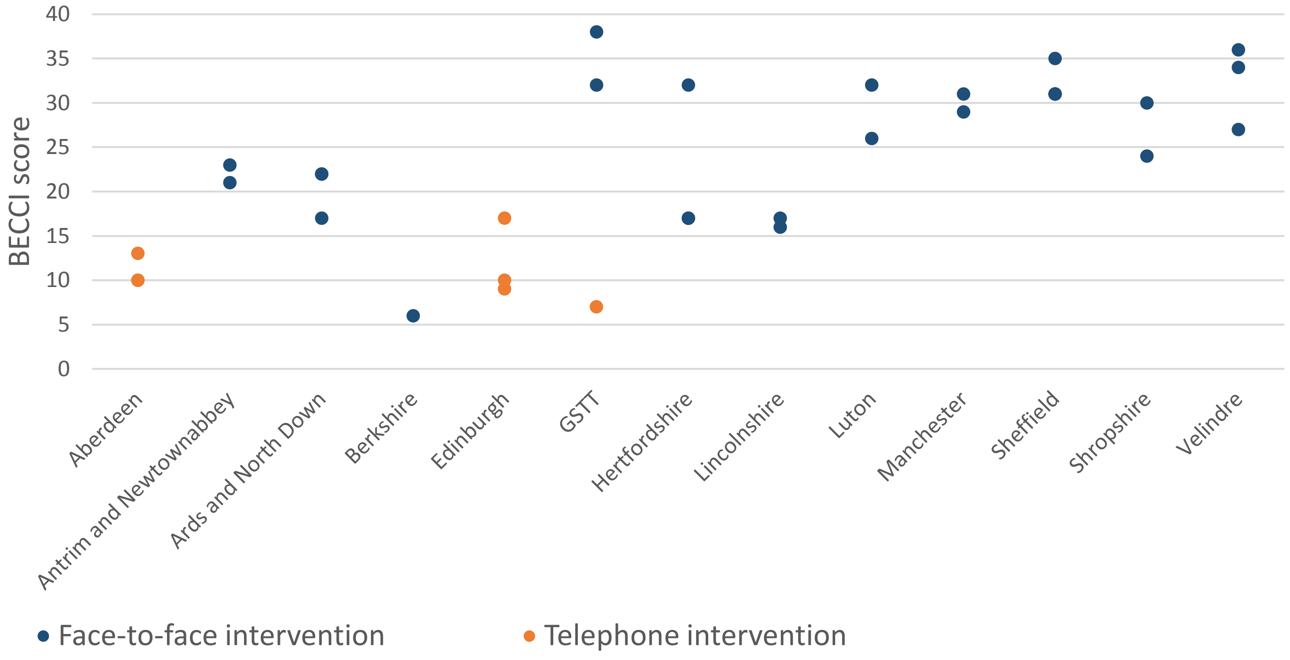


Figure 4.2: Overall BECCI scores for each intervention observed – some data-points represent multiple observations with the same score.

However, this does not necessarily mean that service users have not received a personalised service and the information and support that they require, simply that Practitioners do not always carry out full MI. Indeed, service users generally found the initial intervention positive and helpful.

**Services modify the extent to which they use MI based on their perception of the individual's level of motivation and stage of treatment**. It was rare to find an instance in those observed where an individual was not already predisposed to physical activity. In most cases, service users either had some form of experience of physical activity prior to diagnosis or were actively giving consideration to starting to exercise; 61 per cent of service users said they had done ‘a lot’ or ‘a moderate amount’ of sport or exercise in the five years prior to diagnosis – see page 130.

Where individuals were motivated, Practitioners perceived that MI was not required or appropriate. This perception was also raised by Practitioners in the Macmillan behaviour change training sessions. This goes against the principles and philosophy of MI and reflects a lack of understanding of how MI is used irrespective of how ready service users are to change. We observed multiple instances where the service user simply wanted to be able to restart exercise, but with advice and support relevant to their condition. Some were merely seeking information on the activities available. As a result, these sessions were much less likely to meet the formal requirements of a true behaviour change intervention. It is clear that Practitioners have an understanding of behaviour change techniques; however, the extent to which they are able to apply them in different circumstances is variable. They make assumptions about the extent to which MI is appropriate or required. Additional training and on-going support is needed to enable Practitioners to truly be able to evoke behaviour change within a service user rather than impose it.

## Goal setting

Practitioners recognise that goal-setting is a requirement of the Macmillan Physical Activity Behaviour Change Pathway, although it is not a necessary part of MI. The extent to which goals were formally set and recorded varied considerably both between and within services – no service routinely set goals as part of the interventions we observed. In some instances it was clear that the individual was not ready to set specific behavioural goals, and it would have been either impractical or demotivating to set them during the intervention. In the best examples observed, Practitioners encouraged individuals to define their own goals and recorded these on the service user’s notes. These were then revisited at the three month stage. In some instances, individuals were prompted by the practitioner to provide a ‘confidence score’ from 1 – 10, regarding the likelihood that they would achieve their goals, and this appeared to be effective in generating a follow-on discussion.

## Personalised offer

Particularly for those services that directly deliver activities, **it is questionable whether the physical activity offer is always a truly personalised one**. To be considered personalised, the physical activity offer needs to be suitable for the individual and its selection reached as a result of a co-created plan. In very few of the interventions observed across the 14 services did the practitioner undertake a true needs assessment nor did the service user leave the meeting planning to participate in an activity outside those that the service directly delivered. **No services delivered a truly personalised offer on every occasion**. This lack of a completely personalised offer may be a consequence of some providers having prior experience in running exercise on referral schemes and defaulting to this model.

The lack of a personalised offer was most apparent in Berkshire which offered only a condition specific circuit activity. Here the approach adopted by the HCPs during the behaviour change intervention was inadequate and did not meet the standards required by Macmillan. Service users were offered no real choice of activity and received a circuits induction session prior to the initial behaviour change intervention.

We recognise that phase 1 services (see page 17), in particular, reported signposting service users to a wide range of other activities. And it may be that the activities delivered (primarily circuits classes) aligned perfectly with the interests of the service users involved. For example, the circuit class in Berkshire proved to be very popular, attracting waiting lists of service users wishing to participate. However, more could be done to explore personal preferences which are outside of the activities delivered as part of the programme to ensure that services more closely follow the NHS's Shared Decision Making principle.[86]

---

[86] https://www.england.nhs.uk/ourwork/pe/sdm/

## How services deliver the behaviour change interventions

Table 4.2 below provides an overview of the different ways services endeavoured to deliver the initial behaviour change intervention.

| | Method | Location | MI Trained | Level 4 Can Rehab trained |
|---|---|---|---|---|
| **Aberdeen** | Phone | N/A | Yes | No |
| **Antrim and Newtownabbey** | Face-to-face | Leisure centres or coffee shop | Yes | Yes |
| **Ards and North Down** | Face-to-face | Leisure centres, coffee shops or service user home | Yes | Yes |
| **Dorset** | Group | Bournemouth University | Yes | Yes |
| **Edinburgh** | Phone | N/A | Yes | In progress[87] |
| **GSTT** | Face-to-face and phone | Cancer centre | Yes | Yes |
| **Hertfordshire** | Face-to-face | Leisure centres | Yes | Yes |
| **Lincolnshire** | Face-to-face | Service user home | Yes | Yes |
| **Luton** | Face-to-face | Active Luton leisure centres | Yes | Yes |
| **Manchester** | Face-to-face | Community halls/leisure facilities, service user home | Yes | Yes |
| **Sheffield** | Face-to-face | Flexible, university, coffee shops, drop in clinics | Yes | Yes |
| **Shropshire** | Face-to-face | Macmillan information centre in Princess Royal Hospital or Hamar centre in Royal Shrewsbury Hospital grounds | Yes | Yes |
| **Velindre** | Face-to-face | Velindre cancer centre | Yes | Equivalent training – staff are physiotherapists |

Table 4.2: Delivery of the initial behaviour change intervention

Most services undertake behaviour change-interventions face-to-face. The Scottish model is the exception and initial service user engagement takes place by telephone. While originally these sessions may have been designed as telephone triage sessions only, it is clear that they are considered by practitioners to be behaviour change interventions. There is no further opportunity for initial behaviour change prior to participation in the programme. GSTT also offered a telephone intervention, though they have recently

---

[87] At time of interview, an Edinburgh staff member was shortly to undertake Macmillan motivational interviewing training.

introduced the option of a face to face intervention.[88] We explore the benefits and limitations of the different approaches later in this chapter.

Interventions are usually delivered by the Move More Practitioner and all have received MI training. However, in a number of services this task is shared with support staff within the team. Support staff at the two services in Scotland had not undertaken MI training at the time of our observations; their behaviour change interventions were noticeably weaker than those of the other services (see Figure 4.2). The lower scores are also affected by the method of delivery – see section on sub-group analysis below.

Practitioners value the Macmillan MI training and most felt that they had learned new techniques and improved their MI skills as a result. Practitioners would welcome regular refresher training and in particular opportunities to further role-play difficult scenarios that they may experience, in order to improve their techniques. This further supports our recommendation that additional training and on-going support relating to Practitioners delivering MI is required.

In almost all instances, the staff have also undertaken level 4 cancer rehabilitation training or equivalent. It is important for all staff undertaking interventions have a comprehensive understanding of cancer and physical activity. This is so that they can understand the specific needs of PLWC and how these change as they progress through their cancer journey.

## Analysis by sub-group

### National model

The principal difference in behaviour change delivery is found in Scotland. With the exception of GSTT, all services in England, Wales and Northern Ireland deliver interventions face-to-face. In Scotland the initial behaviour change intervention is carried out over the telephone.

**Services that delivered interventions face-to-face (England, Wales and Northern Ireland) received higher BECCI scores than those that used telephone based approaches (Scotland)**. This is illustrated by Figure 4.2 – interventions delivered by telephone are highlighted in orange. The telephone approach in Scotland scored an average of only 11.5 in comparison to the face to face interventions in Northern Ireland (21) and in England and Wales (26). Some caution is needed here as the Scotland and Northern Ireland averages are based on very small samples of observations.

---

[88] GSTT interventions observed were conducted face to face

| Description of item | Scotland average (n=6) | Northern Ireland average (n=5) | England & Wales average (n=22) |
|---|---|---|---|
| Practitioner invites patients to talk about BC | 1.3 | 1 | 2.5 |
| Practitioner demonstrates sensitivity to talking about other issues | 2.2 | 2 | 2.6 |
| Practitioner encourages patient to talk about current behaviour | 1.2 | 1.8 | 2.8 |
| Practitioner encourages patient to talk about change | 1.0 | 2.2 | 2.4 |
| Practitioner asks questions to elicit how patient thinks & feels | 0.7 | 1.6 | 2.3 |
| Practitioner uses empathic listening statements when patient talks | 1.0 | 2 | 2.6 |
| Practitioner uses summarises to bring together what patients says | 0.5 | 2.6 | 2.2 |
| Practitioner acknowledges challenges about BC that patient faces | 1.0 | 2.8 | 2.1 |
| Practitioner provides information it is sensitive to patient concerns | 0.7 | 1.8 | 2.2 |
| Practitioner activity conveys respect for patient choice | 1.0 | 2 | 2.6 |
| Practitioner & patient exchange ideas about patient BC | 1.0 | 1.2 | 2.0 |
| **Practitioner BECCI score** | **11.5** | **21** | **26.3** |

Table 4.3: Average BECCI score for national service models

A positive circumstance to note is that both Move More Aberdeen and Move More Edinburgh have made significant improvements in their intervention process over the course of the evaluation. As a result of the feedback they have received, both now offer an intervention closer to the Macmillan model. Practitioners follow a redesigned script that assists them in discussing behaviour change. More questions are now asked which gauge the service user's physical activity background and which attempt to identify what the users are interested in undertaking. However, as indicated by the low BECCI scores, the interventions are still not MI consistent. In eight of the 11 statements Scotland services scored 1 (minimally) or lower.

The reason for the low scores in Scotland is clearly related to the method of delivering the intervention – by telephone. Appointments are not usually made in advance of the behaviour change call. The quality of the calls is heavily reliant on the circumstances of the service user at the time of the call. As a result, we witnessed interventions that were conducted in less than ideal circumstances, for example, while the service user was travelling, or when, otherwise, they only had a limited amount of time to talk. In these cases the behaviour change aspect of the conversation was less evident, as the priority tended to be on providing details of the programme and on the activities available. The approach can also mean multiple attempts are required before contact with the service user is achieved and the task can become more burdensome than it need be.

This is not to say that behaviour change interventions cannot be successfully delivered by telephone. For example, one recent randomised controlled trial examining the effects of telephone-based motivational interviewing on reducing metabolic risks in middle-aged and older women who are at high risk of physical inactivity found that it can have a positive benefit.[89] However, if telephone interventions are to be used, services must make appointments with individuals in advance, setting out the amount of time that will be needed (minimum 30 minutes). In this way, services can ensure that there is sufficient time to properly conduct the intervention.

### Group based behaviour change interventions

While it is does not form part of any national model, it is worth taking time to consider the other main alternative approach to delivering the behaviour change intervention – group-based interventions.

The Living Well Active service in Dorset is unique in that it does not offer interventions on a one-to-one basis, although it will signpost to a one-to-one service as required: one-to-one interventions, there, are delivered by 'My Health My Way', a self-care support service.

The primary method of intervention in Dorset is via a group setting. This approach was adopted so that it could be more easily scaled-up as necessary.

> *There's two million people living with cancer [… and] it's growing, it will be four million. Are we going to be [able] to actually offer each of those a one-to-one service for a behavioural change? [We asked ourselves] is there the opportunity to explore whether […] group motivational change would be an option.*
>
> — **Service staff member, Dorset**

The service offers a monthly support meeting, 'Enrich Your life in 28 days'. This is held at Bournemouth University; the event includes a 30 minute presentation from the Move More practitioner, a guest Living Well speaker, an update on new Living Well opportunities, and a group discussion between people affected by cancer. The service draws on a pool of 10 service user volunteers to deliver talks on their journey at events. The

---

[89] Lin, C.. Chiang, S. Heitkemper, M.. Hung, Y. Lee, M. Tzeng. Tzeng, W. and Chiang,, L. (2016) Effects of telephone-based motivational interviewing in lifestyle modification program on reducing metabolic risks in middle-aged and older women with metabolic syndrome: A randomised controlled trial. *International Journal of Nursing Studies* Aug;60:12-23.

sessions can attract substantial numbers (19 people attend the session we observed) and feedback suggests that these events are viewed positively.

> *It's quite encouraging to see when there's other people, because then you don't, sort of, feel on your own, really. Also you can encourage each other, and you can have a quick chat before or after and, […] kind of say, 'Well actually, we can do this and we're okay, and we can support each other'.*
>
> — **Service User, Dorset**

When compared to the model based on advice from Macmillan's Expert Advisory Group, the group sessions as currently delivered cannot be considered to be a true behaviour change intervention. There is very little evidence of discussions on current levels of activity amongst attendees nor is there any opportunity to really talk about individual circumstances in any depth. There are limited opportunities for two-way discussions. However, the events do provide an opportunity for the practitioner to discuss motivation, the importance of activity and for informal goal setting. Attendees are invited to share what they have achieved since the last meeting, which is certainly motivating. In essence, it is much closer to what could be considered brief advice in a group setting. Although it does not meet the Macmillan recommended approach, MI can be done well in a group setting and has been explored in other settings, primarily in drug and alcohol research with promising results[90]. There are training and resources available to support this.[91] Macmillan should consider exploring the opportunities, benefits and limitations of group-based approaches further.

## Healthcare / community models

The main distinction between services based in healthcare, community and leisure settings is the extent to which they can access a range of locations at which to deliver the intervention interviews. There appears to be more flexibility offered to service users by community and leisure based services. Services delivered by leisure providers, in particular, are able to draw from their portfolio of community and leisure facilities. For example, the two services in Northern Ireland have a good range of local leisure centres, many with cafes on site, at which they can deliver interventions. Some services offer the opportunity to meet in a local coffee shop. One service (Lincolnshire) predominantly offers interventions in the service-user's home, and two other services (Manchester and Ards and North Down) also offer this. Lincolnshire's experience is that home visits offer considerable benefits in terms of service user engagement; we discuss this in Chapter 6.

---

[90] Krejci, J. and Neugebauer, Q. (2015) Motivational Interviewing in Groups: Group Process Considerations. *Journal of Groups in Addiction and Recovery* 2015:Vol 10 Iss. 1 23-40

[91] Wagner, C. and Ingersoll, K. et al (2012) *Motivational interviewing in Groups* London: The Guilford Press

In contrast, healthcare based services (GSTT, Shropshire and Velindre) only offer interventions in a healthcare setting.

For the service users, there does not appear to be one single ideal choice of location. Some service users place value on being able to attend a meeting away from a healthcare environment. Some appreciate the ‘normality’ and anonymity that this provides.

> *[Service users] can come into [the leisure centre café] and nobody would know [they have cancer] apart from the fact they’re sitting with somebody with a Macmillan bade on. It’s just a massive pro that it is in the community […] it’s not hospital based, it’s not clinical.*
>
> — **Service staff member, Ards and North Down**

Others find a healthcare setting more practical as it allows them to schedule the intervention for the same day as a medical appointment.

Healthcare based services, in particular, should consider whether they could offer greater flexibility in the location of interventions in order to ensure that the varying preferences of potential service users are met whilst maintaining sufficient levels of confidentiality and openness.

Table 4.4 overleaf shows the average BECCI scores for interventions delivered in healthcare and community settings (excluding Scotland). While the healthcare based services achieve a higher average score, we do not think this is as a result of the setting per se.

| **Description of item** | **Av across healthcare based (n=8)** | **Av across community based (n=19)** |
|---|---|---|
| Practitioner invites patients to talk about BC | 2.6 | 2.2 |
| Practitioner demonstrates sensitivity to talking about other issues | 2.6 | 2.4 |
| Practitioner encourages patient to talk about current behaviour | 2.8 | 2.5 |
| Practitioner encourages patient to talk about change | 2.6 | 2.2 |
| Practitioner asks questions to elicit how patient thinks & feels | 2.5 | 1.8 |
| Practitioner uses empathic listening statements when patient talks | 2.6 | 2.3 |
| Practitioner uses summarises to bring together what patients says | 2.3 | 2.1 |
| Practitioner acknowledges challenges about BC that patient faces | 2.2 | 2.3 |
| Practitioner provides information it is sensitive to patient concerns | 2.1 | 1.9 |
| Practitioner activity conveys respect for patient choice | 2.6 | 2.5 |
| Practitioner & patient exchange ideas about patient BC | 2.1 | 1.8 |
| **Practitioner BECCI score** | 27.0 | 24.0 |

Table 4.4: Average BECCI scores for healthcare and community based services

## Conclusions

MI training is valued by service staff and helps them improve their interview technique; where staff had not received training in MI the interventions they delivered were weaker. Interventions were personalised and Practitioners empathetic and supporting. Service users found the interventions helpful and the experience a positive one. However, interventions do not always follow the Macmillan recommended model or effectively use MI techniques. Services modify the approach according to their understanding of the service user's needs and motivation. As a result, there was great variation in the quality of interventions that were observed. Additional and ongoing training is required to enable staff to more confidently and consistently deliver effective MI.

Interventions delivered by telephone were the least likely to provide good quality MI. In their current format, telephone interventions should not be used. If BC interventions are to be delivered by telephone, appointments should be made in advance so that the service user is prepared and has the time for a meaningful conversation.

As currently configured, group interventions do not meet Macmillan's requirements for the BC intervention. In sessions observed the Practitioner met only a few of the core requirements as set out at the beginning of this chapter. However, the format does provide a valuable opportunity for mutual support and motivation and group sessions are positively received by service users who participate. Effective MI in groups is possible and emerging evidence in different settings is promising. . To do this productively requires specific skills.

## Recommendations

### For Macmillan / Future funders

MI training needs to be an on-going process, with opportunities provided to practice, reflect and receive updates and refresher training. In particular, more training and support is needed on how MI can be used for those already apparently motivated or predisposed towards physical activity.

Macmillan and future funders should consider exploring the opportunities, benefits and limitations of group-based approaches further. Where adopted, training should be provided to ensure group approaches are of a good standard.

Macmillan and future funders should recommend that Practitioners consider using the Move More pack as part of conversations if appropriate.  The pack should be offered to all service users.

### For services

If BC interventions are to be delivered by telephone, appointments should be made in advance and recipients should be aware of the purpose of the call and the estimated length of the call so that the service user is prepared and has time for a meaningful conversation that lasts for a minimum of 30 minutes. Practitioners need to be trained with the same level of competency and skills for telephone as for face-to-face interventions.

Practitioners should not undertake behaviour change interventions unless they have completed training in MI.

Services should ensure that Practitioners devote the whole intervention to discussing behaviour change. Any requirements for data collection should be completed prior/post the intervention.

Healthcare based services, in particular, should consider whether they could offer greater flexibility in the location of interventions in order to ensure that the varying preferences of potential service users are met whilst maintaining sufficient levels of confidentiality and openness.

# 05. Physical activity provision

*This Chapter explores the range of physical activities that services provide to service users. We explore the benefits and limitations of services delivering activities directly and of signposting to other provisions. We also discuss the role of group sessions for PLWC.*

## Key points

- Overall services offer access to a wide range of physical activities that are either delivered directly or provided by others. However, no services observed consistently offer access to all the activities that form part of Macmillan's minimum recommended offer. Some services that deliver activities directly place greater emphasis on promoting these. The physical activity offer is not always a personalised one.
- There is no one size fits all physical activity offer. An appropriate offer is one that takes into account local facilities and services and provides activities at a variety of times and locations, based on the needs of service users.
- Closed classes offer service users the chance to exercise in a safe environment with an instructor who understands their condition. Service users enjoy circuit sessions and value them highly.
- Classes (and closed classes in particular) also offer an important opportunity for social contact and mutual support.
- A key success factor is that instructors should be knowledgeable about the physical activity and the needs of PLWC. They also need to be approachable and be able to develop good rapport with a range of service users
- Services based in leisure settings benefit from easier access to a wider range of classes and facilities. This can make the transition from free sessions to continued activity more straightforward than that in a healthcare setting.
- Signposting can be an effective way of enabling service users to access a wider range of services than can be delivered directly. Providing ongoing support to actively assist service users to access signposted services is an important part of this approach.

## Physical activity minimum offer

The Macmillan model suggests that a range of activities should be accessible to service users in order to ensure that they can access something appealing and suitable to them. As a minimum, the activity offer should include:

- cancer/long term condition specific sessions where required
- health walks
- encouragement to increase activity in daily life
- sports including adapted sports (e.g. walking football))
- community activity (e.g. Zumba, Yoga) and
- the Macmillan Move More DVD.

There is no requirement for services to provide any of the activities themselves, though they may wish to do this to meet local demand. All services should signpost to other physical activity provisions in order to ensure that services users can access a wide range of activities. Where appropriate they should work with local providers to ensure activities are appropriate for PLWC.

Local physical activity opportunities

**Minimum offer**

- Access to Macmillan Move More DVD
- Access to health walks
- Encouragement to increase activity in daily life
- Access to sports
- Access to community activity
- Access to cancer specific sessions

**Signposted or delivered directly**

Figure 5.1: Recommended minimum physical activity offer

## What physical activities are services providing access to

Based on our observations and the evidence collected, while all services offer access to at least *some* of the activities listed above, none offer all consistently to all service users. Some services also appear to place greater emphasis on certain activities. While some services are perhaps closer to the Macmillan recommended model in this regard, none can be said to be meeting it fully.

Most services have chosen to deliver at least one physical activity directly and the majority also signpost to external physical activities. The frequency of signposting varies across services, as does the extent to which services actively assist service users to access signposted services.

This relates to the point made in the previous Chapter about the extent to which services are offering a truly personalised service. It is arguable that if services only promote a limited range of options, this is not personalised and could mean that some potential service users are discouraged from engaging if the activities offered do not appeal to them. We only have data from those who *have* engaged, so it is difficult to determine the extent to which this is the case.

Table 5.1 overleaf provides an overview of services' physical activity offers.

| | **Mainly direct delivery or signposting** | **Direct delivery activities offered** | **No. of directly delivered sessions** | **Cancer specific only?** | **Opportunity to continue activity after set no. of sessions** | **Activities led by** | **Signpost to other activities?** | **Examples of signposted activities** |
|---|---|---|---|---|---|---|---|---|
| **Aberdeen** | Direct delivery | Circuits, gentle movement, gardening, walking, challenge events | 12 | Mixed | No | Service staff, external instructor, volunteers | On occasion | Health walks,<br>Living Well sessions |
| **Antrim and Newtownabbey** | Direct delivery | Circuits, Nordic walking, walking football, leisure centre activities and facilities | 5 free taster sessions | Circuits, Nordic walking and walking football | Yes – circuits continue to be offered free, minimal charge for walking | Move More practitioner,<br>other leisure centre staff, volunteers | Yes | Gardening |
| **Ards and North Down** | Direct delivery | Circuits, leisure centre activities and facilities | 5 free taster sessions | Circuits | Yes (with reduced leisure centre membership available), circuits have minimal fee. | Move More practitioner, other leisure centre staff | Yes | Walking football, Active Ageing classes |
| **Dorset** | Signposting | N/A | N/A | N/A | N/A | N/A | Yes | Wide range of up to 30 activities including: walking football, dragon boat racing, table tennis, Ambling |
| **Edinburgh** | Direct delivery | Circuits, gentle movement, gardening, walking | 12 | Mixed | No | Service staff, external instructor volunteers | On occasion | Health walks |
| **GSTT** | Direct delivery | Circuits, bowls | 8 weeks | Yes | Yes (dependent on take up) | Service staff | Yes | Exercise on referral, range of community-based opportunities |
| **Hertfordshire** | Direct delivery | Gym, leisure centre activities, cycling | 12 | No | Yes | Service staff,<br>leisure centre instructors | Yes | Walking for Health, range of community-based opportunities |
| **Lincolnshire** | Signposting | Challenge events | N/A | N/A | N/A | More More practitioner | Yes | Walking for Health |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Luton** | Direct delivery | Gym, gardening, walking football, walking netball, foot golf, Yoga, walking cricket, swimming | 12 | Open | After taking out reduced rate membership | Service staff, leisure centre instructors | On occasion | Wide range of up to 20 activities including: Just bowl, Tai Chi, walking, archery and aqua aerobics |
| **Manchester** | Direct delivery | Circuits, gentle movement, Tai Chi for health , Zumba, dance, running, green gym, back to basketball | One year | Closed | Yes | Service staff, external instructor | On occasion | Wide range of up to 20 activities including: dragon boat racing and outdoor AthleFIT, walking for health |
| **Sheffield** | Signposting | Gym sessions, Walking football | N/A | Closed | N/A | Move More Practitioner | Yes | Range of activities including: leisure centres, walking for health, foot golf, badminton and Race for Life |
| **Shropshire** | Signposting | Walking | N/A | N/A | N/A | Move More Practitioner | Yes | Mainly home based activities, walking for health, 17 other activities including Back to Ballroom and Parkrun |
| **Velindre** | Direct delivery | Circuits, cycling | 6 weeks | Yes | No | Service staff | Yes | Exercise on referral, walking for health |

Table 5.1 Physical activity offers

## Provision of cancer / long term specific condition sessions

Half of the services directly offer cancer specific circuit style activities. These comprise a series of different exercises that enable service users to work different body parts at their own pace and level. Circuit classes are closed - that is, they are only open to PLWC (and in some cases to people with other conditions such as heart conditions as well).

**Closed classes offer service users the chance to exercise in a safe environment with an instructor who understands their conditions. Closed classes also offer privacy and help to overcome barriers that some may perceive in relation to open classes** (such as feeling able to remove a wig).

Some services offer one-to-one sessions with service users in the gym, leisure centre or home. Like closed classes these provide exercise tailored to the needs of PLWC, although sessions in public places do not offer the same level of privacy. This could be off-putting to some, although we have no evidence to confirm this.

They also provide an important source of mutual support. Closed classes allow service users to engage with others with similar conditions, who may have gone through similar experiences during their treatment journey. This can help to motivate service users to push themselves and sustain their participation.

But not all service users feel this way. Some prefer to engage in activities open to all and appreciated the 'normality' of such a situation. This underlines the importance of offering access to a range of closed and open sessions.

From our observations, it is clear that service users that had selected to undertake circuit session enjoy and value them highly and this is reflected in the high retention rates relating to attendance at these classes. It is not clear whether these sessions have been offered as a result of local need or whether circuits have been available from the start of the service and the service users have been mostly directed to them.

> *Well, I love the exercise.  So, even on days when I don't feel like getting out there and doing anything, you feel so much better afterwards, having done it.  So, it works regardless of if you've got side effects from chemotherapy, or are going through anything*
>
> — **Service User, Velindre**

Service users particularly value the fact that many of the circuits activities can be replicated at home, which make it easier for them to increase their overall fitness levels. Circuits also allow the instructor to adapt the exercises to the needs of individual service users. However, in some instances, service users felt that the level of activity circuit classes offered was too easy for them or that circuit classes were boring and they were not encouraged to undertake other activities by the Practitioner.

> *I got a wee bit fed-up with it because I could only do the exercises sitting down, and so I got just a bit bored actually, with having to put a foot in and do the arm exercises all the time.*
> — **Service User, Edinburgh**

Some were keen to push their limits in order to return to previous levels of physical activity and found the lack of variety or challenge in the exercises demotivating, and this caused these service users to stop attending. It is important that instructors provide personalised routines for each service user and consider whether some need more advanced exercises than others.

**Classes (and closed classes in particular) also offer an important opportunity for social contact and mutual support**. Many service users talk about the dramatic effect that treatment has had on their lives, and particularly about increased levels of fatigue. As a result, even those who were very active prior to diagnosis often spoke of experiencing isolation at points during their treatment pathway. Many place a high value on being able to socialise with others – and sometimes this is more important than the exercise itself.

> *I think that's one of the main reasons I went, was to meet other people that are feeling this way and going through whatever they're going through, and having people who know the answers to the questions you've got really and can sympathise with you.*
> — **Service User, Velindre**

> *One of the sessions that we have in Stockport… all the users know each other and it's got to the point where there is one lady that picks up three other ladies on route to the session. They weren't friends prior to the session, that's the friendship that they've developed throughout the session*
> — **Stakeholder, Manchester**

Some activities provide specific opportunities for service users to socialise as well as exercise. For example, the Nordic walking class in Antrim and Newtownabbey is followed by tea and coffee and a chance to chat. Particularly where they are delivering activities directly, services should consider how they can build opportunities for social interaction into activities.

While classes are open to men and women, in practice they appear to attract more women than men. Some services have introduced men-only sessions, which have proved popular. Four services, (Antrim and Newtownabbey, Dorset, Luton and Sheffield) introduced walking football to attract more men. One service reflected that men tend to prefer to participate in individual pursuits, such as the gym or swimming. This underlines the importance of ensuring that services have a clear understanding of the needs and wants of their service users and tailor their activity offer accordingly, providing access to a range of individual and group, closed and open activities.

## Health walks

Some services (Aberdeen, Edinburgh, Antrim and Newtownabbey, Shropshire and Luton) offer walking groups as a directly delivered activity for service users and many other services signpost to walking groups such as Walking for Health (England, Northern Ireland), Paths for All (Scotland) and Let's Walk Cymru (Wales). In Berkshire, for example, the service established good links with the four accredited Walking for Health Schemes across the county. In total 19 health walks were available on a weekly basis. This led to over 214 referrals to the walks in 2014.

In Scotland, walking is one of the four activity options available to service users. Initially Practitioners had offered closed walking sessions for PLWC only. However, take up was very low and attracting PLWC to attend these walks was difficult. As a result, services established relationships with general walking groups and provided them with volunteers who had received cancer specific training as well as walk leader training. These volunteers are able to then plan the walk according to the needs of the PLWC, for example by decreasing the pace or shortening the overall walk as required. While numbers of PLWC who attend these sessions are relatively low (there is insufficient demand to make a closed group sustainable), providing access to a general group in this way means that those PLWC who are interested in walking can attend whilst safe in the knowledge that there is someone there with appropriate knowledge and expertise if required. This illustrates how facilitating access to non-PLWC specific activities ensures individual interests can be met.

## Encouragement to increase activity in daily life / use of the Move More DVD

Macmillan does not define physical activity purely in terms of sport or organised exercise. This is clearly recognised by services and communicated effectively to service users during interventions and informal support sessions. Service users are asked to reflect on their level of activity and to consider opportunities to undertake home based activities such as gardening and walking. In Lincolnshire and Shropshire, in particular, this is a clear focus in their offer, and they make good use of the Macmillan activity DVD included in the Move More pack.

## Sports and other physical activities

Services report signposting PLWC to a wide range of physical activity opportunities. In the six phase one services (Sport England funded) alone, service users have been signposted to

64 different activities ranging from 'Back to Ballroom' to walking football. See Appendix 2 for a fuller list of these activities.

Some services highlight generic Exercise on Referral programmes as common activities that they refer service users to. These are usually (though not exclusively) run by local authority leisure centres and offer a 12 week supervised programme of activity that should be tailored to the needs of the individual. Schemes vary across the UK and not all service staff are able to refer individuals directly to a scheme (this means that PLWC have to approach their GP directly, which can be a barrier to sustaining or increasing activity levels). In some instances, Exercise on Referral programmes have been already heavily oversubscribed; this can lead to substantial delays between being referred and undertaking the activity. However, using this route, service users are more likely to receive an appropriate standard of care (although not cancer specific care) than they would from other external providers which are not formally assessed by Move More Practitioners.

## Incentives

A number of services have offered incentives to encourage the take up of activities. These have included a voucher scheme for carers of PLWC in Berkshire and football tickets in Manchester. We understand from staff that these incentives have proved helpful in generating participation and ensuring adherence, however we do not have any evidence to confirm this.

## National and local partnerships

A number of services have been effective in establishing partnerships with external physical activity providers. In some instances, these have been local relationships, brokered by the Move More practitioner. For example, three services (Sheffield, Luton and Dorset) have established relationships with professional football clubs and this has increased the scope of their offer. In Sheffield, a service user who is a member of the walking football group is now enrolled as a volunteer for the Sheffield United Community Foundation.

Macmillan, centrally, has also been instrumental in brokering national partnerships that have proved beneficial at the service level. For example, in 2017 Macmillan established a one year partnership with the Bowls Development Alliance (BDA) aimed at raising funds for PLWC and also encouraging service users to find out more about bowls and get involved in their local clubs. Since this partnership was established, GSTT have requested bowls equipment and now offer taster sessions during Health and Wellbeing events. In Dorset, the service, with support from Macmillan, has established a partnership with Table Tennis England and weekly sessions are held, staffed by volunteers, attracting an average of ten participants each week.

## The role of the instructor

**Well trained and approachable instructors and activity leaders are clearly critical to the success of any directly delivered activity**. For directly delivered activities, the instructor is usually either the Move More practitioner or a member of the service team. Service users highlighted the importance of having a good rapport with their instructor for their continued participation and enjoyment in the sessions. They told us that it is important for instructors to have an understanding of their illness and an understanding of their current fitness levels.

> *I would say, if [the service] is going to be rolled out nationally [the instructors] would have to be highly trained and well aware of what their charges are capable of.*
>
> — **Service user, Antrim and Newtownabbey**

Individuals that exercised on their own (either in a gym or at home) using a personalised routine require more ongoing support or contact with Practitioner to remain motivated to continue their activity. Practitioners report that without this support service users were more likely to revert to inactivity.  Conversely, individuals who received regular visits from their Move More practitioner or who attended group sessions were more likely to undertake sustained participation. In these latter cases, services users commented on the importance of the positive relationship they had with the practitioner. Practitioners were described as understanding and as not pressurising them.

Where services users occasionally reported negative experiences of activities, this was often due to what was perceived to be a lack of understanding on the part of the instructor (in some instances this was the Move More Practitioner, although this mainly related to activities not delivered by service staff). In some instances, service users felt that the instructor was not sufficiently aware of their condition and consequently were asking them to undertake exercises that were not possible in their condition. In other instances, particularly activities open to all, service users indicated that they did not feel confident undertaking particular activities led by someone that they, at least, felt was insufficiently trained. Ensuring that instructors understand the needs of PLWC is more easily achieved for activities delivered directly by services.

## Sub-group analysis

### Direct delivery and signposting models

As indicated in the previous Chapter, based on our observations, services that directly deliver activities tend to prioritise these over the signposting of service users to other activities. This is less of an issue for services that predominantly signpost rather than deliver services directly. Although, across all services, we observed no instances where the service user was offered a free choice of any activity outside the parameters of the menu of opportunities, based on our interviews, service users do not feel disappointed in the range of activities offered. However, this limitation does significantly restrict the extent to which the service can be considered a truly personalised one. We should also bear in mind that those we spoke to were service users who had engaged in the programme – those who may have been disappointed in the offer and dropped out were not represented in our fieldwork. Services staff indicated that a limited directly delivered offer can dissuade some people from engaging with the service.

All directly delivered physical activity offers are limited to a set number of *free* sessions (measured either in sessions or weeks). Typically, these offers range from five taster sessions (Northern Ireland services) to 12 sessions (Aberdeen, Berkshire, Edinburgh, Hertfordshire and Luton). However, in Manchester, the activity offer is open for 12 months, and service users in Northern Ireland can continue to attend classes for as long as they wish for no or minimal cost (£2.50 per session).

There remain practical barriers limiting participation in some activities. Service users continue to say that accessibility can be a deciding factor in regard to attendance. The location of activities can be a problem for those who lack their own transport and where public transport is expensive or patchy. It is encouraging to find that many services have improved their coverage of activities. However for many, achieving this has been a time consuming process and one that has required substantial negotiation to source venues that are appropriate and cost effective. The need for additional resources could affect sustainability and the availability of suitable venues will affect the possibility of scaling the programme up.

Most directly delivered activities are still only offered during the daytime and during the week. This will often preclude those service users who are working. One practitioner felt there would not be sufficient demand to sustain evening or weekend sessions as most of the service users were not in work at the time of referral.

On the other hand, signposting to services has the potential to open up a wider range of activities to service users – offered at a range of times and venues and on an on-going basis. By signposted services we mean any that are not directly delivered by services themselves. While all services have signposted service users to external physical activities, three (Lincolnshire, Sheffield and Shropshire) predominantly signpost service users, with very little, if any, activity directly delivered. Lincolnshire, in particular, has had considerable success with this model, achieving high levels of on-going engagement. Lincolnshire **actively assist services to access the activities signposted to and provide formal follow-up to ensure that the activity is right for them. This type of on-going support is important to make signposting models successful**. Lincolnshire argue that they are able to spend more time with each service user as they are not directly delivering substantial levels of physical activity themselves.

We did encounter a few instances in which service users of signposting only services would have preferred to be undertaking activities in a group setting but this did not appear to be offered. This reinforces the **need for a varied menu of opportunities to be available to ensure that service users are able to access a physical activity offer that is personalised to them**. Where popular activities are not already available for signposting, it is reasonable for services to consider providing them.

To ensure a signposting model is effective requires more concerted support from suitably trained Practitioners at regular intervals to ensure that the service user is undertaking an appropriate activity and has access to guidance about how to exercise in a way that is safe for them. It is particularly important that instructors at signposted activities have an understanding of the needs of people affected by cancer. This is why Lincolnshire Practitioners offer to attend the first session with the service user in order to ensure that the activity is appropriate. Providing this type of on-going personalised support for all would need to be adequately resourced.

All services, when signposting, need to consider the appropriateness of the activity for PLWC. Some services (for example, Dorset) offer Macmillan's LearnZone training in basic cancer awareness to third party instructors before signposting service users to them. However it is not possible to ensure that all external exercise professionals receive the required cancer awareness training. We encountered a few instances across the 14 services where service users felt that their instructor was not appropriately trained and consequently did not feel sufficiently supported or equipped with the correct guidance.

## Community, leisure and healthcare based models

**Services based in a leisure setting (for example Luton, Ards and North Down ) can benefit from being able to provide access (with reduced membership/fees and trained instructors) to a wider range of facilities and classes than those in a healthcare setting** - although the extent to which this happens in practice varies. Services based in a leisure setting are particularly useful for those who want to access a gym or a pool to work individually but would like some initial one-to-one support from trainers who understand their condition and can advise on appropriate exercise. Services led by leisure providers are also able to offer activities at a range of locations; this often makes the offer more accessible to service users.

> *We have 250- plus group fitness classes a week plus various swimming pools an athletics track and a golf centre.  So we are lucky that a lot of activities we can do in-house.  We also have very good links with our County Sports Partnership who offer different types of activities that we can try and push people toward in addition to what we already do*
>
> — **Stakeholder, Luton**

One of the Scotland services said that, if they were to set the service up again, they would focus on identifying the leisure providers first, ensuring that there was a wide geographical coverage on accessible transport routes and in close proximity to the healthcare centres referring the PLWC.

Leisure based services can also benefit from their closer links to other sports and leisure providers and organisations, including, for example, Community Sports Partnerships and the National Governing Bodies.

For services based in a healthcare setting (GSTT, Shropshire, Velindre and Berkshire) the range of direct delivery on offer is limited to closed circuit style activities for PLWC. Activities are provided for a set period, with little or no scope to extend this, and formal support usually ends at this point. In a few instances, PLWC attending the GSTT service have been offered extended access to the programme, but this has only been possible because there have been unused spaces in classes. Such extended access requires a transition from attending a directly delivered activity to attending an external community activity. However, organising this can be more difficult for healthcare based services than for those in a community or leisure setting, who often have good relationships with local activity providers. Some services noted that the transition from attending activities in a healthcare setting to attending a community based activity can generate anxiety in PLWC, particularly older service users, which can be difficult to overcome. **Users of services delivered by leisure organisations can often continue to access activities with reduced membership rates or nominal charges. The fact that these activities are often delivered by the same instructors as the free sessions means that access to informal support remains, and the transition is easy**. This is valued by service users and can help ensure that the activity is sustained.

It is possible for healthcare based services to provide access to a wide range of community based activities. In GSTT, the service has invested resources in identifying external physical activity providers in each of the London Boroughs it supports and in producing a booklet listing opportunities. However, it is not clear how effective this has been. Healthcare based services may need to invest more resources in identifying local opportunities and establishing relationships with leisure providers.

## Conclusions

Overall services offer access to a wide range of physical activities that are either delivered directly or provided by others. However, no services observed consistently offer access to all the activities that form part of Macmillan's minimum recommended offer. Some services that deliver activities directly place greater emphasis on promoting these. The physical activity offer is not always a personalised one.

Some services that deliver activity sessions themselves (predominantly circuits type sessions) tend to promote these as part of the intervention rather than providing a fully person-centred offer where the service user is asked what activities they are interested in and wish to participate in.

That said, circuits appear to be popular and are valued by service users in those that self-select their participation. This activity allows service users' access to tailored exercise appropriate to them that they can replicate at home. Closed sessions allow service users to exercise in a safe and private environment and provide important opportunities to obtain mutual support and encouragement from others with similar experiences.

There is no one size fits all physical activity. An appropriate offer is one that takes into account local facilities and services and provides activities at a variety of times and locations. Some service users prefer to engage in physical activities alone, rather than as part of a class; others appreciate the 'normality' of taking part in physical activities open to the public, while there are also those who prefer to engage primarily with other PLWC.

A key success factor is ensuring that instructors are knowledgeable about the physical activities and the needs of PLWC. They also need to be approachable and able to develop good rapport with a range of service users. This is much harder, although not impossible, to maintain where activities are signposted to, rather than delivered directly.

Services based in a leisure setting benefit from easier access to a wider range of classes and facilities which can make the transition from free sessions to continued activity more straightforward than it is in a healthcare setting. In some instances, activities can be offered as a free taster and / or at reduced rates with continued access to the same instructors; this helps to provide continuity.

Signposting can be an effective way of providing access to a wider range of activities than can be directly delivered and is therefore likely to be an important part of providing a personalised physical activity offer. But signposting requires that there be good systems in place to provide on-going support to service users, ensuring that they continue to be able to undertake physical activities that meet their needs. It also requires maps and paths to connect people and services.

## Recommendations

### Macmillan / Future funders

Macmillan or future funders should emphasise to services that physical activities should be offered/signposted in line with service users' needs and preferences. There is benefit in reiterating to new services that there is no requirement to have a local directly delivered activity and, with the right support mechanisms in place, signposting can be an effective means of providing access to a wider range of activity.

Where possible, Macmillan or future funders should continue to develop national level partnerships with sports and physical activity organisation National Governing Bodies as this helps to open up opportunities for services, locally.

### Services

Service users who express a desire to change behaviour should be encouraged to identify an activity that suits them. .. No matter what preference they have, Practitioners should do as much as possible to facilitate the service user’s choice. All decision making should be service user led.

Services should seek to facilitate access to as wide a range of physical activities as possible, including closed and open sessions, group and individual activities and activities undertaken as part of daily living. Services should review the profile of service users and consider how the portfolio of activities available may need to be adjusted to ensure it meets the diverse interests of users – for example, by ensuring there are activities likely to appeal to men, and ensuring wide geographical coverage. Services should identify activity providers before deciding if there is a need for directly delivered activity to fill gaps. Services that deliver activities directly need to ensure that the intervention explores service users’ physical activity preferences and interests and does not focus solely on promoting the particular activities that the service itself offers. This should include the negotiation of support activity and the continuation of activity after the end of free sessions.

All services when signposting need to consider the appropriateness of the activity for PLWC. If required Practitioners should work with external providers to ensure that they are appropriately trained and feel sufficiently supported to provide activities for PLWC.

Where activities are directly delivered, it is important that instructors provide personalised routines for each service user and consider whether some need more advanced exercises than others.

Services should consider how they can build opportunities for social interaction into activities.

# 06. On-going behaviour change support

*In this chapter we look at how services are meeting the Physical Activity Behaviour Change Care Pathway requirement to provide on-going support with behaviour change. We cover the provision of formal and informal support.*

## Key points

- Of the 14 services evaluated, only Lincolnshire offers a formal process of support and follow-up over a minimum period of 12 months.
- In almost all services, support is informal and based around the 'open door' principle. The nature of the contact varies with each service and with each service user.
- We encountered very few instances where service users indicated that they had not received sufficient support. In some instances, service users did not need or want any follow up support.
- Service users appreciate the availability of support, and they feel reassured that if anything went wrong, they could raise this with the trainer.
- Physical activity sessions offer a good opportunity to provide support and they allow staff to build up a strong rapport with service users.
- Practitioners generally perceive that their support offer is primarily focused on what happens during the delivery of activity. It is not clear that all understand that the support should be for a minimum of 12 months.
- The current delivery model adhered to by some services does not allow sufficient resources to provide formal follow-up for the potentially greater numbers of service users.

## On-going behaviour change support

The preferred Macmillan physical activity behaviour change model includes on-going behaviour change support for every service user. This support should occur at regular intervals for a minimum of 12 months. The key characteristics of this element of the Physical Activity Behaviour Change Care Pathway are:

- Long term support is agreed with the individual at the initial and any subsequent interventions.
- An automatic system is put in place for reviewing individual progress at regular intervals at a time/location suitable to the individual.
- Progress against goals is reviewed.
- A review of activity choice is undertaken– finding an alternative if required.
- A review of cancer status and any other changes is undertaken.
- Practitioners should use a tailored motivational guiding style.

As illustrated by figure 6.1 below, support should be provided during and after service users participate in activities.

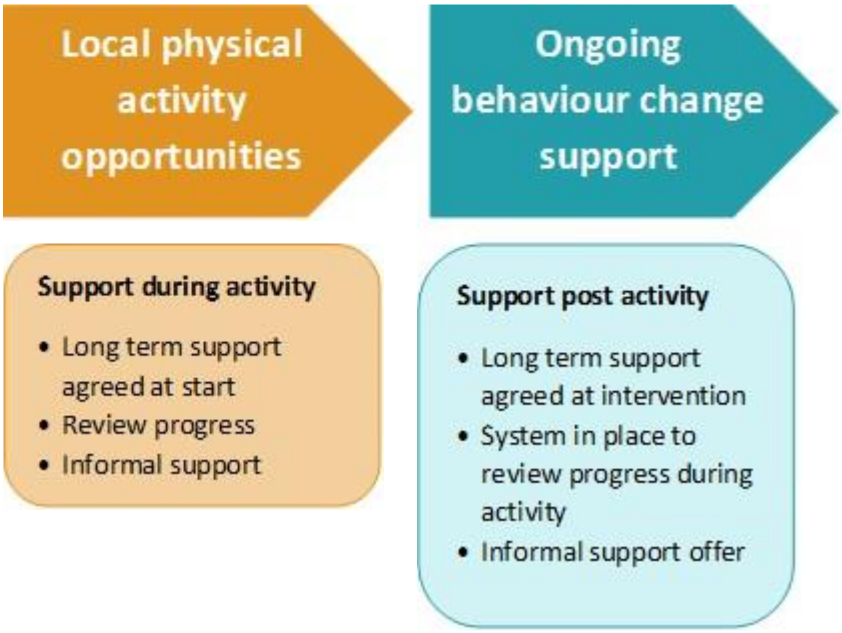


Figure 6.1: Overview of on-going behaviour change support requirements

## Behaviour change support provided by services

### Formal follow-up behaviour change support

**With the exception of Lincolnshire, none of the (other) services offer an automatic system for reviewing progress at regular intervals or a formal process of support and follow-up over 12 months**. By formal, we mean an interaction with the service user and practitioner that is planned and scheduled at the start of the behaviour change intervention and that this is offered consistently to all service users. We found no evidence that services (with the exception of Lincolnshire) agreed a long term support process with the service user at the initial behaviour change intervention.

In contrast to other services, Lincolnshire provides formal support over 12 months that is both flexible and personalised to the individual's need. During the initial intervention (undertaken in the service user's home) the practitioner discusses and agrees an appropriate support plan. This is not a fixed provision; the frequency and method of support varies depending on the individual's needs. Negotiating and agreeing support is a specific strategy of MI.

> *We base [the plan] on how much support [the service users] need, so it could be twice a month, it could be three times a month, could be once a month, could be once every three months, it depends on the person, because everyone's individual, and that's the only basis.*
>
> — **Staff member, Lincolnshire**

Follow ups in Lincolnshire tend to be face to face, again at the service user's home, though can also be over the phone if preferred. These meetings provide an opportunity for staff to gain a clear understanding of the individual's circumstances, to examine the progress that has been made and to revisit goals. Where service users are signposted to activities, staff attend the first session with the service user in order to provide initial support. Where possible, the support is provided by the same staff member throughout, in order to ensure continuity of care and build rapport; this is generally welcomed by the service user. There is a greater focus on the first three months of engagement; this is in order to develop the relationship – it is this period which is most labour intensive.

Lincolnshire's on-going, formal and relatively intensive support is likely to be the key factor in explaining their high levels of follow-up data. Service users may feel that they have a strong relationship with the service and are therefore more obliged to participate.

**Apart from Lincolnshire, the services cannot be considered to adequately meet the on-going support requirements of the Macmillan Physical Activity Behaviour Change Care Pathway or the evidence base**. The most noticeable consequence of this is the fact that Lincolnshire has much better longer-term follow-up data than other services. Without good data from other services it is difficult to ascertain the impact of the lack of formal on-going support on outcomes. NICE Guidance PH49 recommends that feedback and monitoring is provided for a minimum of 1 year in order to bring about long-term behaviour change. Without this ongoing support, service users may relapse to inactivity. Outcomes data reported in Chapter 8 shows activity levels are maintained, but this data is only for those who have completed questionnaires who are more likely to be those who remained engaged. Qualitative interviews with service users indicated some had stopped participating in physical activity, particularly as a result of changes to their health or returning to work.

**We encountered very few instances where service users felt that they had not received sufficient support. In some instances service users did not want any follow up support**.

In some services, the current delivery model does not allow for sufficient resources to provide formal follow-up for a substantial proportion of their service users. To be able to offer more substantial support would require additional resources, a reduction in service user numbers or the reallocation of resources from other activities, such as delivering classes.

## Informal follow-up behaviour change support

In almost all services, the support provided is informal and ad hoc and varies greatly between services and individuals. Formal support offers are not normally agreed at initial interventions. Instead, Practitioners clearly communicate that they can be contacted whenever service users require support and offer an open door policy.

> *You're given their contact number if you have any queries, or if you need to ask them anything. So, they are accessible if you need them. They will phone up as needs be.*
> — **Service User, Edinburgh**

Service users appreciate the availability of support, and feel reassured that if anything went wrong, they could raise this with the practitioner.

> *(The trainer) will keep in touch with me to see how I am, and he even invited me down for a coffee last week. I went down and had a chat about what I could do and what I couldn't do.*
> — **Service User, Antrim and Newtownabbey**

We observed many instances where the practitioner indicated that they would be in contact with the service user in 12 weeks to ‘see how they are getting on’. In these cases, it appears that Practitioners are using the requirement for data collection at three months as an opportunity to follow up with service users.

The nature of the informal support varies with each service and with each service user. In particular, support is adjusted according to the service user’s physical and mental health needs. Support is provided at face-to-face meetings, by phone, via text messages and via e-mail. Face-to-face support often takes place at the activity location or during a specific event such as a drop in session, taster session or a discovery day. There is no specific pattern of support discernible across the 14 services. No service employs just one, single approach, most have employed a variety of different methods, based on the preference of the service users.

Similarly, the type of support Practitioners provide varies. This can range from a very informal ‘how are you getting on’ conversations to a text message highlighting that support is available if the service user needs it.

## Behaviour change support during physical activity provision

Four services (GSTT, Edinburgh, Aberdeen and Berkshire) offer formal follow-up for the duration of all activities that they directly deliver. This follow-up is used to provide the service user with an opportunity to review the progress they have made against the goals set prior to attending the sessions and to adjust the levels of intensity of the exercises accordingly.

Staff in these services carry out a formal exit interview at the termination of the service-delivered activities, again re-examining goals and working with the service user to consider next steps. Reviews are thus an opportunity to discuss the exercises, following the end of the programme-delivered activities. This is valuable as a way of bridging the gap between finishing an activity and being signposted to another one (particularly where there are waiting lists).

Most services offer informal support as part of directly delivered physical activities, or support which is related to this (for example, one practitioner described how they might call a service user because of missed classes). As a minimum, the Practitioners generally endeavour to have a quick chat with all service users during the exercise sessions to see how they are getting on and to provide advice where necessary.

**Physical activity sessions provide a good opportunity to provide support**. The on-going nature of sessions allows service users to build up a rapport with the staff. Service users say that they feel fully supported and that they do benefit from the help. They told us that they were able to speak with the practitioner before, during, or after exercise sessions.

Most service users felt confident enough to follow the exercise regime while receiving only light-touch support from the Move More practitioner. Where service users raised concerns or had queries about their physical health or the exercises they were doing, services were able to provide the additional support necessary. For example, an elderly service user, who had other conditions (in addition to cancer) which affected their physical health, said that the staff member had made themselves available outside of the scheduled meeting times:

> *(The practitioner) did say 'I'm here if there are any other things or issues that come up, then please let us know,' and he would see what he could do to support me.*
> — **Service User, Lincolnshire**

This suggests that, at least during directly-provided activities, the support needs of service users are being met.

With the exception of Lincolnshire, we found no evidence that Move More Practitioners had put in place formal support procedures with those service users that they referred to external activities.

## Support post activity

When directly delivered physical activity sessions come to an end the support provided by services is reduced (and continues to vary between service and service user). In some cases service users receive no further communication from their Move More practitioner (except in relation to data collection). In other cases the practitioner maintains some level of contact.

Move More Practitioners generally perceive their service model as one that is designed around meeting the needs of the service user during the delivery of an activity and consequently support offers are principally focused on this period (more closely matching the exercise on referral approach). **It is not clear that all Practitioners see the programme offer as something that lasts 12 months**. This may be because services find it harder to move away from historic 12 week exercise on referral programmes. Almost all consider formal follow-up contact to be principally driven by the need for data collection. There may be merit in Macmillan revising the specifications for new services to ensure that the nature of the programme and the follow-up requirement is made clear.

Perhaps unsurprisingly, service users, like the service staff, tended to view the service as beginning with the intervention and ending after the completion of the physical activity. Few understood that it was a longer intervention and most thought the service was a fixed exercise programme. As a result, for the most part, services users did not view the reduction in support as problematic. Where contact with the Move More practitioner had ended, most of the service users were content with this because they had got the help they felt they needed from the project and had moved on with their lives. Furthermore, some people said that because they no longer needed qualified support that they would feel guilty using the service, perceiving that this would mean depriving someone else who could benefit more. Only in a minority of instances did we find that service users felt let down by the termination of support.

While Lincolnshire alone provides formal support for the full 12 months, there, paradoxically perhaps, the ending of support can come as more of a shock to service users – after receiving such high levels of support. This was not a common occurrence, but it appears that the process relating to exiting the service was not clearly communicated with them.

## Closing cases

Reasons for closing cases referred to the programme are collected but not consistently so across all projects and service users. For example, out of the 4,763 service users engaged to date, we have a closed case reason for only 1,173. Except in the case of GSTT, we cannot tell for certain whether the other service users are still engaged with the programme or not. The most frequently applied reasons for closing cases are as follows: the service users has completed the 12 months of the programme, is not contactable by the service, is already active, is unable to participate for health reasons (not cancer related), requires no further support.

## Conclusions

With the exception of Lincolnshire, services do not meet the Macmillan recommended pathway for providing formal support and follow-up over 12 months. Support tends to be informal, ad hoc and reactive to requests from the service users. Support is often provided as part of activity sessions delivered by the service. Once these end, opportunities for on-going support generally diminish. However, service users overwhelming felt they received the support that they needed and do not necessarily feel that anything is missing or that they necessarily required on-going support.

Not all Practitioners (or service users) understood the programme as one that lasts 12 months and some services did not have the resources to deliver formal on-going support for 12 months to all their users.

## Recommendations

### Macmillan / Future funders

Macmillan and /future funders should ensure that future services prioritise providing a formal support offer for a minimum of 12 months. This should be a personalised offer, appropriate to the service user, and in line with NICE public health guidance PH49.Services should be sufficiently resourced to provide ongoing support for 12 months.

There may be merit in Macmillan and future funders revising the specifications for new services to ensure that the nature of the programme and the follow-up requirement is made clear. Services should be sufficiently resourced to provide ongoing support.

### Services

Where possible, support should be provided by the same staff member in order to ensure continuity of care. There may be benefits in front-loading this support in order to establish a relationship with the service user.

# 07. Service management

*This chapter covers the key mechanisms used to manage the services. It covers staffing and the role of volunteers and steering groups, training, opportunities for networking, and case management systems.*

## Key points

- The Move More practitioner is responsible for raising awareness of the programme and conducting behaviour change sessions.
- Where there is no dedicated administrator, the practitioner is also responsible for managing the referral process in its entirety (including arranging appointments and follow-ups) and for collecting data.
- The one element of training that service staff feel is missing is that related to counselling and emotional support
- Active champions, particularly from healthcare backgrounds, are particularly useful to have on steering groups.
- Healthcare based services or those that mainly signpost service users may benefit from more representatives of the leisure and/or community sectors being present on their steering group in order to ensure that they can link effectively with a wide range of activity providers.
- Community and leisure based services may wish to focus on recruiting members that are most likely to help generate referrals.
- Practitioners welcome the networking opportunities that Macmillan provides.

## Staffing the service

The majority of projects are centred on the Move More practitioner role. With the exception of in Shropshire, the Move More practitioner role is a full time one. The role is often supported by service support staff and in some instances additional administrative staff. Here we outline the key roles and highlight areas of effective practice and learning.

### Move More Practitioner

**The practitioner is responsible for raising awareness of the programme and conducting behaviour change sessions**. They will also source, recruit and liaise with leisure providers (particularly in the community based model). **Where there is no dedicated administrator, the practitioner is also responsible for managing the referral process in its entirety** (including arranging appointments and follow-ups) and collecting data. In a number of services, the practitioner also delivers at least some physical activity. The practitioner is typically a trained exercise professional or a cancer specialist physiotherapist with a Level 4 Cancer Rehabilitation qualification and MI training.

Effective Practitioners are passionate about the role of physical activity and its benefits and are motivated to work with the client group and empathic towards their situation. They typically come from a physical activity background and have experience of engaging with people with similar long term conditions. In one service (GSTT), the practitioner is a specialist physiotherapist. Practitioners are highly-motivated, flexible and able to draw on effective influencing skills. They are able to support PLWC through the service by listening and engaging in an encouraging manner. Service users highly value receiving continuity of service directly from the practitioner.

Practitioners appear most comfortable when engaging with service users directly and tend to prioritise the needs of the service user over the more administrative aspects of the role such as data collection. There is merit in considering whether future services should include a dedicated post to undertake the more administrative tasks.

We found that across the services, practitioners have strong communication skills. However, we also found that it was rare that a practitioner had established effective relationships across *both* the leisure and the healthcare sectors. In most instances, the practitioner was most effective when operating in one of the sectors rather than the other due to their prior experience of engaging within that preferred sector. As regards the exceptions, the practitioner often had pre-existing relationships with *both* sectors which had been established prior to joining the service.

Practitioners often felt that they had underdeveloped programme/project management skills. Many come from a practitioner background which has not always provided them with opportunities to develop these skills. Consequently, some Move More Practitioners and stakeholders who were interviewed felt that they were on a considerable learning curve. Time management skills and the ability to prioritise service tasks were most commonly cited as potential development areas.

> *The biggest thing for me was time management, I was always used to sticking to rotas and booking sheets and being told when and what I was going to be doing. Whereas now it's very much a case of okay where do I fit these people in, where do I keep myself some down time to do my admin? Time management was the biggest change for me.*
>
> — **Move More Practitioner**

As discussed in Chapter 4, despite the support provided by Macmillan, Move More Practitioners require further opportunities to improve their behaviour change and MI skills. We recommend that a package of support that includes on-going training opportunities and supervision must be provided to all future Move More Practitioners.

## Support staff

In addition to the Move More practitioner, some projects also involve administrative and project support staff (for example, support assistants, fitness instructors). These staff roles support the Practitioner and can involve a variety of tasks. In both Scottish services, for example, the support staff deliver behaviour change interventions by telephone. People in support roles can be particularly effective for delivering physical activity sessions. Services have recruited staff with the background and the attributes necessary for delivering engaging activities that PLWC clearly enjoy. However, based on our observations, support staff appear to be less effective in carrying out the behaviour change interventions – particularly the interventions conducted over the telephone in Scotland – and should not undertake this task without further training. Whilst most have received some form of MI training, it is evident that staff in support roles are less experienced than Practitioners and consequently received lower scores against the BECCI tool.

> *You know, occasionally a more junior member [of staff] will come along and you can tell the difference, because they may not be motivating people in the same way as someone that's very energetic and personable would. I guess that's just a learning curve as well though. They have to learn how to do that.*
>
> — **Stakeholder, GSTT**

## Service lead

The service lead (where this role exists) typically line manages Practitioners and is responsible for the strategic direction and contract and budget management of the service. This role is not always a funded component of the service (their time is given 'in kind') and consequently leads will likely spend only a limited amount of time on the service, alongside other projects. In some instances, for example in Luton, this role has largely been subsumed within the practitioner role as the service has grown.

## Volunteers

Volunteers are an integral part of service delivery in Scottish Move More services (Aberdeen has 25 and Edinburgh has 12), and both services have made a considerable investment in providing training. Volunteers deliver three of the four activity options available to service users (these three are gentle movement, walking and gardening). Only the circuit class is delivered by an exercise professional (assisted by a volunteer). The volunteering opportunities are clearly popular, as demonstrated by the very low turnover of volunteers experienced by both services - Aberdeen have never advertised for volunteers and have a volunteer waiting list of 150 people.

All these volunteers receive core training. This covers information on Macmillan, how to engage with PLWC and other key issues. The training lasts approximately half a day and is delivered by the service team. Additional training is dependent on the type of activity that the volunteer will undertake. The most comprehensive training is for the gentle movement class – this requires 20 hours and an external trainer. A minimum of six people need to undertake the training to make it viable. This can prove logistically challenging for services and consequently they have to coordinate with other Move More services to generate sufficient numbers. A train the trainer approach might help to make this more sustainable.

> *So sometimes you're having to coordinate that across maybe four or five projects, to be able to actually put on one of the training courses. We're quite keen for that to become more sustainable, so perhaps by having a train the trainer model, where we can get somebody local trained up to be able to deliver that one when we need it.*
>
> — **Service Staff, Aberdeen**

Other services use volunteers, although to a lesser extent. In Antrim and Newtownabbey, for example, the walk leaders for the Nordic walking sessions are volunteers. The Macmillan brand is so well recognised that people come forward and volunteer to support services. Volunteers are typically retired people or they are students seeking to gain work experience. Many of the volunteers are motivated to be involved as they want to give back to the programme, having participated themselves or because they have a personal or family experience of cancer.

A small number of services have involved ex-service-users as project champions. **Service-user advocates are a powerful way to advertise the service to PLWC**. We have observed several instances where service users have talked about their personal experiences to PABC at Health and Wellbeing events. This has sparked debate and interest amongst attendees. We recommend that services actively involve PLWC in promoting the service they are using, wherever possible.

Service users are also sometimes involved in overseeing services including, for example, in Shropshire and Manchester, where service users sit on the service steering group.

### Steering groups

All services have steering groups that provide oversight for the service, although the frequency with which these groups meet and their effectiveness varies. A steering group that works well was seen as vital by interviewees. **Active champions, particularly from healthcare backgrounds, are particularly useful to have on steering groups**. Almost all Move More Practitioners felt that at least one member of the group had been able to open doors and achieve things they would not have been able to achieve otherwise.

> *Having their lead nurse and one of their clinical nurse specialists in the steering group, as a champion for the service, has really encouraged the hospital team to make referrals and they are key to selling this project to people diagnosed with cancer.*
> — **Macmillan Development Manager**

Steering groups include a wide range of roles, including PLWC, CCGs, Macmillan Information Centre managers, representatives from public health bodies and strategic decision makers. Across the services however, the most commonly cited steering group members were:

- a Move More practitioner;
- a local Macmillan representative;
- at least one healthcare staff member – most commonly a CNS or Lead CNS;
- a host organisation representative; and
- at least one activity provider (for example, a local leisure provider).

**There is no one size fits all model of the ideal steering group as this is heavily dependent on the delivery model and local conditions**. For example, healthcare based services or those that mainly signpost service users may benefit from more representatives of the leisure and/or community sectors on their steering groups to ensure that they can link effectively with a wide range of activity providers. On the other hand, community and leisure based services may wish to focus on recruiting members that are most likely to help generate referrals.

## Staff training and skills

All Move More Practitioners have completed the Level 4 in Cancer Rehabilitation training (whether they directly deliver a session or not) and most relevant service support staff have done so too. All Practitioners have received training in MI. While some had prior experience gained in other roles, those that had undertaken the MI training offered by

Macmillan found it to be positive. While some had attended refresher training, a number of interviewees indicated that it would be beneficial for them to access further MI training in order to redress bad habits and discuss good practice with others.

> *Assuming that everyone was going to be re-trained in sufficient MI just by putting on that three days, I think is a bit naïve. I think there should have been follow ups and regular, sort of, top ups, training on that.*
>
> — **Service staff. Sheffield**

**The one element of training service staff feel is missing is that related to counselling and emotional support**. Several service staff felt it would be beneficial to access training that would support both their own emotional needs in the role (for example, when a service user passes away) as well as those of the service users.

Services spend a significant amount of time persuading HCPs and other key stakeholders such as Macmillan information teams, to refer potential service users to the service. Macmillan have developed 'Very brief advice training (understanding physical activity and cancer) 'to help HCPs to encourage PLWC with very brief advice intended to motivate them to make a lifestyle change. Overall the training was viewed as very useful, but the impact was limited by the number and types of HCPs that attended and the frequency with which this training is provided (although it is also available online as a webinar). Services had mixed success in recruiting large numbers of HCPs to attend the training. Macmillan provided training locally for phase one services to encourage as wide an attendance as possible, and in some instances Practitioners undertook 'train the trainer' training which was trialled by Macmillan in 2016. Attendance has varied across the services and seems to reflect the extent to which the particular service is embedded within the healthcare setting. We found few instances across services where the training had been held more than once. The levels of staff turnover and staff availability are such that Macmillan should consider ways to make the 'Very brief advice training' available in a variety of formats and on a more frequent basis for local HCPs.

Move More Practitioners were often aware of the package of online resources available through LearnZone, and in some instances they were aware that it was available to HCPs and had promoted it to their colleagues. However, we encountered few instances where this resource had been used by the Move More practitioner themselves; mostly this was due to lack of time.

## Project networking

Cluster meetings are compulsory events that Move More Practitioners in England must attend. In Scotland and Northern Ireland, services attend communities of practice which are run by the services. In both types of meetings, services enjoy the opportunity to hear what others are doing and they find the wider Macmillan updates particularly valuable.

Overall, Practitioners view attending the meetings as an effective way for them to improve their service delivery. For some, the ability to share ideas and discuss good practice with local services is particularly valuable.

> *it's a really good opportunity for us to look at okay what's not working for us but might be working for somebody else in their model. What can we basically take pieces of each other's services to make eventually what should be one whole model that everyone will follow in the future.*
>
> — **Move More practitioner, England**

Some of the earliest established services find the sessions less useful as they tend to 'lead the way' with lessons learnt and best practice, and so they learn less at these meetings that they feel they could implement. Conversely, projects that started later find the meetings more helpful and are keen to implement the learnings imparted, in their own projects. For example, Hertfordshire felt they were doing well in their marketing efforts but were unable to 'crack' access to GPs. In one cluster meeting they learnt that another Move More service had been able to get a 'pop-up' on their local GPs systems.

The meetings are also effective ways for Macmillan to promote national programmes and opportunities that services may wish to participate in. For example, GSTT signed up to participate in the 'Just Bowl' programme that is offered through the Macmillan Bowls Development Alliance partnership, which was first promoted through these meetings.

Knowledge exchange workshops are centrally run by Macmillan across the UK. Services from Scotland and Northern Ireland found these more useful than the English services did since they had few other opportunities to engage in networking activities. In regard to one service, the Move More Practitioner indicated that through attendance at such a workshop they had established an effective working relationship with another service practitioner. They appear to be of most use to those Practitioners that are not able to attend cluster meetings in England. In Scotland, for example, we encountered instances where Practitioners received guidance on new methods of behaviour change delivery which they would not necessarily have been aware of otherwise.

> *They are really worthwhile, even though it takes a lot of travel to get there, again, just being able to talk to other projects. I got some good ideas from a team over in Northern Ireland, which I would have never come across otherwise. They tend to give you a bit of an update around the research, and updates around the national evaluation as well, which is good to know, just how things are progressing. I'll certainly be going along to the next one.*
>
> — **Move More Practitioner, Scotland**

Practitioners from English services were more likely to tell us that that they found workshops 'useful, not vital'. This view is reflected in the quotation below.

> *It's interesting to go, but from a learning perspective I think probably there are times that it's limited. Not always but there are times when it's limited.*
>
> — **Move More Practitioner, England**

## Case management

The majority of services use the VIEWS system as their primary data recording tool. Services feel that its functionality has been much improved since its introduction and it is considerably more user friendly than it was. Staff are particularly glad of the new ability to flag service users who are due for data collection follow-ups. However, as the flagging function is relatively new, many services had already set up their own trackers in Excel and have continued to use these. Of services which did not use VIEWS, all (bar Lincolnshire who have commissioned a bespoke system to enable data collection by tablet) would be happy to switch to VIEWS but would require considerable resource to transfer existing data. While, for Practitioners in these services, using their existing system was not seen to be a particular barrier, data management protocols (for example, back up and data security policies) varied considerably across services. In at least one instance, a considerable amount of data has been lost. Robust data security policies and practices should be a pre-requisite for funded services in the future.

We explore the challenges the services experienced in collecting, monitoring and evaluating data at length, in Chapter two.

## Local challenges to service delivery

The 14 services are situated across the UK and while some experience unique challenges a number share similar issues.

### Geography

The principle challenge is geography. Services such as Lincolnshire, Shropshire and Velindre cover wide rural constituencies. In Lincolnshire's case it can take over an hour for a practitioner to travel to attend an appointment (even with two Practitioners to cover the county). Lincolnshire offers initial interventions (and follow ups if desired) at the service user's home. This is a key enabling factor in establishing long term engagement with the service. Home visits remove any potential transport difficulties that may arise for the individual. The fact that the practitioner visits them also appears to substantially reduce the number of cancelled appointments. It also helps to relax the individual and establish lasting rapport.

> *They relax more, and they talk to you more, and we've got more time. You can sit there for an hour, and the first half an hour is probably just sometimes it's a little bit of chit-*

> *chat, try and make them feel comfortable, and they're just getting to know you, then they open up to you. So, I think it really opens up that, I suppose, ability to build rapport with them, and for them to get to know you*
> — **Service staff member, Lincolnshire**

In some instances (Shropshire and Lincolnshire) the size of constituency is such that directly delivering activities is not practical. Instead, the focus is on finding ways to encourage service users to become more active. This includes signposting to appropriate activities as well as helping service users to become more active as part of their everyday routine.

In other services, distances to centres where activities are offered is less of an issue than is access to, and the cost of, transport. Where transport is a barrier, community-led services that are able to offer a range of locations for both the behaviour change intervention and the activity sessions are welcomed by service users.

### Complexity of local healthcare provision

The complexity of local healthcare provision can be challenging for some services. In Berkshire for example, the service had to negotiate across seven CCGs, two NHS Trusts and six local authorities. This kind of activity can be time consuming and particularly challenging for community and leisure based services. Even when undertaken by healthcare based services it can be problematic. For example, the Velindre service accepts referrals from three other health boards as well as from their own. The practitioner has worked hard to establish relationships with all the health boards involved. In GSTT, the constituency covers a range of local authorities, each with their own regulations with regard to offering activities on referral. This has made it harder for the service to provide timely exit pathways for community led activities. In Aberdeen, the constituency served by the healthcare trust is wider than the constituency of the service. Here we found instances where HCPs referred individuals to the service who were not then able to join, which was problematic. Improved communication with the service constituency is required to ensure that HCPs remain encouraged to refer into the service.

## Conclusions

The Move More practitioner is the principal delivery role within the services and in some instances it is the only delivery role. This role is often responsible for a wide range of tasks and consequently we have found cases where this has proved to be impractical. Practitioners are often skilled at, and motivated by, engaging and supporting service users and tended to prioritise the fulfilling of service users' needs over other aspects of the role. Practitioners appear to be less comfortable when undertaking project management, administrative and data collection activities.

As services grow in popularity, administrative tasks become more time consuming. Getting the practitioner to do them does not necessarily represent good value for money. Dedicated administrative support could potentially free up resources so that the practitioner can spend more time engaging and supporting service users and this could help to improve the quality of data collection.

It is rare to find a practitioner that is effective in engaging in both the healthcare and the leisure settings. Where this does occur, it is often due to relationships established prior to the service being established.

Practitioners welcome the networking opportunities that Macmillan provides. Cluster meetings/Communities of Practice are considered by most as effective conduits by which ways of improving their service delivery can be communicated – by sharing ideas and discussing good practice. Knowledge exchange workshops are also viewed positively by Practitioners, particularly those from Scotland.

The one element of training service staff feel is missing is that which relates to counselling/emotional support. A number of service staff felt that it would be beneficial to access training that would support both their own emotional needs in the role (e.g. when a service user passes away) as well as those of the service user.

Despite considerable additional support provided by CFE and Macmillan throughout the evaluation, the quality of data varies considerably across the 14 services and across different aspects of the minimum dataset. Services found completion of the survey at follow-up sampling points particularly challenging, and this is reflected in the high non-response rates. The quality and completeness of the data limits the analysis that is possible as a result. Data collectioon is seen as a time consuming task, and one that is considered of low priority in a number of services.

## Recommendations

### Macmillan / Future funders

Macmillan and future funders should continue to make the Cancer and Physical Activity training available in a variety of formats and on a more frequent basis for local HCPs so that they are better able to and more inclined to deliver very brief advice on physical activity to their cancer patients.

Macmillan and future funders should continue to provide services and Practitioners with opportunities to network with each other and share best practice. These opportunities should be provided by a mixture of regional and national events and offer something for both new and well established services.

Where a minimum dataset is to be used in future, data collection should be a condition of grant. Questionnaires should be standard across all services, including common response scales, question ordering and layout.

If data collection is to remain a key part of the Physical Activity Behaviour Change Care Pathway, this needs to be appropriately resourced. Staffing models need to include dedicated and specialist time for supporting service users in completing the questionnaire; for chasing follow-up; and for entering, cleaning and analysing the data. Alternatively, Macmillan may wish to outsource data collection to an independent data collection agency.

Macmillan and future funders should consider whether there is scope for providing further guidance to services on the rationale behind the questionnaire and on how they should communicate this to service users.

Macmillan should ensure that all services understand that the questionnaire should be self-administered by service users. Services should be supported and encouraged to use the online version of the questionnaire with service users completing the questionnaire on a tablet device if necessary.

Services should be supported and encouraged to make use of the questionnaire data for planning, improving and sustaining their services, as this is likely to lead to services valuing data collection more. Services that have effectively used the data should be facilitated to share their approaches and their results with others who have yet to exploit the data available in order to provide ideas and inspiration. Services will require access to analytical expertise in order to effectively use the data.

Robust data security policies and practices should be a pre-requisite for funded services in the future.

### Services

We recommend that services separate the Move More practitioner role from other more administrative tasks such as data entry and data collection.

Healthcare based services and those that mainly signpost service users, may benefit from having more representatives of the leisure and/or community sectors on their steering groups, in order to ensure that they can link effectively with a wide range of activity providers. Community and leisure based services may wish to focus on recruiting members that are most likely to help generate referrals.

Services should consider using the online version of the questionnaire. This could involve service users self-completing the survey on a tablet provided by services as part of the initial intervention process or in follow-up sessions.

Services should consider adopting a more strategic approach to reminding service users to complete follow-up questionnaires. This should include calling service users at different times and/or on different days, in order to boost response rates.

# 08. Outcomes and impact

*In this chapter we explore the outcomes for, and the impact on, services users, in terms of physical activity levels, sports participation, health and quality of life.*

## Key points

- Many of the programme's service users were previously active, prior to diagnosis. However, a substantial proportion of questionnaire respondents (32 per cent) said they did 'very little' sport or exercise prior to diagnosis.
- Overall, in relation to those who provided data at start and follow-up points, we see statistically significant increases in physical activity levels.
- The most substantial increases in activity levels take place during the early stages of participation in the service.
- Most service users talked about the positive difference in their levels of activity, as compared with their levels during diagnosis and treatment.
- Service users acknowledge that the Move More programme has helped speed up the process by providing opportunities for, and also advice about, exercise at the level appropriate to their condition.
- Service users hold the support of Practitioners in high regard. In particular service users value the fact Practitioners understand how cancer affects physical abilities.
- For those who provided data at baseline and follow-up points we also see statistically significant, if small, improvements in quality of life, perceived health, and reductions in fatigue. Again, the largest improvements are seen over the first three months.
- Service users felt that, overall, their energy levels are higher than before they participated in the programme.
- Other benefits reported by service users include greater ability to cope with symptoms and co-morbidities, increased confidence, improved self-esteem.

## Physical activity levels

### Prior activity levels

**Many of the programme's service users were previously active prior to diagnosis**. Most (61 per cent) of the service users who completed the questionnaire said that they did either 'a lot' or 'a moderate amount' of sport or exercise in the five years leading up to their diagnosis. This is reflected in the interviews with service users, many of whom said they led an active lifestyle prior to their diagnosis of cancer; they regularly engaged with physical activity and understood its benefits.

For this group of service users, being active prior to diagnosis is linked to their motivation to get involved in the programme. For many, their aim was primarily to regain a part of their life that would provide them with a sense of 'normality'. However, they wanted help and advice in order to understand how to tailor work-outs and activities to their changed abilities following diagnosis, and to understand how activities could fit alongside their treatment and recovery. Service users spoke about mentally wanting to achieve their former levels of fitness but acknowledging that in reality this was not possible:

> *I was quite an active person and obviously you hold back a bit because you don't want to [do] too much too quickly. Even though your mind wants to do it, your body doesn't flow if you're not fit.*
> — **Service User, Manchester**

The programme offers service users the opportunity to better understand their new physical abilities and constraints and work within them.

**A substantial proportion of questionnaire respondents (32 per cent) said that they did 'very little' sport or exercise prior to diagnosis**. We also found this to be the case during some of the interviews with service users. Motivations for becoming more active for these service users varied but were often related to their cancer diagnosis and a desire to give themselves the best chance of recovery. For some, the diagnosis had been a 'light-bulb' moment, causing them to want to change their lifestyles. This aligns with literature that indicates a cancer diagnosis can provide a 'teachable moment'.[92]

---

[92] Rabin C. Promoting Lifestyle Change Among Cancer Survivors: When is the Teachable Moment? A*merican Journal of Lifestyle Medicine*. 2009;3(5):369–78.

> *I'd stop off after work and have a few pints on the way home, smoked, ate all the wrong things.  Now, I mean, obviously I don't smoke.  I still have a drink but very occasionally, and I eat very, very healthily.  Like I say, my view of life now is keep yourself as fit and healthy as possible, which I wasn't doing prior to that.*
> — **Service user, Manchester**

For some previously inactive service users, a lack of time in which to undertake physical activity, alongside work and family life commitments, had acted as a barrier. For these individuals, the diagnosis had given them pause to reflect and to then prioritise physical activity.

**Levels of physical activity on engaging with the programme, based on the self-reported Scottish Physical Activity Questionnaire (SPAQ) measure are generally high**, even after we excluded those reporting more than 1,400 minutes per week. The average (mean) number of minutes of physical activity per week was 345 (n=2,607) – almost six hours. Most people (69 per cent, n=1,786) reported doing over 150 minutes of activity per week at the start. Thirteen per cent (n=328) were classed as inactive, undertaking less than 30 minutes of activity per week. This is a much lower proportion than those who said they did 'very little' sport or exercise prior to diagnosis. This may be because people often do not consider some of the types of physical activity counted by SPAQ (for example, housework and walking at work) as sport or exercise.

The physical activity levels reported are considerably higher than what we might expect in a health age matched population sample. Over-reporting of physical activity is not uncommon and self-reported physical activity is often quite high (including when measured with tools like the SPAQ). We have recorded high physical activity levels throughout this evaluation. It was for this reason that the objective measure pilot studies (see page 42) were instigated, and it will be interesting to see how levels of activity measured using the accelerometers compare to self-reported levels.

However, while the figures are high, the same instrument is used at each sampling point. Thus, while the absolute values may be inaccurate, the relative difference should provide an indication of change, although high starting levels do limit the scope for change. The results show a clear increase in physical activity levels and reductions in inactivity, following engagement with the programme.

## Changes in activity levels

The overall average (mean) minutes of physical activity per week increases by 130 minutes to 475 (n=1,112) at three months. It increases by a further 34 minutes to 509 (n=580) at six months, with another small increase of 12 minutes to 521 minutes (n=305) by 12 months. These figures are only for service users who responded to all the questionnaires, and therefore do not necessarily provide an accurate reflection of behaviour change. For example, if those who are least active drop-out and do not complete the follow-up questionnaire this will result in increased averages.

We address this by looking at the same group of people (the 'completers') at each sampling point, although this inevitably reduces the base number of service user responses. This 'completers only' approach allows us to track the changes in behaviour of those who did provide sufficient data and thus understand the extent to which the intervention has the potential to change behaviour and outcomes. However, the limitation of this approach is that the service users who provide data at all sampling points are not necessarily representative of service users as a whole. They may be more motivated to engage with the service and to change their behaviour. Accordingly, the results may overestimate outcomes. The economic analysis in the following chapter takes a more conservative intention-to-treat approach when analysing the data.

Table 8.1 below shows **statistically significant (p<0.01) increases in physical activity levels for those who provided data at start and 3 months (340 minutes to 472 minutes, n=982), start and 6 months (340 minutes to 509 minutes, n=519) and start and 12 months (from 364 minutes to 526 minutes, n=260)**.

| | N | Mean start | Difference |
|---|---|---|---|
| **Start & 3** | 982 | 339.97 | 132*** |
| **Start & 6** | 519 | 340.27 | 168.58*** |
| **Start & 12** | 260 | 364.28 | 161.5*** |

**Table 8.1: Mean changes in minutes of physical activity per week for service users who completed the questionnaire at start and 3 months, start and 6 months and start and 12 months.[93]**

The increase of 132 minutes activity between baseline and 3 months is less than the 182 minutes increase from baseline at 12 weeks found by the evaluation of a 12-week supervised exercise programme for women being treated for early stage breast-cancer.[94]

Table 8.2 compares levels of physical activity for the 982 service users who completed both the baseline and the 3-month follow-up survey. Physical activity is grouped into four categories (29 minutes a week or less, 30 to 89 minutes a week, 90 to 149 minutes and 150

---

[93] Asterisks indicate significance level of the two-sided t-test of the difference in means for a paired sample. *** p<00.01%, ** p<00.05%.

All beneficiaries with an overall SPAQ score greater than 1400 have been excluded from the analysis.

[94] Mutrie, N. Campbell, A. Whyte, F. McConnachie, A. Emslie, C. Lee, L. Kearney, N. Walker, A. and Ritchie, D. (2007) Benefits of supervised group exercise programme for women being treated for early stage breast cancer: pragmatic randomised controlled trial. *BMJ* http://www.bmj.com/content/334/7592/517

minutes or more a week). The cells are colour coded to show those whose activity levels moved up to the next category (green), those whose activity levels remained broadly the same (orange) and those who dropped into a lower category of physical activity level.

We can see that most were already very active and remained so at 3 months. Of those who were inactive at baseline, 15 per cent (n=15) remained so at three months, while 60 per cent (n=60) were reporting 150 minutes or more of activity per week. Among those who were very active at baseline (150 minutes per week or more) nearly all (93 per cent, n=627) remained so at three months. Just 2 per cent (n=13) had dropped to being inactive. Most of those who reported baseline activity levels of between 30 and 149 minutes had increased their levels at three months – and many had increased their activity levels to over 150 minutes.

| | | Activity at 3 months | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Minutes exercise per week | | 0 to 29 minutes | | 30 to 89 minutes | | 90 to 149 minutes | | 150 minutes or more | |
| | | Count | Row % | Count | Row % | Count | Row % | Count | Row % |
| Activity level at start | 0 to 29 (n=101) | 15 | 14.9% | 16 | 15.8% | 10 | 9.9% | 60 | 59.4% |
| | 30 to 89 (n=99) | 7 | 7.1% | 19 | 19.2% | 10 | 10.1% | 63 | 63.6% |
| | 90 to 149 (n=104) | 4 | 3.8% | 6 | 5.8% | 12 | 11.5% | 82 | 78.8% |
| | 150 + (n=678) | 13 | 1.9% | 14 | 2.1% | 24 | 3.5% | 627 | 92.5% |
| | Total (n=982) | 39 | 4.0% | 55 | 5.6% | 56 | 5.7% | 832 | 84.7% |

**Table 8.2: Comparison of activity levels between start and three months**

Tables 8.3 and 8.4 provide similar analyses between baseline and 6 months and baseline and 12 months. Again, we see a similar pattern of most service users maintaining or increasing their activity levels (in many cases to over 150 minutes). Among those inactive at baseline and who completed the 12 month survey, none were still inactive at this point.

| | | Activity at 6 months | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Minutes exercise per week | | 0 to 29 minutes | | 30 to 89 minutes | | 90 to 149 minutes | | 150 minutes or more | |
| | | Count | Row % | Count | Row % | Count | Row % | Count | Row % |
| Activity level at start | 0 to 29 (n=61) | 4 | 6.6% | 6 | 9.8% | 6 | 9.8% | 45 | 73.8% |
| | 30 to 89 (n=42) | 1 | 2.4% | 6 | 14.3% | 8 | 19.0% | 27 | 64.3% |
| | 90 to 149 (n=60) | 2 | 3.3% | 1 | 1.7% | 3 | 5.0% | 54 | 90.0% |
| | 150 + (n=356) | 3 | 0.8% | 4 | 1.1% | 11 | 3.1% | 338 | 94.9% |
| | Total (n=519) | 10 | 1.9% | 17 | 3.3% | 28 | 5.4% | 464 | 89.4% |

**Table 8.3: Comparison of activity levels between start and 6 months**

|  |  | Activity at 12 months |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|
|  | Minutes exercise per week | 0 to 29 minutes |  | 30 to 89 minutes |  | 90 to 149 minutes |  | 150 minutes or more |  |
|  |  | Count | Row % | Count | Row % | Count | Row % | Count | Row % |
| Activity level at start | 0 to 29 (n=30) | 0 | 0.0% | 5 | 16.7% | 3 | 10.0% | 22 | 73.3% |
|  | 30 to 89 (n=22) | 2 | 9.1% | 2 | 9.1% | 2 | 9.1% | 16 | 72.7% |
|  | 90 to 149 (n=23) | 1 | 4.3% | 3 | 13.0% | 0 | 0.0% | 19 | 82.6% |
|  | 150 + (n=185) | 7 | 3.8% | 1 | 0.5% | 5 | 2.7% | 172 | 93.0% |
|  | Total (n=260) | 10 | 3.8% | 11 | 4.2% | 10 | 3.8% | 229 | 88.1% |

**Table 8.4: Comparison of activity levels between start and 12 months**

Figure 8.1 illustrates the proportion of survey respondents at start and 3, 6 and 12 months whose activity level broadly increased, decreased or remained the same.

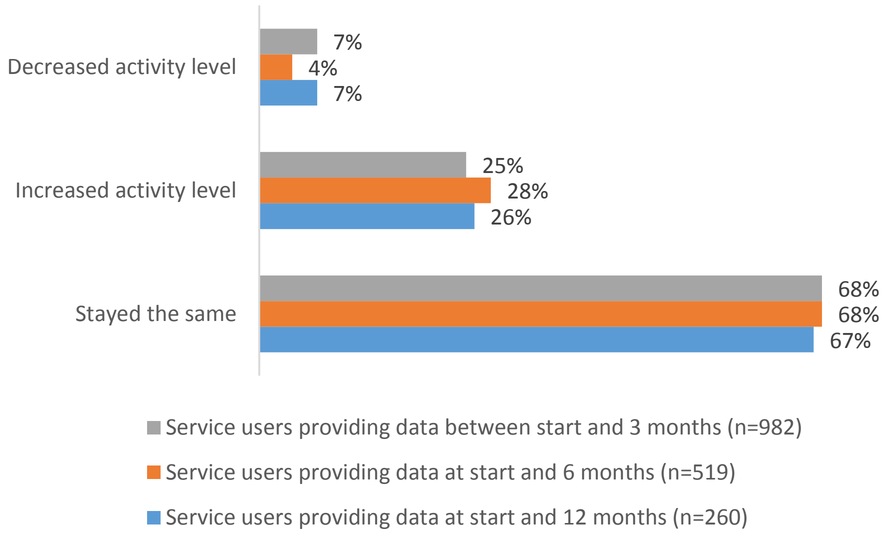


**Figure 8.1: Proportion of service users providing data that change in category of activity level**

If we look at the 160 people for whom we have survey responses at all four sampling points, we see a similar pattern – see figure 8.2. They report an average (mean) of 330 minutes per week at the start, increasing by 152 minutes at three months, by a further 40 minutes at six months and then declining slightly by just 9 minutes at 12 months. This demonstrates that the most substantial increases in activity levels take place during the early stages of participation in the service.

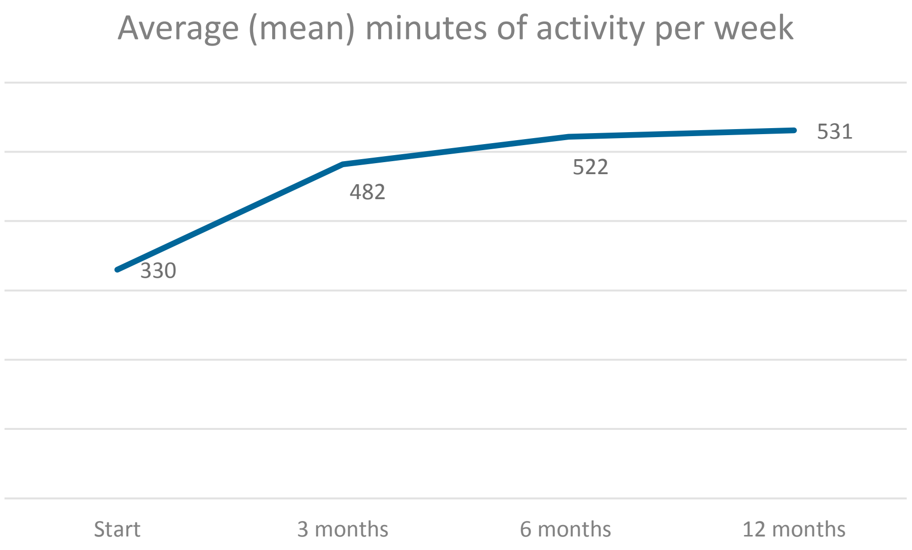


**Figure 8.2: Average (mean) minutes of activity per week for service users providing data at all 4 sampling points (n=160)**

### Sub-group analysis

Except for service users in Northern Ireland, where the sample sizes are small and between start and 12 months within the healthcare model, sub-group analysis of physical activity levels demonstrated statistically significant improvements in physical activity levels for all sub-groups (nation, community / healthcare models and signposting / direct delivery models) between start and 3, start and 6 and start and 12 months ($p<0.01$ for all): see tables 8.5, 8. 6 and 8.7 in Appendix 3. Increases in mean minutes of physical activity of 97 minutes or more were seen between start and three months, start and six months and start and twelve months. As a result, it is difficult to use this information to demonstrate that any one particular model is more or less effective in increasing physical activity.

The SPAQ results are very positive, but we must remember that the survey responses are not necessarily representative of the entire population of people participating in the programme. People with a positive experience may be more likely to complete the questionnaire and those who remain engaged with the programme (and thus undertaking physical activity) are more likely to complete the follow-up surveys. The results are likely to be biased towards those who continue to engage in physical activity. As part of the qualitative research we spoke to some people who had not continued with physical activity, and their experiences are explored on page 137.

## Participation in sports

Table 8.8 below shows the number and proportion of service users who reported participating in at least 1 x 30minutes of sport per week at start, 3, 6 and 12 months. The table also shows the mean minutes of sport per day and the mean minutes of sport per week undertaken by those who were meeting the 1x30 minutes indicator at each sampling point.

|  | Number of service users | Mean minutes of sport per day | Mean minutes of sport per week |
|---|---|---|---|
| Start | 323 (15 per cent) (base=2137) | 80±57.9 | 164±157 |
| 3 months | 295 (34 per cent) (base=868) | 80±53 | 168±167 |
| 6 months | 155 (32 per cent) (base=481) | 85±49 | 186±170 |
| 12 months | 96 (33 per cent) (base=293) | 74±45 | 161±135 |

**Table 8.8: Number and proportion of service users participating in at least 1 x 30 minutes of sport per week, mean minutes of sport per day and week for those who met this indicator.**

Of those who were doing no sport at baseline (n=622), 17 per cent (n=108) were doing at least 1x30minutes of sport at 3 months.

Of those who met the 1x30 indicator, 62 individuals provided data at both start and three months. At the start, these 62 individuals averaged 150 minutes of sport per week. At 3 months, this same group reported a significant increase ($p<0.05$) in time per week playing sport (mean 205 minutes of sport week).

## Qualitative insights on physical activity

**Most service users talked about the positive difference in their levels of activity compared with their levels during diagnosis and treatment**. However, most people also said they were more active before the cancer than they are now:

> *It has helped an awful lot. I'm able to go out in the garden, do more things in the garden, and around the house. But it still takes me twice as long as what it would have taken me before I got the cancer, but I feel I can cope better with it, and yes, the exercises have helped me.*
> **— Service User, Edinburgh**

The SPAQ collects data on moderate and vigorous intensity physical activity but does not differentiate between these two. Talking to service users, many describe their current activity levels as 'moderate'. They are active but within the parameters of their changed physical ability – which has diminished as a result of cancer. PLWCs are very conscious of not over-exerting themselves during recovery because they wish to conserve energy in order to enable their bodies to heal and are aware that over doing it can have adverse consequences.

> *It's hard going to the gym, it's proven to help with fatigue but at the same time it's knowing your limit and knowing when I need to rest, so it is quite tricky.*
> **— Service User, Hertfordshire**

This is balanced with an expressed need to ‘be themselves’ and return to previous levels of activity. Undertaking more moderate activity is considered an approach towards achieving this balance.

Although some service users attributed the increase in their activity levels to the support provided by services, most of these people said that they were minded to be physically active anyway and would have raised their activity levels at some point on their own. However, evidence shows that while some health-related behaviours such as diet, and smoking improve after cancer diagnosis, physical activity levels reduce significantly.[95] It may be that service users overestimate the extent to which they would increase their activity without the service, although it is difficult to say for certain without data from a comparable group of non-service users.

**Service uses acknowledged that the Move More programme has helped speed up the process by providing opportunities and advice concerning activity levels appropriate to their condition**. This supports another finding – that people held in high regard the support of Practitioners in terms of these Practitioners understanding the service users’ physical capabilities after receiving treatment and beyond.

Most service users interviewed who were still engaging in physical activity were positive about the future and felt they would be able to maintain or increase their current levels of physical activity, though perhaps not to re-gain their levels of activity, pre-diagnosis. In these instances, service users told us that they were primarily motivated by the need to improve their fitness and/or lose weight. Only a minority questioned whether they would be able to maintain their current levels and this overwhelmingly related to health concerns.

Some of the service users we spoke to were no longer engaging in physical activity. A deterioration in health was the primary reason why these service users stopped exercising; this was sometimes due to non-cancer related illnesses but was more likely to be linked to cancer. A change in cancer status or another health concern is one of the top four reasons why services closed cases (see page 115). Many service users indicated that they experience periods in which they are unable to undertake activity and/or felt controlled by their symptoms. Bouts of ill-health can also negatively affect service users’ confidence in relation to re-starting activity.

---

[95] Campbell, A. Foster, J. Stevinson, C. and Cavill, N. (2015) *The importance of physical activity for people living with and beyond cancer: A concise evidence review.* Macmillan Cancer Support

> *I had a chest cough, which lasted for about four and a half months, so that (a) made me feel that I didn't want to do it, and (b)[…][…] once I started [physical activity] over, a bit reluctant to do things.*
>
> **Service User, Aberdeen**

Treatment can also interrupt participation in physical activity. Service users' physical activity of choice may not always be possible when undertaking treatment – for example, when the activity is swimming. In most of these instances, service users did not indicate that they were supported by service staff through this process, nor did they seek to undertake an alternative activity during their treatment.

> *I started chemo last July and I finished the chemo in November, but I shouldn't go near a swimming pool. After the chemo finished, I was told I really ought to leave it two or three months.*
>
> **Service User, Berkshire**

A few service users had stopped undertaking physical activity because of other health conditions they had experienced (such as having a hip replacement, migraines and aches and pains). Some commented that cancer had made them more acutely aware of their body's weaknesses and limitations and they were more likely to be cautious about pushing themselves to undertake additional physical activity. Where this feeling of caution had occurred during the programme, some service users indicated that their Move More practitioner had provided alternative physical activity programmes (predominantly the Move More DVD) to undertake at home. But many also said they felt unmotivated to do this alone and in hindsight required higher levels of support from the practitioner. Overall, the lack of ongoing formal support in many of the services evaluated may have affected the extent to which service users were supported to continue to undertake physical activity following changes to their health.

For younger service users, a return to employment was a significant reason for no longer participating in the programme. There were two main reasons for this. Some no longer had sufficient time and energy to continue. For others, the activity they had previously participated in was held during the working day and they had been unable to source something similar in the evening. While the number of service users expressing this view may be limited, it should be noted that service users selected for interview were not necessarily representative and by definition only included those who had been able to engage with the programme. Again, this emphasises the importance of services providing access to activities at a range of times and locations.

## Health related quality of life

The key measure of HRQoL is EQ5D. **Among those who completed these questions at all data collection points (n=147) there was a statistically significant (p<0.01) increase in overall quality of life between start and 3, start and 6 and start and 12 months. The largest increase is between start and three months and the rate of increase after this reduces** – see figure 8.3 overleaf.

Table 8.9 below also shows statistically significant (p<0.01), although small, increases in EQ5D for those service users who gave data at start and 3 months, start and 6 months and start and 12 months.

| | N | Mean start | Difference |
|---|---|---|---|
| **Start & 3** | 851 | 0.72 | 0.05*** |
| **Start & 6** | 468 | 0.71 | 0.11*** |
| **Start & 12** | 212 | 0.7 | 0.12*** |

Table 8.9: Mean change in EQ5D score for service users providing data at start and 3, start and 6 and start and 12 months.[96]

It is notable that the changes in health related quality of life are relatively small when compared to the more substantial changes in physical activity. We might expect to see a greater increase in quality of life, given the activity level changes. This could be due to the over-reporting of physical activity.

The trends in each of the individual aspects of the measure can also be seen in Figure 8.3. Across all measures we can see an upward trend in scores for those reporting ‘no problems’, with particular improvements in mobility, usual activities, and regarding pain and anxiety. In these areas the numbers of individuals reporting ‘some problems’ decreased considerably. It is worth noting that respondents’ ratings for dealing with pain showed a steady increase, with the predominant score becoming ‘no problems’ by the three month stage. The scores for ‘usual activities’ exhibited the largest increase across the measures, rising from 48 per cent at baseline to 73 per cent at 12 months.

---

[96] Asterisks indicate significance level of the two-sided t-test of the difference in means for a paired sample. *** p<0.01, ** p<0.05.

**Figure 8.3 - EQ5D-3L overall index scores and percentages of those reporting no, some and severe problems for each aspect. Respondents with ratings for all data collection points (n=147)**

## Sub group analysis

Comparison of the quality of life score by sub group becomes problematic due to the small sample sizes for some of the sub-groups and data collection points. Sample sizes in England/Wales and Scotland are sufficient to provide a comparison between start and 3, 6 and 12 months. However, it is only possible to carry out an analysis on the change in quality of life scores for service users from Northern Ireland between start and 3 months. We find small but statistically significant increases in quality of life scores for services users in England and Wales (combined sample) between start and 3, start an 6 and start and 12 months (results at all sampling points are statistically significant at p<0.001). Scotland and Northern Ireland both showed very small, non-significant changes. See table 8.10 in Appendix 3.

Significant increases in quality of life scores were evident between start and 3 months and start and 6 months, regardless of whether services signpost service users or deliver activities directly (all significant at p<0.01), although the increases for direct delivery were very small. However, it was only in services which signposted service users to external activities where improvements in quality of life scores were statistically significant between start and 12 months (p<0.001, n=129). See table 8.11 in Appendix 3.

There was a small but significant increase in the mean quality of life scores of service users who attended activities in a community setting between start and 3 months, start and 6 months and start and 12 months (p<0.01). We only saw a significant difference in mean scores for the healthcare setting for those who provided data at start and six months (p<0.001). The difference in mean scores for those who provided data at start and 3 months was very small and not significant. The sample size for those at start and 12 months was too small. See table 8.12 in Appendix 3.

## Self-assessed health

We found that **service users reported statistically significant improvements in their perceived state of health between baseline and 3 months (p<0.01), 3 and 6 months (p<0.01) and 6 and 12 months (p<0.01)**. Overall health is reported by respondents on a scale of 0 to 100, where 100 is the best imaginable health. 152 Service users provided information at all four sampling points and their average rated health is shown in figure 8.4 below. The largest increase is observed between start and 3 months, with more modest increases thereafter. This aligns to the finding that the largest increase in physical activity takes places in the first three months of engagement with the service.

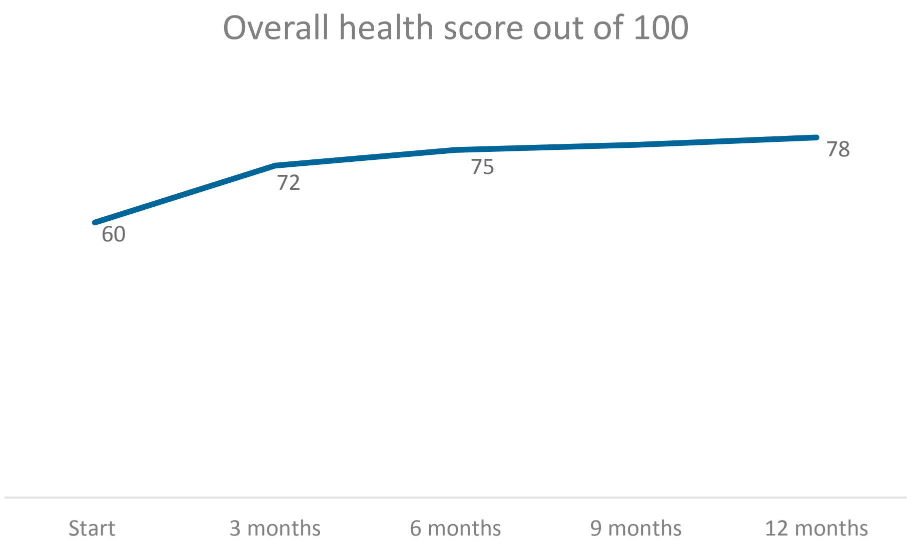


**Figure 8.4: Overall self-reported health score for those who responded at all 4 stages (n=152)**

Service users described a variety of ways in which their health had improved as a result of participating in the programme. For some service users the increased physical activity was the catalyst for further lifestyle behaviour change, particularly in relation to diet and nutrition.

> *[Walking] has been really good, because while doing it, I decided to, in effect, diet at the same time, and so over the past six months I've lost nearly a stone. So, to me, combining the fact that I can now walk, you know, I've got the ability to walk better, I don't get out of breath, and they've got my medication stabilised.*
>
> — **Service User, Shropshire**

Some service users reported that they had lost weight as a result of the activities. Others reported that they have lost a lot of muscle density as a result of their treatment; however, as a result of physical activities, such as core exercises, they have been able to build strength again. This has improved stamina and the ability to undertake daily activities.

> *I have much more stamina, so as I said, I try to walk to work, and it's taking me less and less time. It used to be quite long, but now about twenty minutes.*
>
> — **Service User**

Many service users have comorbidities. A number talked about the benefits of physical activities in reducing or controlling the negative effects of these other health conditions – from heart problems to less serious conditions such as minor illnesses. One service user talked about having a heart murmur and that the activities were helping them to remain healthy.

## Fatigue and energy levels

Fatigue is the most common side effect reported by PLWC. Fatigues levels are assessed using the FACIT (Functional Assessment of Chronic Illness Therapy).[97] A higher score on the scale indicates a reduction in fatigue, with a score of 52 indicating no fatigue.

Table 8.13 below shows **statistically significant ($p<0.01$) increases in FACIT score for service users who provided data at start and 3 months, start and 6 months and start and 12 months**.

| | N | Mean start | Difference |
|---|---|---|---|
| **Start & 3** | 909 | 30.61 | 2.38*** |
| **Start & 6** | 500 | 30.93 | 3.06*** |
| **Start & 12** | 268 | 29.57 | 3.29*** |

Table 8.13: Mean changes in FACIT score for service users providing data at start and 3 months, start and 6 months and start and 12 months.[98]

For those who completed baseline and the 12 month follow-up surveys, the mean score at start was 29.6, increasing to 32.9 at 12 months.

Figure 8.5 overleaf shows the average (mean) scores for the 166 service users who answered the FACIT question at all four sampling points. This shows increases in FACIT score (meaning a decrease in levels of fatigue) between start and 3 months and between 3 months and 6 months, with minimal change between 6 and 12 months.

---

[97] See www.facit.org/FACITOrg for further information

[98] Asterisks indicate significance level of the two-sided t-test of the difference in means for a paired sample. *** $P<0.01$, ** $p<0.05$.

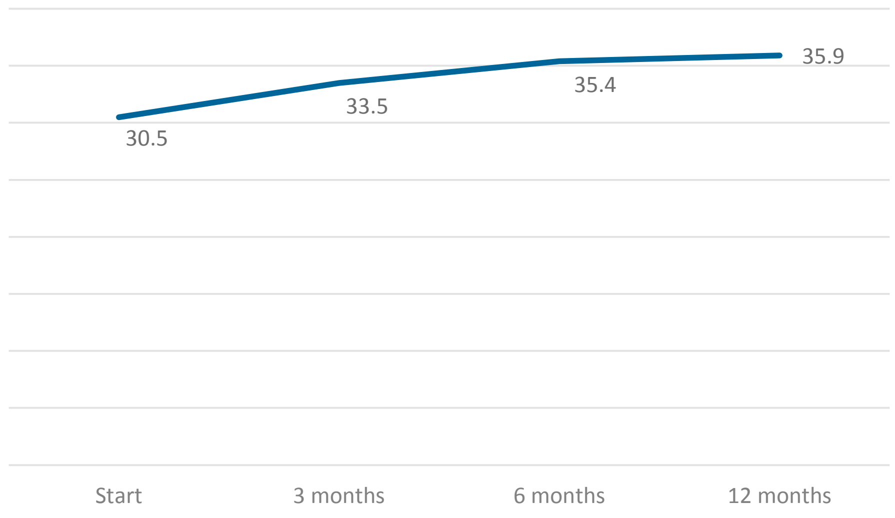


**Figure 8.5: Average (mean) FACIT score for those who responded at all four stages, n=166**

There is on-going work aimed at understanding what changes in FACIT scores count as clinically significant, and experts in the field have yet to reach a consensus.[99] Cella et al (2002) suggest a minimum clinically important difference of 3.0.[100]

Qualitative interviews with service users corroborate the quantitative findings on fatigue. They report that engaging in physical activity has generally increased their energy levels. Most felt that, overall, their energy levels were higher than before they participated in the programme.

> *I look back and I just see my energy levels were so low because of fatigue, which you can't describe to anybody, really. Huge fatigue. So, my family remembered me before I got cancer as being very active, saw me go through this period where I was really completely inactive, so they're happy that I've now become active again.*
>
> — **Service User, Dorset**

As a result, they are often now able to complete tasks in less time. Some stakeholders also cited additional lifestyle benefits of engaging with physical activity.

> *We have found that the patients that have engaged in physical activity – they realise that they are very breathless when they start, actually, they give up smoking as well and that makes the activity easier.*
>
> — **HCP, Shropshire**

---

[99] http://www.facit.org/FACITOrg/FAQ

[100] Cella, D. Eton, D. Lai, J. Peterman, A. and Merkel, D. (2002) Combining anchor and distribution-based methods to derive minimal clinically important differences on the Functional Assessment of Cancer Therapy (FACT) Anaemia and Fatigue Scales.

Service users also stated that their energy and fatigue levels fluctuate considerably on a day-to-day basis, often as a result of treatment. Most felt they had no control over their fatigue levels, though we did find some who reported that certain exercises can help to limit fatigue. For example, one service user worked closely with their instructor to develop tailored exercises to help manage her fatigue level.

### Sub-group analysis

In addition to looking at overall changes in FACIT, we undertook analyses based on nation, setting and approach to delivery.

Significant reductions in fatigue were reported by participants in England and Wales (combined sample) ($p<0.01$, n=791) and Northern Ireland ($p<0.05$, n=62) between start and 3 months. While service users in Scotland showed small improvements in their fatigue levels, these changes were just outside being significant at the 95% level ($p=0.09$, n=55). Small sample sizes in Scotland and Northern Ireland make meaningful analysis impossible when comparing changes in fatigue scores between baseline and 6 and 12 months. See table 8.14 in Appendix 3.

In relation to service users of services that signposted-only, there was a statistically significant decrease in fatigue between start and 3, 6 and 12 months ($p<0.01$). For those completing questionnaires at start and 12 months (n=126), their mean score increased from 32 to 39. Service users from services that delivered activities directly reported smaller but significant increases in scores between start and 3 and start and 6 months. However, there was no real change for those completing questionnaires at start and 12 months – the mean score remained at about 27 (n=141). See table 8.15 in Appendix 3.

Looking at those who participated in activities in a community setting, we see statistically significant decreases in feelings of fatigue between start and 3, 6 and 12 months ($p<0.01$). Those who participated in activities delivered in clinical settings showed no significant changes in fatigue between start and 3 and start and 6 months, but there was a significant *increase* in fatigue between start and 12 months, indicated by a decrease in mean scores from 20 to 17.6 (n=74, $p<0.05$). See table 8.16 in Appendix 3.

## General self-efficacy

We measure self-efficacy through a series of ten statements that service users score on a scale of 1 to 4, where a higher score indicates better self-efficacy. The scores are summed to give an overall rating out of 40.[101]

---

[101] This approach is a standard approach and one that has been used in PLWC. See: http://onlinelibrary.wiley.com/doi/10.1002/pon.3428/abstract

Table 8.17 below shows the average scores for the 59 service users who provided data at all 4 sampling points. This shows a small overall increase but the differences are not statistically significant.

| | Mean score |
|---|---|
| **Start** | 29.9 |
| **3 months** | 30.3 |
| **6 months** | 30.9 |
| **12 months** | 31.5 |

Table 8.17: Average (mean) score for general self-efficacy for those who responded at all four stages, n=59

Taking the larger samples of those who responded at start and 3, start and 6 and start and 12 months (see table 8.18) we see a similarly small increase in average scores; these are statistically significant.

| | N | Mean start | Difference |
|---|---|---|---|
| **Start & 3** | 650 | 29.66 | 0.44** |
| **Start & 6** | 344 | 29.87 | 1.15*** |
| **Start & 12** | 118 | 29.92 | 1.41*** |

Table 8.18: Mean change in GSE score for service users providing data at start and 3, start and 6 and start and 12 months.[102]

## Subgroup analysis

When analysed by national grouping, only services in England and Wales combined demonstrated statistically significant differences in self-efficacy scores between baseline and 3 months ($p<0.05$, n=538); although the changes were very small (mean score increased from 29.9 to 30.4). Differences in mean self-efficacy scores in Northern Ireland and Scotland between start and 3 months were even smaller and not significant, although we have much smaller sample sizes for these nations. Analysis by nation between start and 6 and start and 12 months is not possible due to the small sample sizes for Scotland and Northern Ireland in particular. See table 8.19 in Appendix 3.

We see a small but significant difference in mean scores between start and 6 months for services delivered in community settings – mean scores increased from 30 to 31.7 ($p<0.01$,

---

[102] Asterisks indicate significance level of the two-sided t-test of the difference in means for a paired sample. *** $P<0.01$, ** $p<0.05$.

n=254). The difference in mean scores over the same period in relation to healthcare settings is smaller (0.6) and not significant (p=0.15, n=88). See table 8.20 in Appendix 3.

Services that predominantly signpost and those that delivered services directly had similar statistically significant but small increases in mean scores for self-efficacy between start and 12 months. Mean scores for signposting services increased from 29.7 to 31.8 (p<0.05, n=38); mean scores for direct delivery services increased from 29.7 to 31.5 (p<0.01, n=93). See table 8.21 in Appendix 3.

## Qualitative evidence of other impacts

### Mental wellbeing

The impact of the programme on service users' mental wellbeing was generally positive, but the level of impact varied. Prior to participation in the programme, PLWC were likely to state that they had relatively low levels of life satisfaction. Most commonly their illness or treatment was cited as the primary factor in this. Interviewees were roughly evenly split between people who said they were able to maintain a positive frame-of-mind during their diagnosis and treatment and those who said that they found this period very challenging for their mental health. Those in the former group talked about having a strong and positive frame-of-mind and high self-esteem before joining Move More. This positivity appears to be related to having support from family and friends, as well as having resilience and a determination to get on with their life.

> *I would say completely satisfied because I think that apart from having aged a few years when all of this has gone on and obviously you're not necessarily as fit as you were four years ago, I am perfectly happy with how I feel and what I'm able to do on the exercise front and how it enables me to go on and do the rest of things in my life.*
>
> — **Service user, Berkshire**

People in the latter group talked about how the diagnosis and treatment negatively impacted upon on their self-confidence and self-esteem. This was made worse in some cases where the service user felt a long way from returning to previous levels of fitness. One service user spoke about the depths of depression he suffered:

> *For two and a half years ago, I couldn't walk ten yards and I was so depressed. I was probably nearly suicidal with it.*
>
> — **Service User, Manchester**

These latter service users experienced more substantial improvements in their mental wellbeing. Benefits included greater resilience and determination, improved self-esteem, having a positive outlook and not letting less important things distract them.

> *I think mental health, it's massive. I think it gets underplayed how much having cancer affects your mental health. It's hugely emotional and coming out of that -, you go through so much when you're actually going through all the treatment and mainly your focus is getting through the treatment. You hold it all together whilst it's all going on, and then once the treatment finishes, you go into a panic stage.*
> — **Service User, Manchester**

However, interviewees generally indicated that this increase in satisfaction was due to improvements in health and/or an end to treatments, only a minority attributed it to increased physical activity. On the other hand, the support and interaction they received from the services and other participants was felt to make a difference.

**There are two particular elements of the Move More service that helped people with their mental health. The first is the advice, support, and encouragement provided by Practitioners**. This was important because it helped to guide people through a period of uncertainty and inform them about what activities they could and could not do. Some service users spoke about Practitioners working with them to understand their physical capabilities and harnessing their strengths and interests in order to achieve realistic goals. This had a direct impact on people's mental wellbeing. Service users felt that being supported to come to terms with their new situation and to think about a way ahead helped focus their mind and build their confidence and self-esteem:

> *(The trainers) are all looking forward, they're all giving you things that will help you in the future. You begin to think differently … I mean, I'm talking to you. I wouldn't dream of talking to people like you, to be honest. I'd have put the phone down, and said, 'No thanks, I'm not interested.'*
> — **Service User, GSTT**

In one example, the service user talked about her initial reluctance to accept support from her family. The service user acknowledged that this was not helpful to her mental wellbeing, in that she felt isolated and depressed as a result of not talking about her diagnosis. But once she started to build a trusting relationship with the Move More practitioner, she began to feel more comfortable about being open with family members.

> *I sheltered everybody from how I was actually feeling, because I felt I had to be strong for everybody. It's not a pleasant thing for the whole family to watch you go through. That's the problem I created for myself, but with (the support of trainer), I got over that.*
> — **Service User, Lincolnshire**

**The second element of support came from other service users. A lot of interviewees spoke highly of the moral support and succour they got from fellow service users – the feeling that they were not alone in dealing with their condition**.

## Confidence / self-efficacy

**Related to improvements in mental wellbeing, service users also spoke about becoming more confident and outgoing**. For example, the service user below indicated that her family members have seen a change in her since she started engaging in physical activity:

> *They've definitely seen a change in my personality and that I'm more outgoing and a lot happier in myself.*
> — **Service User, Ards and North Down**

Service staff also observed and reported changes in service users' confidence.

> *She just blossomed. She just changed dramatically, her whole body stature, she started wearing brighter clothes, started wearing make-up and went and had her hair done. She developed the confidence to do all of that. I think it was not only the physical activity class that she was doing but it was because we'd actually spoken about other things that were quite meaningful to her, and it was the collective bit*
> — **Service staff member, Shropshire**

This also highlights how wider support for issues outside of physical activity (provided by services, other service users and linked services that services refer on to) contributes to the achievement of positive outcomes.

Some of these service users went on to become ambassadors for the programme and to talk about their experiences at health and wellbeing events and to patients in hospitals and at cancer-site specific support groups. This enabled them to develop their public speaking skills and illustrates their greater confidence.

More specifically, the programme also appears to have helped increase service users' confidence levels in being more active – from undertaking day-to-day activities to doing more strenuous activities in competitive sport. Most service users reported feeling more confident in engaging in physical activity now than they did prior to involvement in the Move More programme. We found some taking part in activities that they would not have previously considered doing. Those who had been in good health anyway felt that they became more confident in pushing themselves further and in some cases were motivated to take up other exercise activities, including sport – something that they indicated they would have been less likely to do without the Move More programme. For example, service users who have never had a gym membership are now members. Other examples include attendance at non-cancer specific exercise classes such as Zumba, Pilates, and yoga.

> *I'm a lot more willing to go and try something new, as I said. Before, I thought, 'I'll never go and use a gym,' but now I know how to use it, and I would.*
> — **Service User, Luton**

For some service users to whom we spoke it has now been a year or more since they started participating in the programme. These individuals report that they feel more settled with their diagnosis and have a better understanding of their body in terms of what they are and are not able to do. They feel more confident in regard to trying new activities and continuing to challenge themselves.

> *I constantly go out and I push myself with various activities. I'm not afraid of my lymphedema, as I used to be. I used to be very scared, from all the dos and don'ts, what I should and shouldn't do. Then, I pushed it. So, I've done things like anti-gravity yoga, using the hammock. I have pushed myself with weights, but not too far, just to try and see how well my arm would react and respond. It's an individual thing. Nobody knows what's going to happen.*
> **— Service User, Shropshire**

It appears that what underpins this confidence is the physical strength, balance and endurance that people gain from taking part in the activity, which gives them more confidence in their ability to get out-and-about, do routine household chores and do some level of sport, or to try a new type of sport suited to their capabilities.

## Social isolation

**For most people, undertaking exercise in a group environment appeared to have a substantial effect in terms of reducing feelings of social isolation**. These sessions allowed the service user to meet with other people who have experiences of cancer diagnosis, treatment, and of recovery. Seeing others in similar circumstances take part also helped to motivate service users to continue exercising.

> *When I was tired and didn't have much energy I just thought: there are other people that are also going through this. I think it just helps to know that there are other people.*
> **— Service User, Velindre**

Some people have formed enduring friendships as a result of attending the group activities. Service users talked about exchanging contact details, keeping in touch on-line, and even meeting up for a drink to catch-up on how they were doing:

> *The people who I met in that group I'm still in contact with now. So, we help each other out, or we'll go for a coffee, you know. Meet for coffee, just have a sit down and a chat.*
> **— Service User, Velindre**

Others simply wanted to move on with their lives after participation in the programme. People had family-life and employment to return to.

> *If I met one of them in the street, I would be more than happy to spend time with them. But it wasn't a 'This was a bonding social club, and we'll be penfriends ever after,' business.*
>
> — **Service User, Edinburgh**

## Impacts on carers and families of people living with and beyond cancer

The benefits of the programme for carers and family members generally related to seeing the service user more positive. Seeing a loved one being more active, confident and independent has a positive effect on family and friends.

> *It is lovely to hear that they've seen them go through a terrible period of ill health and often depression that has set in and to see how happy its making them feel that, you know their partner's now out and about and doing things. So yes I can definitely see that it's helped the whole family*
>
> — **Stakeholder, Dorset**

We found evidence that the programme has helped to ease the pressure on carers and has provided them with some respite as service users' strength and independence increases and fatigue lessens. As they return to undertaking self-care and chores, so family members can reduce the support they provide with these tasks.

Several service users also indicated that the programme had helped to encourage other family members get involved in physical activities.

> *The thing about the involvement with the Health and Wellbeing programme is the fact that this is a fixture, if you like, and it is something each week that both my wife and I look forward to doing. We look forward to going, we look forward to seeing the little lass that is our wellbeing advisor. We look forward to seeing her and we have our hour's table tennis and enjoy it. It is, as I say, something that is not prescribed, something that we choose to do and look forward to.*
>
> — **Service user, Luton**

# Conclusions

Self-reported data suggests service users have maintained or increased their levels of physical activity following engagement with the service. However, the initial levels of activity were high in relation to the population at large, and the sample is likely to be biased towards those who are more motivated.

For those who provided data at start and follow-up we found statistically significant increases in average amounts of physical activity between baseline and 3, 6 and 12 months.

Of those who completed questionnaires at start and 12 months, none who were inactive at the start remained so by 12 months.

We found statistically significant improvements in the service users' perceived state of health and health related quality of life between baseline and 3 months, 3 and 6 months and 6 and 12 months. However, the largest increase is observed between start and 3 months, with more modest increases thereafter. Service users articulated a variety of ways in which their health had improved as a result of participating in the programme and for some the increased physical activity was a catalyst for further behaviour change.

We found statistically significant decreases in levels of fatigue in service users between baseline and 3 months, baseline and 6 months and start and 12 months. Qualitative interviews with service users support this finding. They report that their energy levels have increased since participating in the programme.

The outcomes analysis takes a completers only approach. The downside to this is that the sample may not be representative of the population of service users as whole. The members of the sample may be more motivated than average to participate in the intervention, and if so this will lead to an overestimate of outcomes. In particular, different levels of success in collecting data means the results over-represent data from a small number of services.

While analysis of outcomes for different sub-groups shows significant increases in physical activity levels for all nations, delivery models and settings at most stages where sufficient data is available, the results are more mixed for other outcomes. It is therefore difficult to draw conclusions from this that particular models are more or less effective in achieving outcomes. Smaller sample sizes for some outcomes for some models affect our ability to detect significant changes.

Service users do not always attribute improvements to their increased physical activity. Without a control or other comparator group it is difficult to say with any certainty whether the service has improved service users' health and mental wellbeing or whether this would have happened anyway. Given the myriad health and wellbeing challenges that PLWC are likely to face, it may be difficult for them to pinpoint which factors have made a difference and the relative importance of each. Successfully completing treatment and overcoming cancer (a large proportion of service users have been effectively treated and are in remission or cancer free) is clearly a major factor contributing to many service users' feelings of wellbeing. However, we would expect the reported increases in physical activity to make some impact on health, including mental wellbeing.

What is clear is that service users value and derive benefit from the specialist support and guidance provided by the service staff and the mutual support of other service users. Most of those we spoke to were motivated and inclined to increase their physical activity levels, either because they had been active prior to diagnosis because they were motivated to improve their fitness to better overcome cancer. However, it seems likely that they would not have been able to enhance and maintain their physical activity as successfully without the crucial support provided by the service. The provision of ongoing support, particularly where service users experience further health problems, is an important part of ensuring that PLWC can continue to adapt their physical activity accordingly.

## Recommendations

### For Macmillan and future funders

Macmillan, future funders and commissioners should be aware of and promote the wider benefits for PLWC of undertaking physical activity. These include improvements in mental wellbeing, reduced fatigue and social isolation. Benefits can also be felt by families and carers of PLWC.

Evidence of outcomes achieved could be strengthened with more robust longitudinal data and a controlled trial or quasi-experimental evaluation with a comparison group.

### For services

Services should also promote the wider benefits of physical activity to potential service users, their families and HCP.

Services should consider how they might encourage the family and / or carers of PLWC to participate with them in physical activities.

# 09. Economic analysis

*This Chapter presents the results of the economic analysis. The economic analysis calculates the change in cost and the change in outcome from baseline to 3 month follow-up. The average change in cost divided by the average change in outcome is a measure of the cost effectiveness of the Physical Activity Behaviour Change Care Pathway.*

The primary aim of this analysis is to calculate the cost per improvement in four outcome measures: physical activity (SPAQ), fatigue (FACIT), health related quality of life (EQ-5D) – which is also used to calculated quality adjusted life years (QALYs) – and self-efficacy (GSE). The economic analysis calculates the change in cost and the change in outcome from baseline to 3 month follow-up. The average change in cost divided by the average change in outcome is a measure of the cost effectiveness of the Physical Activity Behaviour Change Care Pathway. The analysis also provides estimates of cost per quality adjusted life year (QALY) based on the effects of the programme lasting for 3 months and 12 months. The economic analysis adopts a pragmatic approach and wherever possible a range of estimates is provided by varying the assumptions used. This means that some of the estimates are more conservative than others.

The economic analysis generally takes a 3 month perspective because not all services are at the same stage in their operating cycle. The services have been established for periods of between 12 and 47 months and this has implications for the number of service users recruited and the number providing follow-up data at 3, 6 and 12 months.[103] This makes using 12 month follow-ups impractical for some services. 3 months has generally been used as this is where the data is strongest, although we have also looked at changes in health-related quality of life (EQ-5D) at 6 months and 12 months for those projects where sufficient data is available.

Average change per service user can be calculated in a number of ways. The most conservative calculation is based on an ‘intention to treat’ (ITT) analysis, which assesses outcomes for all service users who enrolled on the programme. The least conservative analysis uses data on ‘completers only’: i.e., those service users who completed 3 months of programme (see pages 32-34). It is not straightforward to define completion for this

---

[103] In particular the two services in Northern Ireland have only been established for 12 months and receiving referrals for between 8 and 10 months, whereas all other services have been established for at least 24 months.

intervention, as it is not a time limited programme with a defined end point; 3 months has been used as this is where the data is strongest.

ITT analysis assesses outcomes for all service users who enrolled on the programme (i.e. provided baseline data), regardless of whether they dropped out at any stage. An implication of this approach is that for service users who were present at baseline, but not follow up, the change in outcome at follow-up was assumed to be zero (i.e. no change from baseline), which decreased the estimate of the average change. ITT analysis is the recommended approach here because it represents a good approximation for 'real world' treatment pathways involving physical activity programmes, where drop-out and non-adherence are common. We present the average change in outcome using both the ITT and the completers only approach. This provides a range of estimates for the estimated effectiveness of the intervention. For more information on the method, rationale and caveats of the economic analysis see pages 33 - 40 in Chapter 2.

## Outcomes results

Table 9.1 reports mean outcomes at baseline and 3 months on both an ITT and completers only basis. All outcomes show improved scores at 3 months, and these increases are higher in the completers only analysis, illustrating that ITT analysis is the more conservative approach. The table also reports the significance level of the statistical difference in mean scores over time using a paired two-sided t-test[104]. It is clear from this table that while the changes are small they are all statistically significant; changes in FACIT, EQ-5D and SPAQ are significant at $p < 0.01$ and changes in GSE are significant at $p < 0.05$.[105] This is a result of the large sample size which produces very precise estimates. For SPAQ for example, the mean minutes exercise per week at baseline among the n=2464 service users who provided baseline outcomes is 353 minutes[106]; this increases to 402 minutes at month 3, a highly statistically significant change. This increase of 49 minutes compares favourably to a pooled analysis of two exercise referral schemes reported in a recent systematic review, which identified an increase of 55 minutes.[107] However, it is lower than the increases achieved in a 12 week supervised exercise programme for women being treated for early stage breast cancer; this resulted in a 182 minute increase from baseline at 12 weeks, and a 64 minute increase 6 months after the intervention.[108]

---

[104] A paired test is appropriate here because the responses at baseline and follow-up are from the same individuals.

[105] No existing studies were found that enable a comparison of GSE scores. For FACIT, one study of exercise in women being treated for breast cancer found no significant change in FACIT score (www.ncbi.nlm.nih.gov/pubmed/24570186.)

[106] This is the mean for the truncated SPAQ responses.

[107] Campbell F, Holmes M, Everson-Hock E, et al. (2013) A systematic review and economic evaluation of exercise referral schemes in primary care: a short report. *Health Technology Assessment*, 19.60. (p.45).

[108] Mutrie, N et al (2007) Benefits of supervised group exercise programme for women being treated for early stage breast cancer: pragmatic randomised controlled trial. http://www.bmj.com/content/334/7592/517

|  | FACIT[3] |  |  | EQ5D Index |  |  | GSE |  |  | SPAQ[4] |  |  |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
|  | Start | 3m |  | Start | 3m |  | Start | 3m |  | Start | 3m |  |
| **No of service users** | 2310 | 1090 |  | 2322 | 445 |  | 1771 | 859 |  | 2464 | 1093 |  |
| ***Mean outcome*** |  |  |  |  |  |  |  |  |  |  |  |  |
| **ITT analysis[1]** | 31.0 | 31.9 | *** | 0.72 | 0.73 | *** | 29.6 | 29.7 | ** | 353 | 402 | *** |
| **Completers only[2]** | 31.0 | 32.1 | *** | 0.72 | 0.87 | *** | 29.6 | 30.4 | ** | 353 | 480 | *** |

**Table 9.1: Mean Outcomes – Intention to Treat (ITT) and Completers Only analysis**

Notes: Asterisks indicate significance level of the two-sided t-test of the difference in means for a paired sample: *** P<1%, ** p<5%.

1. In ITT analysis outcomes are assessed outcomes for all service users who enrolled on the programme (i.e. provide baseline data), regardless of whether they dropped out at any stage. For service users not present at follow up their baseline value is assessed at follow up, which is equivalent to the assumption that there is no change in outcome for that service user.
2. In completers only analysis, outcomes are averaged across completers only.
3. FACIT is reverse coded for ease of comparison with the other outcome measures which are all increasing in health.
4. All SPAQ distributions are truncated to omit the top 5% of values.

It is worth stressing here that, in the ITT analysis, outcomes for those baseline respondents who did not provide follow-up data are set at their baseline value, hence these significant improvements in mean outcomes are realised even when a substantial number of the people who started the programme are assumed to display no change at follow-up. Hence, these estimates are good, safe approximations of expected 'real world' changes in outcomes. It is also worth noting that the improvements in outcomes are small, and as a result may not be clinically meaningful despite their statistical significance. For example, a change in EQ5D of 0.01 is unlikely to be clinically meaningful. Pickard et al (2007) examine minimally important differences in the EQ-5D index for a sample of 534 cancer patients and find a minimum clinically important difference of 0.08 when the EQ5D was judged against the Functional Assessment of Cancer Therapy (FACT) scale and the Eastern Cooperative Oncology Group performance status (PS) ratings.[109] Cella et al (2002) suggest that a change in score of 3.0 on the FACIT fatigue scale is the minimum clinically important difference.[110]

For the completers only analysis it is important to stress that for all four outcomes, at month 3, less than half of the original service users remain, and that this group may not be representative of the population of service users as whole; for example, they may be more motivated than average to participate in exercise, hence the 'completers only' analysis is likely to be an overestimate of the effectiveness of the intervention.[111]

Table 9.2 (Appendix 3) reports the results of paired t-tests for the statistical difference in mean outcome scores over time by service; where outcomes are calculated using ITT analysis. Tests are not reported where cell sizes are smaller than 30. In all cases there is considerable variation across services.

Baseline levels in FACIT scores range from 20 for Guys to 36.4 for Dorset. Changes in FACIT score range from -1.8 for Shropshire to 3.1 for Lincolnshire. Nine of the thirteen services display significant improvement in FACIT score to month 3, and two (Guys and Shropshire) display a significant decrease in the (reverse coded) score, reflecting worse levels of fatigue at month 3 than at baseline.

In relation to the EQ5D health related quality of life index, baseline levels range from 0.64 for Manchester to 0.79 for Antrim and Newtownabbey. Changes range from 0 for Cardiff

---

[109] Pickard AS, Neary MP, Cella D. (2007) Estimation of minimally important differences in EQ-5D utility and VAS scores in cancer. *Health and Quality of Life Outcomes*. 5:70.

[110] Cella, D. Eton, D. Lai, J. Peterman, A. and Merkel, D. (2002) Combining anchor and distribution-based methods to derive minimal clinically important differences on the Functional Assessment of Cancer Therapy Anaemia and Fatigue Scales *Journal of Pain and Symptom Management* 24:6, (p.547)

[111] The follow-up rate for EQ-5D is only 19 per cent largely as a result of one of the larger services (Guys) not collecting a comparable outcome measure. Guys used the newer, but as yet largely unadopted, EQ5D-5L instrument rather than the EQ5D_3L that is recommended by NICE.

and Herts to 0.06 for Lincolnshire. Five services display statistically significant increases in EQ5D to month 3; these generally represent very small increases in the index.

Baseline levels for GSE range from 26.1 for Antrim and Newtownabbey to 33.2 for Luton, and changes range from -0.6 for Luton to 0.6 for Lincolnshire. Three services display significant improvements to month 3 and one (Luton) exhibits a significant deterioration.

In relation to the SPAQ baseline, the number of minutes of exercise per week varies from 208 in Antrim and Newtownabbey to 554 in Dorset.[112] Changes range from -3 for Shropshire to 143 for Cardiff. Nine services exhibit significant improvements in SPAQ to month 3.

### Sub-group analysis

Tables 9.3a to 9.3c (Appendix 3) report the paired t-tests for the statistical difference in mean scores over time by service sub-group – when outcomes are calculated using ITT analysis.

As shown in Table 9.3a, at month 3 all national sub-groups exhibit significant changes in FACIT scores and SPAQ. There is no significant change in EQ5D for Scotland, and no change in GSE for Scotland or Northern Ireland.

Table 9.3b shows that at month 3, both delivery models display significant changes in FACIT, EQ-5D and SPAQ, but the signposting only model is the only one to show a significant change in GSE score.

In Table 9.3c, it can be seen that both settings exhibit significant increases in FACIT and SPAQ to month 3. Only the community setting shows significant changes to the EQ-5D and GSE score. It should be borne in mind when making these comparisons that some of the differences in statistical significance across sub-groups are largely driven by sample size and do not truly reflect changes in the mean outcome levels. In particular, national service comparisons are distorted by larger sample sizes in relation to the services in England (83 per cent of all service users at baseline). Also the services in Northern Ireland are relatively new compared to the services in Scotland and England.

## Cost analysis

The perspective of the cost analysis is that of the provider. This requires an estimate of the total cost (TC) of delivering the Physical Activity Behaviour Change Care Pathway; that is,

---

[112] The overall SPAQ distribution at each time point is truncated to omit the top 5% of values. All mean SPAQ responses are larger than expected but this will not affect the analysis of change over time.

the change in costs from baseline (before intervention) to follow-up. The relevant costs include all the direct costs of delivery, including any in-kind contributions such as free venues provided for activities. These data have been collected from each service using a costing template, and they represent the actual costs of delivery over a specific period of time as reported to us by the services. Services sometimes found it challenging to provide information on the full costs of delivery: see Table 9.4, Appendix 3 for further information on how the costs were calculated.

Cost data are reported in Table 9.4, Appendix 3. These total costs cover a varying number of months for each service. Total costs range from £39,059 for Antrim and Newtownabbey to £273,269 for Luton, with a mean total cost of £158,242. To ease comparison, mean monthly costs for each service are also reported, and these are also shown graphically in Figure 9.1. Monthly costs range from £3,255 for Antrim and Newtownabbey to £8,206 for Lincolnshire, with a mean of £6,023.

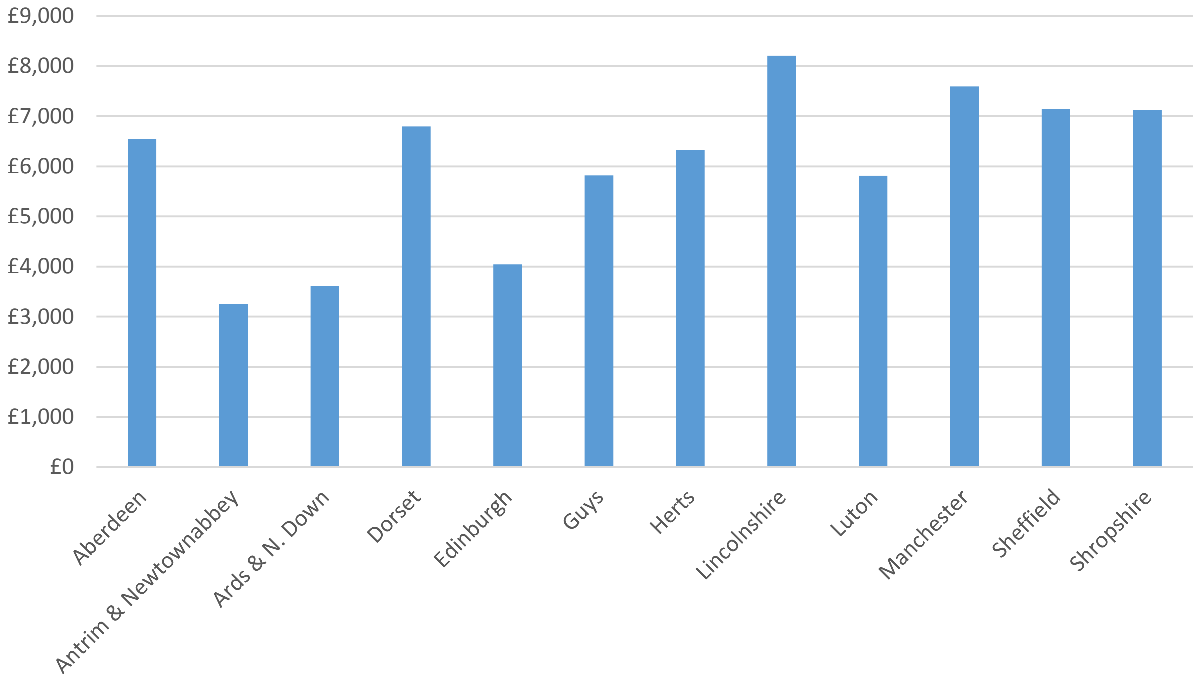


**Figure 9.1: Monthly costs by service**

Note: Cardiff and Berkshire are omitted from the analysis of costs because the cost information provided was not comparable.

Table 9.4 also reports costs for different categories of expenditure; these categories include set-up and running costs, in-kind contributions and staff costs. The proportions of total costs represented by each of these categories are also shown graphically in Figure 9.2.

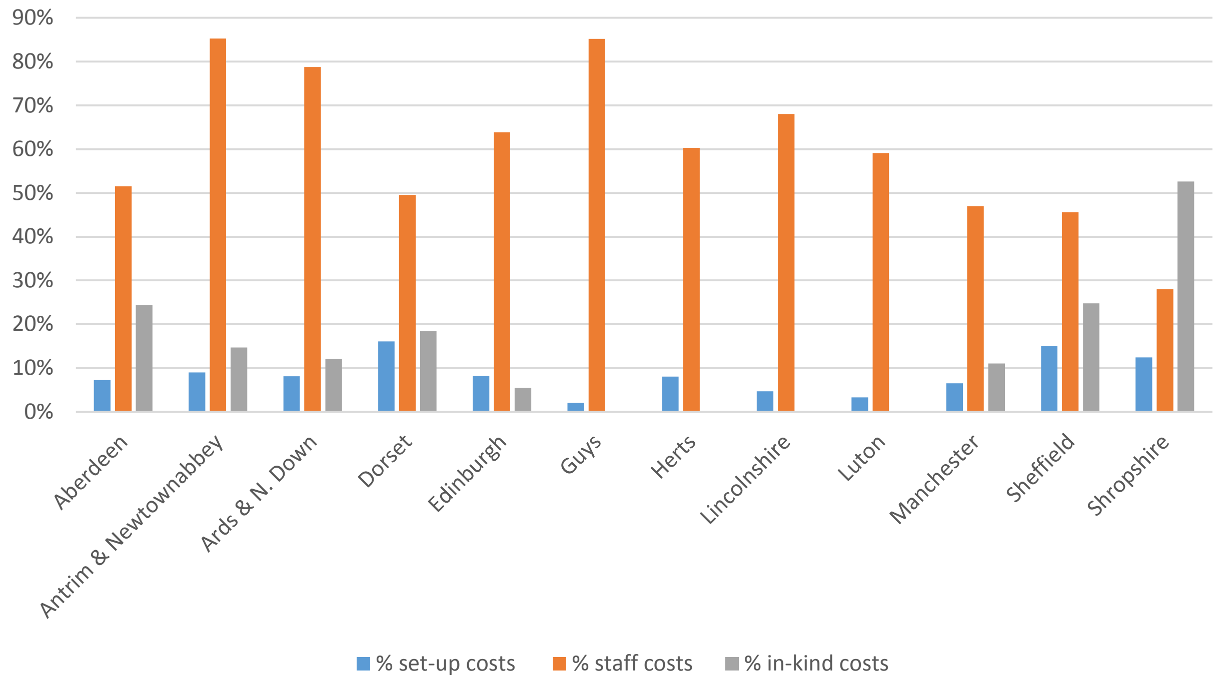


**Figure 9.2 Proportion of total costs due to set-up, in-kind and staff costs by service**

Note: Cardiff and Berkshire are omitted from the analysis of costs because the cost information they provided was not comparable.

In the analysis that follows an important distinction is made between set-up costs and running costs. See pages 34-35 for further details on what is included under each.

The extent of set-up costs varies from service to service.[113] In some instances, for example Guys, the service built on an existing project and as a result the set-up costs for the Move More programme were relatively small in comparison to those of some services that were set up from scratch. Lincolnshire and Dorset's set-up costs include a substantial investment (£9k and £15k respectively) in IT systems. As a proportion of total costs, set-up costs range from only 2 per cent for Guys to 16 per cent for Dorset, with a mean of 8 per cent. This variation in the proportion of set-up costs to total costs was also identified in the Lets Get Moving feasibility study, where it largely reflected how intervention costs were allocated across existing services.[114] Clearly, the longer a service has been running, the smaller the share of set-up costs is, in its total costs. In order to deal with this, and because the economic analysis generally takes a relatively short-term 3 month perspective, in the analysis that follows, cost estimates will be presented both including and excluding set-up costs.

---

[113] The service in Herts was unable to provide estimates of set-up costs due to staffing changes since the service was established. Set-up costs for Herts have been imputed as the average proportion of total costs for all other services (8 per cent).

[114] https://www.gov.uk/government/publications/lets-get-moving-care-pathway-feasibility-study-results

For all services, staff costs represent a large proportion of the running (and total) costs, but this displays wide variation, ranging from 28 per cent for Shropshire to 85 per cent for Guys and Antrim and Newtownabbey.

Some services found it difficult to estimate some of the in-kind costs incurred by them. For example, where vouchers or discount cards were given to service users to access sports and leisure facilities, it was not always possible to know precisely how many of these had been used. Four services do not report any in-kind contributions, but for the others the contribution ranges from a modest 5 per cent for Edinburgh to a very large 53 per cent for Shropshire.

## Average cost per service user

As is the case for the outcome analysis, there are a number of ways of calculating the average cost per service user. The most conservative approach assumes that a service user is someone who completes the programme. This is the approach recommended in the Macmillan evaluation framework.[115] The least conservative approach averages the cost over all service users who started the programme, regardless of their length of engagement.

Again it is worth noting here that completion is not straightforward to define in the context of this programme, which does not have a defined end point.  For the 3 month perspective of the cost analysis, start and completion are defined via the provision of primary outcome information (SPAQ); a starter is someone who provides baseline SPAQ data (n = 2293), and a 3 month completer is someone who provides SPAQ data at a 3 months follow-up (n = 1045).

The estimated costs for 3 months have been calculated from the monthly cost estimates reported in Table 9.4, that is, total costs divided by the number of months a service has been running, and multiplied by 3. Two estimates are provided, with and without the inclusion of set-up costs. These figures are reported in Table 9.5 (see Appendix 3). It is clear from this table that the exclusion of set-up costs makes little difference to the estimates, so costs including set-up costs are discussed below; this represents a slightly more conservative approach than if set-up costs were excluded.[116]

Table 9.5 reports mean costs per service user for each service and the overall mean cost per service user across all services. If costs are averaged across all starters, the mean cost per service user is £111 (£101 excluding set-up costs). However, taking the (recommended) cost per completer approach results in a mean cost per completer of £291 (£265 excluding set-

---

[115] www.macmillan.org.uk/documents/aboutus/health_professionals/physicalactivity/cancer-physical-activity-standard-evaluation-framework-measurement-tools.pdf

[116] As well as the absolute cost levels, the ranking of services by monthly cost is largely the same whether or not set-up costs are included.

up costs). This cost estimate is similar to that found in previous studies. The Lets Get Moving feasibility study found a mean cost per participant of between £124 and £630[114]. Also, a recent systematic review of exercise referral schemes (which underpins the NICE public health guideline on exercise referral schemes in primary care[117]) found an average cost per service user of £225.[107]

Mean costs per completer vary substantially across services; these are also shown in Figure 9.3 (together with costs averaged across all starters). Costs per completer are lowest for Guys at a mean average of £64 and highest for Aberdeen at a mean average of £531.[118] The Guys service has total costs close to the mean but a very high throughput. In contrast Aberdeen has high costs and a low number of services users (at both start and completion), despite being the most long-established service.

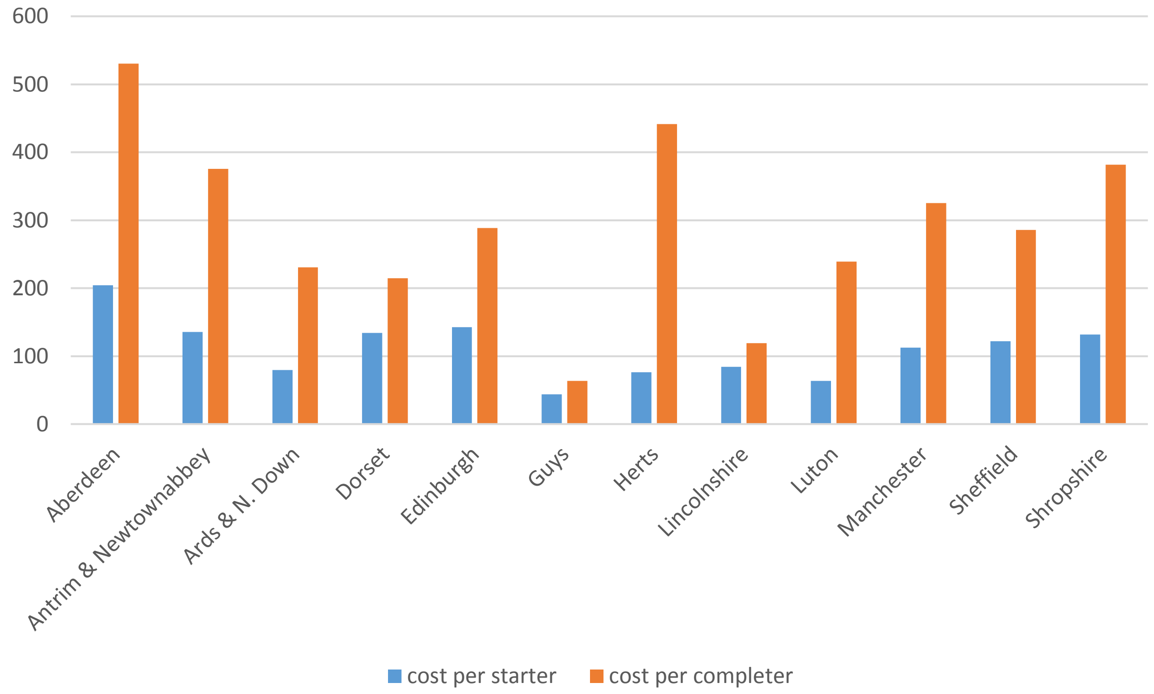


**Figure 9.3: Cost per service user (starters and 3 month completers)**

Note: Cardiff and Berkshire are omitted from the analysis of costs because the cost information provided was not comparable.

Table 9.6 (Appendix 3) reports mean costs per service user by service sub-groups. Nationally, the highest costs per service user are for Scotland; dominated by the high costs for Aberdeen. Northern Ireland has the second highest costs, but it should be noted that both services in Northern Ireland are relatively recently established compared to the other services. In terms of delivery model, the costs for both signposting only and direct

---

[117] www.nice.org.uk/guidance/ph54

[118] Note that the estimate of cost per completer for Antrim and Newtownabbey may be unreliable due to small sample size (<30).

delivery are quite similar. In terms of setting, somewhat surprisingly, the healthcare setting has the lowest mean cost per service user. This is partly due to the fact that this setting achieves higher follow-up rates (59 per cent vs. 41 per cent for the community setting).

## Cost per outcome analysis

An estimate of the average cost per improvement in outcome measure is given by the ratio of the average change in cost divided by the average change in outcome. These results are presented in Table 9.7. The number of starters and completers for each outcome is given in the first two columns, along with the mean cost per starter and per completer from Table 9.5. The next two columns show the mean change in outcomes first as they are calculated using the ITT method, and second as they are calculated using completers only. For FACIT, EQ5D, GSE and SPAQ these values are taken from Table 9.1.

The next four columns of Table 9.7 show the mean cost per outcome for each outcome calculated in four different ways. Column (1) represents the most conservative approach. In this (recommended) protocol the most conservative assumptions about both costs and outcomes are used; outcomes are estimated from the ITT analysis and costs are averaged over completers only. This produces the highest estimates of costs per outcome. In column (2), the mean outcomes are estimated using the ITT approach but the costs are averaged across all service users rather than over completers only.  In column (3), both costs and outcomes are estimated for completers only. In (4), costs are averaged across all service users and combined with outcomes for completers only. This all results in a range of estimates; and for comparative purposes the overall mean of the four estimates is given in the final column of Table 9.7.

Costs per outcome for FACIT, EQ5D and GSE are difficult to interpret and are generally only useful by way of comparison with other interventions, but no other studies were identified which report comparable  statistics.

Cost per unit increase in SPAQ is the average cost of producing another minute of moderate or vigorous activity. These costs range from £1 per additional minute in the most optimistic scenario to £6 per minute in the most conservative, with a mean of £3 (or £60 to £360 for an additional hour of exercise, with a mean of £180). Again, no other studies were identified that report comparable statistics.

| | | | mean change in outcomes 3 months | | mean cost per outcome £ | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Outcome** | **No. Starters** | **No. completers** | **Starters (ITT)** | **completers** | **(1)** | **(2)** | **(3)** | **(4)** | **Mean (1) to (4)** |
| FACIT | 2310 | 1090 | 0.9 | 1.1 | 324 | 123 | 265 | 101 | 203 |
| EQ5D | 2322 | 445 | 0.01 | 0.10 | 29132 | 11092 | 2913 | 1109 | 11062 |
| GSE | 1771 | 859 | 0.1 | 0.8 | 2913 | 1109 | 364 | 139 | 1131 |
| SPAQ | 2464 | 1093 | 49 | 127 | 6 | 2 | 2 | 1 | 3 |
| QALYs (a) | 2322 | 445 | 0.0025 | 0.025 | 116527 | 44369 | 11653 | 4437 | 44246 |
| QALYS (b) | 2322 | 445 | 0.01 | 0.10 | 29132 | 11092 | 2913 | 1109 | 11062 |
| mean cost | £111 | £291 | | | | | | | |

Table 9.7: Costs per outcome and cost per QALY

Notes: Cardiff and Berkshire are omitted from the analysis of costs because the cost information provided was not comparable.

Calculations for mean cost per outcome:

(1) Costs averaged over completers, outcomes ITT
(2) Costs averaged over all starters, outcomes ITT
(3) Costs averaged over completers, outcomes completers
(4) = Costs averaged over all starters, outcomes completers

In ITT analysis outcomes are assessed outcomes for all service users who enrolled on the programme, regardless of whether they dropped out at any stage. For service users not present at follow up their baseline value is assessed at follow up, which is equivalent to the assumption that there is no change in outcome for that service user.

Two conservative assumptions are made to generate QALYS. Firstly, the intervention affects only quality of life and not quantity. Secondly, in QALYS (a) the treatment effect lasts only for the length of the intervention (3 months), in QALYS (b) the intervention effect is assumed to last for 12 months.

## Cost per quality adjusted life year (QALY)

QALY calculation requires an estimate of the change in both quality of life and quantity of life for all members of the service user cohort, and an estimate of the duration of the treatment effect: i.e., how long the change in quality of life lasts. We estimate changes in quality of life using the EQ-5D index. For example, 10 years in a health state valued at 0.8 (on the EQ5D) gives 8 QALYs.

In order to estimate changes in length of life we would need epidemiological or trial data that links physical activity participation to mortality effects in this population (people with cancer diagnoses). We are not aware of any such data; hence, in the absence of this information, we make the (conservative) assumption that the intervention affects only quality of life and not quantity. The QALY calculation is then the change in quality of life multiplied by the duration effect.

The most conservative assumption for duration is that the treatment effect lasts only for the length of the intervention, and that quality of life returns to baseline level when treatment ends. This seems a particularly conservative approach in the context of our 3 month perspective. There is no epidemiological/cohort data that provides information on how quality of life for people with cancer is affected in the long-term by this type of intervention; however, a number of other sources of information are available, although these do provide very mixed results on the longer term effects.

After a systematic review of the evidence on methods of increasing physical activity which was conducted in 2006, NICE concluded that brief interventions are effective at increasing physical activity levels, in the short term (6 to 12 weeks), the long term (over 12 weeks), and in the very long term (12 months or more).[119] For the effect to be sustained for one year, the evidence suggested that several follow-up sessions over a period of 3 to 6 months are required after the initial consultation episode, and this is similar to that which is provided by the Macmillan treatment pathway. In contrast to this, a systematic review of evidence of behavioural interventions to modify physical activity behaviour in general populations and cancer patients and survivors (which was assessed for two sets of NICE public health guidance on behaviour change) found most interventions had no effect three months or more after the end of the intervention.[120] More recently, an evaluation of a 12 week supervised exercise programme for women being treated for early stage breast cancer found sustained increases in minutes per week of exercise up to 6 months after the

---

[119] NICE (2006) Four commonly used methods to increase physical activity: brief interventions in primary care, exercise referral schemes, pedometers and community-based exercise programmes for walking and cycling. (NICE) public health guidance PH2. https://www.nice.org.uk/guidance/ph2.

[120] Holtzman et al, (2004) Effectiveness of behavioural interventions to modify physical activity behaviours in general populations and cancer patients and survivors. Evid Rep Technol Assess (Summ). (102):1-8. assessed for NCE PH6 Behaviour change at population, community and individual levels (2007) and NICE PH 49 Behaviour change: individual approaches (2014)

intervention, and this could be expected to contribute to enhanced health related quality of life.[108] Our own analysis of longer term EQ-5D outcomes from those services that could provide this information (see Table 9.8 in Appendix 3) show sustained increases at 6 months for five of the seven services and sustained increases at 12 months for the one service with sufficient numbers to do this analysis (Lincolnshire).

As a result of the mixed evidence on longer-term effects we provide a range of estimates below (from the effect lasting 3 months to 12 months) and we discuss how varying this assumption will affect the results. The EQ5D index is converted to the number of QALYs generated assuming no change to quantity of life. For duration of treatment we take two approaches.

The most conservative is that the treatment effect lasts only for the length of the intervention (3 months). Here the change in quality of life (change in EQ-5D) generated in 3 months is divided by 4 to provide an estimate of the change in QALYs.[121] A less conservative assumption is that the treatment effect lasts for 12 months. Here the change in EQ-5D is the QALY increase (i.e., purely an increase in quality of life that is assumed to last a year). These results are shown in the last 2 rows of Table 9.7 as QALYs (a) and (b) respectively.

Using the conservative approach (3 months duration) 0.0025 QALYs are generated (a) from the ITT analysis. Using the less conservative approach (12 month duration) 0.01 QALYS are generated. For comparison, a recent study of an 18 week exercise programme for outpatients with cancer in the Netherlands found 0.03 QALYs for patients with colon cancer and 0.01 for those with breast cancer.[122] In contrast, one systematic review of exercise referral schemes in primary care found an average of only 0.003 QALYs produced[45] and another found an estimate of 0.008.[123]

**A wide range of cost per QALY estimates are also produced depending on which duration approach is taken**. Assuming a 3 month duration cost per QALY (a) ranges from £4,437 in the most optimistic scenario to £116,527 in the most conservative. The two least conservative estimates (and the overall mean, £44,246) are a long way above the NICE recommended threshold for cost effectiveness of public health interventions, which is around £20,000 per QALY.[124] However, the two more optimistic scenarios are both well under this threshold. **If we assume the duration of the effect lasts for 12**

---

[121] To put this another way, if quality of life is improved by 0.01 for 3 months (the change in the EQ5D index) and we assume no change in quantity of life and a treatment effect of only 3 months (i.e. same as length of intervention) then the QALY change is 0.01/4 = 0.0025.

[122] May AM, et al (2017) Cost-effectiveness analysis of an 18-week exercise programme for patients with breast and colon cancer undergoing adjuvant chemotherapy: the randomised PACT study, BMJ Open 7:e012187. doi:10.1136/bmjopen-2016-012187

[123] Pavey TG, Anokye N, Taylor AH, et al. The clinical effectiveness and cost-effectiveness of exercise referral schemes: a systematic review and economic evaluation. *Health Technology Assessment (Winchester, England)*. 2011;15(44):i-254. doi:10.3310/hta15440.

[124] www.nice.org.uk/advice/lgb10/chapter/judging-the-cost-effectiveness-of-public-health-activities

**months (b), the most conservative approach results in a cost per QALY above the threshold at £29,132, but all other approaches are below the threshold**.

For comparison, two systematic reviews of exercise referral schemes [47, 60] found mean cost per QALY estimates of £20,876 and £76,276 respectively; both also found that this mean estimate was very sensitive to small variation in assumptions. The 18 week exercise programme for outpatients with cancer in the Netherlands[122] found that the intervention was cost effective for patients with colon cancer, but only had a very small probability of being cost effective for patients with breast cancer, judged against the Dutch public health cost effectiveness thresholds.

To consider the sensitivity of these results further, using the most conservative protocols (QALYs(a) assuming the treatment only lasts for 3 months and column (1)) holding costs per completer constant at £291, the QALYs generated would need to increase six-fold to bring the cost per QALY to below £20,000. Assuming no change in quantity of life this would require the current mean EQ5D increase of 0.01 to be sustained for 6 years on average. Looking at this another way, keeping the QALYs generated constant at 0.0025, the cost per completer would need to be less than £50 to result in a cost per QALY of below the cost effectiveness threshold. This seems unrealistic as the lowest cost per completer across the services is £64 (for Guys) and this is an unusually low value, with the next highest being £119 (for Lincolnshire).

Table 9.9 reports mean cost per outcome for each service sub-group using the protocol from column (1) in Table 9.7: i.e., the recommended conservative approach. The lowest costs per minute of additional exercise are found in England and Wales. Both delivery models and both settings also achieve low costs per minute of additional exercise. The Scottish model is the least cost-effective for FACIT and EQ5D.

The last two columns report cost per QALYs assuming: (a) a 3 month duration of effect; and (b) a 12 month duration. For the more conservative 3 month duration, the signposting only model falls just under the NICE cost effectiveness threshold for public health interventions (£20,000), but all other sub-groups are well above this threshold. The Scottish model has a particularly high cost per QALY, largely due to high costs and low throughput in Aberdeen.[125] **Signposting only achieves a much lower cost per QALY than direct delivery**. **The community and healthcare settings achieve a similar cost per QALY. Assuming the duration of effect lasts for 12 months (b), the service in England and Wales appears cost effective, falling below the £20,000 threshold; as does the 'signposting only' model, and both the community and healthcare settings**.

---

[125] The same caveats to national comparisons discussed in relation to the outcomes analysis, are also relevant here.

| | | Cost per outcome | | | | | |
|---|---|---|---|---|---|---|---|
| | | **FACIT** | **EQ5D** | **GSE** | **SPAQ** | **QALYs(a)** | **QALYs(bb)** |
| **National model** | **England & Wales** | 205 | 18,417 | 921 | 3 | 73,669 | 18,417 |
| | **Scotland** | 502 | 40,194 | | 10 | 160,776 | 40,194 |
| | **Northern Ireland** | 353 | 9,407 | 2,822 | 11 | 37,628 | 28,221 |
| **Delivery model** | **Signposting and Delivery** | 302 | 21,129 | 2,113 | 5 | 84,517 | 21,129 |
| | **Signposting only** | 105 | 4,988 | 499 | 3 | 19,952 | 4,988 |
| **Setting** | **Community** | 226 | 12,447 | 1,245 | 5 | 49,789 | 12,447 |
| | **Healthcare** | 294 | 11,766 | 588 | 3 | 47,062 | 11,766 |

**Table 9.9: Cost per outcome by sub-group using ITT approach and cost per completer.**

Notes: Cardiff and Berkshire are omitted from the analysis of costs because the cost information provided was not comparable.

Costs are averaged over completers, and outcomes use an ITT approach where outcomes are assessed outcomes for all service users who enrolled on the programme, regardless of whether they dropped out at any stage. For service users not present at follow up their baseline value is assessed at follow up, which is equivalent to the assumption that there is no change in outcome for that service user.

Two conservative assumptions are made to generate QALYS. Firstly, the intervention affects only quality of life and not quantity. Secondly, in QALYS (a) the treatment effect lasts only for the length of the intervention (3 months), in QALYS (b) the intervention effect is assumed to last for 12 months.

## Discussion

This section has presented the results of the economic analysis which compares costs to outcomes in order to provide an estimate of the cost effectiveness of the Physical Activity Behaviour Change Care Pathway. A 3 month perspective was generally taken because not all services are at the same stage in their operating cycle, and the number of services users recruited and providing follow-up data at 6 and 12 months was judged to be too small (especially for the more recently established services) to provide reliable estimates of mean costs and outcomes over the longer follow-up period. However, we provide a range of estimates for cost per QALY assuming the effect lasts 3 months and 12 months.

The results show that, overall, the Physical Activity Behaviour Change Care Pathway has demonstrated statistically significant improvements in all four outcome measures. For the primary outcome measure (SPAQ), the improvement in the mean number of minutes exercise per week (49 minutes) compares favourably to that achieved by other exercise referral schemes.[107] However, it should be noted that while improvements in outcomes are statistically significant, they are also small, and as a result may not be clinically meaningful. Unfortunately, it was not possible to identify any studies that could provide estimates of minimal clinically important differences for most of our outcome measures.

There is considerable variation in the outcomes achieved across services; for one service a significant deterioration in FACIT scores was found at month 3 and in another a significant deterioration in GSE score. In terms of the sub-groups of services, all national sub-groups exhibit significant increases in SPAQ; services in Scotland did not achieve a significant increase in EQ5D, FACIT or GSE. However, national service comparisons are distorted by larger sample sizes for the services in England (83 per cent of all service users at baseline). Also the services in Northern Ireland are relative new compared to the services in Scotland and England. The signposting sub-group achieved significant improvements in all outcomes; direct delivery failed to achieve this for GSE. Both the clinical and community settings exhibit significant increases in SPAQ, but only the community setting shows significant changes to FACIT, EQ-5D and GSE score.

It is worth stressing that the main outcomes analysis uses an ITT approach where outcomes for those baseline respondents who did not provide follow-up data are set at their baseline value, hence the significant improvements in mean outcomes are realised even where a substantial number of people of who start the programme are assumed to display no change at follow-up. Hence, these estimates are a good approximation of expected ‘real world’ changes in outcomes. For the more optimistic completers only analysis it is important to stress that less than half of the original service users remain at month 3 and this group may not be representative of the population of service users as whole, which may lead to an overestimate of the effectiveness of the intervention.

This evaluation has used a before and after study design which is not a strong method for attributing cause and effect. Other factors could have affected these changes in outcomes, which are not accounted for in this study, so the change should not be interpreted as being necessarily directly caused by the Physical Activity Behaviour Change Care Pathway.

There is a large variation in monthly costs across services, and this is similar to that found in previous evaluations of exercises referral schemes. The mean cost per completer of £291 is similar to that found in a recent systematic review of exercise referral schemes.[107] This mean value varied substantially across services, being lowest for Guys at £64 and highest for Aberdeen at £531. The Guys service has total costs close to the mean but a very high throughput. In contrast Aberdeen has high costs and low number of services users (at both start and completion), despite being the most long-established service. For the service sub-groups, nationally, the highest costs per service user are for Scotland. In terms of delivery model, the costs for both signposting and direct delivery are quite similar. In terms of setting, somewhat surprisingly, the healthcare setting has the lowest mean cost per service user.

The analysis only considers the direct costs of delivery for this intervention. It does not consider the costs to the service users (for example, travel costs) or any implications for NHS resource use (for example, any resulting effects on GP and hospital visits). The cost information presented here is our best estimate of the costs incurred by services, reported by the services themselves. Services sometimes found it challenging to provide information on the full costs of delivery. This was particularly the case where the service was embedded within another service.

**Cost per additional minute of moderate or vigorous activity range from £1 to £6, depending on whether conservative or optimistic protocols are used**. Similarly a very large range of cost per QALY estimates are produced depending on the assumptions made. **Only the most optimistic assumptions result in a cost per QALY which is below the NICE recommended threshold for the cost effectiveness of public health interventions (around £20,000 per QALY)**.

In the absence of information on the mortality effects of physical activity for people with cancer, and mixed evidence on the duration effects of this intervention, we provide a range of estimates for the quality of life years (QALYs) generated and cost per QALY estimates from the effect lasting 3 months to 12 months.

In terms of the service sub-groups, the lowest costs per minute of additional exercise are found in England and Wales. In terms of cost per QALY, the Scottish model has a particularly high cost per QALY, largely due to high costs and low throughput in Aberdeen. However, it should be stressed that the same caveats to the national comparisons discussed in relation to the outcomes analysis, are also relevant here. Signposting achieves a much lower cost per QALY than direct delivery. The community and healthcare settings achieve a similar cost per QALY.

A number of other caveats outlined in the methods section (see pages 33-40) should be borne in mind when interpreting these results. Completion was difficult to define because the Physical Activity Behaviour Change Care Pathway is not a time limited programme with a defined end point. We note that the Macmillan model for the pathway states that 12 months of on-going support is provided. However, there is no expectation that every service user should remain for 12 months, and services have been established for varying lengths of time, making 12 month follow-up impractical for some services. 3 months generally been used as this is where the data is strongest, although we have also looked at changes in health-related quality of life (EQ-5D) at 6 months and 12 months for those projects where sufficient data is available It should be noted when interpreting these results that progression on outcomes may not have come to full fruition at 3 months. If outcomes improve further in the longer term then the estimates of cost per outcome presented here will be higher than they would be at say 6 or 12 months.[126] However, drop-out rates and non-adherence also tend to increase over time, and this would increase the cost per outcome estimates. Further, we assume that start and completion are defined via provision of outcome information. We acknowledge that survey completion is not necessarily the same as programme completion, but this is the best indicator available.

---

126 Preliminary analysis of longer term outcomes presented in the first draft of this report (using a completers only analysis) showed that mean levels for GSE and SPAQ peaked at 12 months, FACIT at 6 months and the EQ-5D at 3 months.

Finally, we have not carried out any statistical analysis on cell sizes that are smaller than 30 service users, because extrapolating from these small sample sizes can be very misleading. This has limited our ability to consider service-by-service variation and also sub-group analysis is limited by small sample sizes.

# 10. Conclusions and recommendations

*In this Chapter, we draw together key findings from the evaluation. We include a discussion of the different services' operating models and make a series of recommendations for services, Macmillan and future funders.*

## Key findings

### Recruitment

Services have generally found generating referrals from HCPs to be considerably harder and more time consuming than expected. In terms of this, services based in a healthcare setting have an advantage over those based in a community setting. Establishing trust is key – this takes time and is most effective if engaged in face to face and regularly.

All services receive referrals from a wide source of HCPs, although CNSs are the primary source of referrals. All have struggled to generate significant levels of referrals from GPs.

Macmillan information centres can be key in opening up opportunities for engaging with clinical staff and are valuable in providing two-way referrals – into the service but also allowing service users to access additional support such as financial advice, counselling and complementary therapies.

The extent to which services are embedded in the recovery package can have an impact on referral numbers. Where health and wellbeing events are regular and well-attended, they can provide an important source of referrals and help to build relationships with HCPs.

Services use a variety of methods to promote their services to PLWC. All make extensive use of printed materials and most use electronic methods and/or social media. The Macmillan brand is well regarded and helps create trust in the quality of the service.

### Behaviour change interventions

MI training is valued by service staff and helps improve their interview technique. Interventions were personalised and Practitioners empathetic and supporting. Service users found the intervention helpful and the experience a positive one.

Behaviour change interventions are occurring in one of three ways – face-to-face, by telephone and in group settings. These interventions are usually delivered by a Move More

Practitioner who has received MI and level 4 Cancer Rehabilitation training. The MI training is valued by staff and where staff have not been trained, the interventions they deliver are weaker.

Service users found the interventions helpful and the experience a positive one. Practitioners were empathetic and supportive, but interventions do not always follow the evidence-based model that Macmillan have been working in partnership to test or effectively use MI techniques. There is a significant variation in the quality of interventions that were observed. Practitioners do not always carry out full MI but modify the extent to which they use MI, based on their perception of the individual's level of motivation and their stage of treatment. This goes against the principles and philosophy of MI and reflects a lack of understanding of true MI among practitioners.

Initial service user engagement delivered by telephone were the least likely to provide quality MI and resembled very brief advice. In models that used this approach, there is no behaviour change support provided prior to participation in the service.

Group interventions as currently delivered do not currently meet the recommended approach to delivering behaviour change. However, they provide a valuable opportunity for mutual support and motivation.

## Physical activity offer

Overall services offer access to a wide range of physical activities that are either delivered directly or provided by others. However, no services observed consistently offer access to all the activities that form part of Macmillan's minimum recommended offer. Some services that deliver activities directly place greater emphasis on promoting these. The physical activity offer is not always a personalised one.

That said, directly delivered circuits classes appear popular and are valued by service users that choose to participate in them; these classes allow service users to access tailored exercise appropriate to them that they can replicate at home. Closed sessions allow service users to exercise in a safe and private environment and provide important opportunities for obtaining mutual support and encouragement from others with similar experiences.

There is no one size fits all physical activity. An appropriate offer is one that takes into account local facilities and services and provides activities at a variety of times and locations, accessible by public transport. Some service users prefer to engage in physical activities alone, rather than as part of a class. Others appreciate the 'normality' of taking part in physical activities open to all whilst still others prefer to engage primarily with PLWC like themselves.

Services based in leisure settings benefit from easier access to a wider range of classes and facilities which can make the transition from free sessions to continued activity more straightforward than it is in a healthcare setting. In some instances activities can be offered at reduced or nominal rates with continued access to the same instructors; this also helps to provide continuity.

Signposting can be an effective way of enabling service users to access a wide range of services. Signposting alone requires good systems in place to provide on-going support to service users in order to ensure that they continue to be able to undertake physical activities that meet their needs. It also requires maps and paths to connect people and services.

A key success factor is ensuring that instructors are knowledgeable about physical activity and the needs of PLWC. They also need to be approachable and be able to develop good rapport with a range of service users. It is much harder to control this when activities are signposted to rather than delivered directly.

## Behaviour change support

With the exception of Lincolnshire, services do not meet the Macmillan recommended pathway of providing formal support and follow-up over 12 months. Support tends to be informal, ad hoc and reactive to requests from the service users. Support is often provided as part of the activity sessions delivered as part of the service. Once these end, opportunities for on-going support generally diminish. However, service users overwhelming felt they received the support they needed and do not necessarily feel that anything is missing nor that they necessarily required ongoing support.

Not all Practitioners (or service users) understood the programme as one that lasts 12 months, and some services did not have the resources to deliver formal on-going support for 12 months for all.

## Service management

There are two broad operational models within the programme – community based and healthcare based. There are a number of pros and cons to each approach.

The Move More practitioner is the principal delivery role in services and in some instances it is the only delivery role. This role is often responsible for a wide range of tasks and consequently we have found instances where this approach has proved to be impractical. Practitioners are often skilled at, and motivated by, engaging and supporting service users and tended to prioritise their needs over other aspects of the role. Practitioners appear to be less comfortable when undertaking project management, administrative and data collection activities.

It is rare to find a Practitioner who is effective in engaging in both the healthcare and community settings. Where this does occur this is often due to relationships established prior to the service being established.

Practitioners welcome the networking opportunities that Macmillan provides. Cluster meetings/Communities of Practice are considered by most as effective means of improving their service delivery, sharing ideas and discussing good practice. Knowledge exchange workshops are also viewed positively by Practitioners, particularly those from Scotland.

Despite considerable additional support provided by CFE and Macmillan throughout the evaluation, the quality of data varies considerably across the 14 services and across different aspects of the minimum dataset. Services found completion of the survey at follow-up sampling points particularly challenging and this is reflected in the high non-response rates. The quality and completeness of the data limits the analysis that is possible as a result. Data collection is seen as a time consuming task and one that is considered of low priority by a number of services.

## Outcomes and impact

Self-reported data suggests service users have generally maintained or increased their levels of physical activity following engagement with the service. However, the levels of activity are high in relation to those of the population at large and the sample is likely to be biased towards those who are more motivated.

For those who provided data at both start and follow-up, we found statistically significant increases in the average amounts of physical activity being undertaken between baseline and 3, 6 and 12 months. Of those who completed the questionnaires at start and 12 months, none who were inactive at the start remained so at 12 months.

We found statistically significant improvements in service users' own perceived state of their health and also health related quality of life between baseline and 3 months, 3 and 6 months and 6 and 12 months. However, the largest increase is observed between start and 3 months, with more modest increases thereafter. Service users articulated a variety of ways in which their health had improved as a result of participating in the programme, and for some the increased physical activity was a catalyst for further behaviour change.

We found statistically significant decreases in levels of fatigue in service users between baseline and 3 months, baseline and 6 months and start and 12 months. Qualitative interviews with service users supported this finding. They report that energy levels have increased since participating in the programme.

The outcomes analysis takes a completers only approach. The downside of this is that the resultant sample may not be representative of the population of service users. Those within the resultant sample may be more motivated than the average service user to participate in the intervention, and if so this will lead to an overestimate of outcomes. In addition, and most importantly, different levels of success in terms of collecting data mean that the results over-represent the data from a small number of services.

Service users do not always attribute the improvements they experience to their increased physical activity. Without a control or other comparator group it is difficult to say with any certainty whether the service has improved service users' health and mental wellbeing or whether this would have happened anyway. Given the myriad health and wellbeing challenges that PLWC are likely to face, it well may be difficult for them to pinpoint which factors have made a difference and the relative importance of each. Successfully completing treatment and overcoming cancer (a large proportion of service users in the samples have been effectively treated and are in remission or cancer free) is clearly a major factor contributing to many service users' feelings of wellbeing. However, we would expect the reported increases in physical activity to make some impact on health, including on mental wellbeing.

What is clear is that service users value and derive benefit from the specialist support and guidance provided by the service staff and the mutual support of other service users. Most of those we spoke to were motivated and inclined to increase their physical activity levels, either because they had been active prior to diagnosis or because they were motivated to improve their fitness in order to better overcome cancer. However, it seems likely that they would not have been able to enhance and maintain their physical activity as successfully without the crucial support provided by the services.

## Economic analysis

Taking a conservative, ITT, approach, the economic analysis shows that overall the Physical Activity Behaviour Change Care Pathway has resulted in statistically significant improvements in all four outcome measures. This evaluation has used a before and after study design which is not a strong method for attributing cause and effect. Other factors, which are not accounted for in this study, could have affected these changes in outcomes, so the change should not be interpreted as necessarily being directly caused by the Physical Activity Behaviour Change Care Pathway.

There is a large variation in monthly costs across services. However, the mean cost per completer, of £291, is similar to that found by other evaluations of exercise referral schemes.

Estimates of cost per additional minute of moderate or vigorous activity range from £1 to £6, depending on whether conservative or optimistic protocols are used. Similarly, a very large range of cost-per-QALY estimates are produced, depending on the assumptions made. Only the most optimistic assumptions result in a cost-per-QALY which is below the

NICE recommended threshold for the cost effectiveness of public health interventions (around £20,000 per QALY).

In the absence of information on the mortality effects of physical activity for people with cancer, and on the duration effect for this intervention, very conservative assumptions have been made when estimating the quality of life years (QALYs) generated; this may have resulted in a cost-per-QALY estimate that is biased upwards.

## Discussion of operating models

Throughout the report we have explored the contrasts between the different approaches and models of working. Here we draw together some of the key findings from qualitative and quantitative sources in order to identify the strengths, weaknesses, opportunities and challenges of each model.

### National models

Taking the outcomes and economic analysis as a whole, services in England and Wales appear stronger in terms of achieving positive outcomes across the different measures. Assuming effects last for 12 months, the England and Wales model appears to fall within the NICE cost effectiveness guidelines for public health interventions. However, comparisons between the national provisions are distorted by the larger sample sizes produced by the services in England and Wales. Samples for Scotland and Northern Ireland are smaller, meaning that, for these, significant changes are more difficult to detect. Furthermore, the Northern Ireland services are relatively new.

The services in England and Wales cannot usefully be thought of as following a single model, as they are so varied in terms of how they are structured and how they deliver the Physical Activity Behaviour Change Care Pathway. It is difficult to draw conclusions about the effectiveness of these services overall, other than by comparison to the approaches in Northern Ireland and Scotland – these two national provisions are more homogeneous within themselves.

The two Northern Ireland services included in the evaluation have a similar offer and similar ways of working (leisure centre-based, five free taster sessions and the direct delivery of closed circuit type sessions which are led by a single full-time practitioner). However, this is not necessarily the case across all services in Northern Ireland. So, the extent to which this can be described as a national model is limited. Coming on board at a later date, the services have benefitted from learning from elsewhere in the UK.

Early indications are that data collection at baseline in Northern Ireland is good compared that of other services. We found some promising practice in the two services. First, there is, in theory, no time limit in terms of how long service users can engage with the service.

Also, we observed highly personalised and tailored provisions. But our findings from others services suggest that this level of service may not be sustainable in the longer term as the service grows and more service users engage.

The Move More approach in Scotland is based on the approach prescribed by Macmillan Scotland and can be better described as a national approach. The common features are an offer of four activities (circuits, gentle movement, gardening and walking). Initial service user engagement takes place by telephone. While originally these sessions may have been designed as telephone triage sessions only, it is clear that they are considered by Practitioners to be behaviour change interventions. There is no further opportunity for initial behaviour change prior to participation in the programme. The Scotland services also make extensive use of volunteers to support activity delivery. This, in theory, might make the model more sustainable. However, Scotland had the highest costs per service user and has a particularly high cost per QALY. This is largely due to high costs and low throughput in Aberdeen. The relatively poor response rates to the baseline questionnaire contribute to this. This in turn may be linked to the fact that, unlike other services, the initial intervention is conducted by telephone and the questionnaire is posted out to service users. Other services have the opportunity to collect and / or support completion of the questionnaire during a face-to-face intervention.

Based on our observations, effective behaviour change is not currently occurring in the Scotland model.  Performance has improved over the course of the evaluation, based on learning from other services; however, no interventions observed were considered to be acceptable as measured by the BECCI tool. More thought needs to go into creating an environment conducive to effective intervention. The crucial factor is making firm advance appointments with service users at a time convenient to them.

## Signposting compared with direct delivery models

Signposting services predominantly support service users through directing them to activities delivered by other organisations. These services also offer some directly delivered activity, but this is very limited.

The signposting model generally achieves significant changes in outcomes across the 12 months. The signposting model has lower costs per QALY than direct delivery and it falls within the NICE cost effectiveness threshold for public health interventions. The signposting data is dominated by data from the Lincolnshire service, particularly at the 12 month point. This means it is difficult to draw firm conclusions about the effectiveness of the signposting model more generally. It may be that the better outcomes and cost-effectiveness observed is due to other aspects of what Lincolnshire provide, for example, the fact that they are the only evaluated service that provides formal ongoing support for the full 12 months.

Lincolnshire's excellent response rates are likely to be due to their provision of formal follow-up sessions throughout the 12 months. Among the services included in the evaluation, Lincolnshire are alone in doing this. This type of formal support is arguably more important in the signposting model as there is no contact with service users otherwise. Formal support is important in the signposting model to ensure that services are enabled to continue to access an activity that is right for them.

The signposting model potentially frees up practitioner time that can be used in ways other than delivering sessions. For example in Lincolnshire, practitioner time is directed towards providing the on-going, formal support. Without the temptation to 'sell' activities which are directly delivered, signposting models have the potential to provide a genuinely tailored and personalised service.

There is no requirement from Macmillan to deliver activities directly. But signposting to community activities does require Practitioners to have a good understanding of the availability and quality of local activities – where Practitioners come from a healthcare background (as in the case of Berkshire) this can be an issue.

Ideally, the model requires a good range of local activities to which to signpost. Where this is not the case, this can limit the range of opportunities to the self-directed activities only (such as using the Move More DVD and incorporating exercise into everyday activities). This means that participants do not benefit from the social element of classes and the mutual support to be gained from group activities targeted at PLWC. The qualitative findings show that, for many, these are valued aspects of the programme. Another issue is that where local activities are limited and there are waiting lists, this can mean delays before service users can start their preferred activities.

The quantitative evidence for the effectiveness of the direct delivery model is more equivocal. Significant changes were found in physical activity levels between start and 3, 6 and 12 months. However, significant changes for some of the other outcome measures were less consistent across time and were often smaller. The cost-per-QALY is more than for the signposting model. As highlighted above, these differences may be genuine or simply due to larger sample sizes over time for the signposting model.

Direct delivery enables the provision of closed, circuits, type activities. These are particularly popular among PLWC. Service users value activities delivered by trained instructors who are knowledgeable about cancer rehabilitation. In contrast with the signposting model, it is much easier, here, to ensure the quality and appropriateness of activities because they are directly delivered. This gives service users the confidence to return to exercise at a pace and level that is right for them. Directly delivered classes also provide a useful opportunity for Practitioners to engage with and support service users. In the best examples, this reduces the need for more formal follow-up sessions.

The direct delivery model is limited to some extent by the availability of suitable facilities at which to conduct activities. In some cases there is a trade-off between providing activities that are close to communities so that service users do not need to travel long distances and the quality / suitability of venues available.

There is a case to be made that directly delivered activities should always be supplemented by signposting to other activities. This will ensure that the offer is genuinely personalised and not limited by what can be delivered within the constraints of the service. As services grow there is likely to be a limit to the extent to which service users' needs can be catered for by directly delivered activities.

The key benefits and limitations of the two approaches are summarised in figure 10.1 below:

Signposting only

- **Pros:**
  - No direct delivery means resource can be used elsewhere
  - Potential to provide a more personalised offer
  - Within NICE cost-effectiveness thresholds
- **Cons:**
  - Requires understanding of the local activty landscape
  - Quality control - more difficult to ensure activities are approprite and instructors are appropriately trained
  - Requires regular service support
  - No guarantee of closed / group activities for PLWC
  - Can be delays in referrals to other activity

Direct delivery

- **Pros**:
  - Circuit activities enjoyable and provide opportunities to socialise/ get mutual support
  - Abilty to offer quality assured activities with trained instructors knowledgeable in cancer rehabilitation
  - Provides additional opportunities for informal support
- **Cons:**
  - Resource required can be significant and could become unsustainable as popularity grows.
  - Tendency to promote own activities rather than personalised offer

**Figure 10.1: Benefits and limitations of signposting and direct delivery models**

## Healthcare based models compared with community based models

Both healthcare and community settings show significant increases in physical activity levels over the course of the programme. Only the community model, however, shows consistently significant improvements in the other outcomes over time. Again, this may be partly due to the healthcare model having a smaller sample size. Both have similar cost per QALY.

Somewhat surprisingly, the healthcare setting has the lowest mean cost per service user, but both community and healthcare settings achieve a similar cost-per-QALY.

Both models offer considerable benefits – but also challenges. Services delivered from a healthcare setting are better integrated within the local healthcare system. As a result, the service is more embedded within the Recovery Package and engagement with healthcare professionals is more straightforward. Generating referrals from healthcare professionals is a key challenge for community based services.

Community services excel in providing access to a wide variety of physical activities. They tend to be better able to draw on a range of venues. Services delivered from healthcare setting have a more limited offer.

Community settings offer a better transition between free taster sessions and on-going activity. For example, after attending the eight weeks of free sessions provided by GSTT, service users must move on to another provision. This means a new setting and instructors and can mean delays. In contrast, once a service user at the Antrim and Newtownabbey project completes their five taster sessions, they can continue attending classes at the same leisure centre, with the same instructor , for as long as they wish. Figure 10.2 below summarises the benefits and limitations of healthcare and community settings.

Healthcare

- **Pros:**
  - Can be easier to generate referrals (both self and from HCPs)
  - Strong links with healthcare
  - Embedded in recovery package
  - Often well integrated with other Macmillan services

- **Cons:**
  - Restricted behaviour change intervention location
  - Restricted activity offer
  - Transition to community activities

Community

- **Pros**:
  - Variety of physical activity options
  - More locations and thus greater accessibility
  - Transition post activity
  - Continued access to Lvl 4 CanRehab instructors
  - **Cons:**
- More difficult to establish relationships with HCPs and generate referrals
- Can be more expensive

Figure 10.2: Benefits and limitations of healthcare and community settings

## Recommendations

If the Physical Activity Behaviour Change Care Pathway is to continue and be rolled-out more widely, the following should be taken into account.

### For Macmillan and future funders

#### Referrals

As the Recovery Package is rolled out across the UK, services, Macmillan and future funders should work to ensure that the Physical Activity Behaviour Change Care Pathway is embedded within it. In particular, support with physical activity from the services should be a referral options which is part of the Holistic Needs Assessment.

Macmillan and future funders should be aware of and promote the wider benefits of physical activity for PLWC. These include improvements in mental wellbeing, reduced fatigue and reduced social isolation. Benefits can also be felt by families and carers of PLWC.

MI training needs to be an on-going process, with opportunities presented to practice, reflect and receive updates and refresher training. In particular, more training and support is needed on how MI can be used for those already apparently motivated or predisposed towards physical activity.

Macmillan and future policy makers should consider exploring the opportunities, benefits and limitations of group-based approaches further. Where adopted, training should be provided to ensure group approaches are of a good standard.

Macmillan should recommend that Practitioners use the Move More pack as part of conversations as appropriate. The pack should be offered to all service users.

#### Behaviour change interventions

MI training needs to be an on-going process, with opportunities provided to practice, reflect and receive updates and refresher training. In particular, more training and support is needed on how MI can be used for those already apparently motivated or predisposed towards physical activity.

Macmillan and future funders should consider exploring the opportunities, benefits and limitations of group-based approaches further. Where adopted, training should be provided to ensure group approaches are of a good standard.

Macmillan and future funders should recommend that Practitioners consider using the Move More pack as part of conversations if appropriate. The pack should be offered to all service users.

## Physical activity offer

Where possible Macmillan should continue to develop national level partnerships with sports and physical activity organisation National Governing Bodies as this helps to open up opportunities, locally, for services.

Macmillan and future funders should emphasise to services that physical activity should be offered/signposted in line with the service users' needs and preferences. There is benefit in reiterating to new services that there is no requirement to have a local, directly delivered activity and, with the right support mechanisms in place, signposting can be an effective means of providing a wider range of activity.

## Ongoing Behaviour Change Support

Macmillan and future funders should ensure that future services prioritise providing a formal support offer for all service users who need it for minimum of 12 months. This should be a personalised offer, appropriate to the service user, and in line with NICE public health guidelines [PH49].

There may be merit in Macmillan and/or future funders revising the specifications for new services to ensure that the nature of the programme and the follow-up requirement are made clear. Services should be sufficiently resourced to provide ongoing support.

## Service management

Macmillan and future funders should continue to make the cancer and physical activity training package for healthcare professionals available in a variety of formats and on a more frequent basis to local HCPs so that they are better able to and more inclined to deliver very brief advice on physical activity to their cancer patients.

Macmillan and future funders should continue to provide services with opportunities to network with each other and share best practice. These opportunities should be a mixture of regional and national events and offer something for both new and well established services.

## Data collection and evaluation

Where a minimum dataset is to be used in future, data collection should be a condition of grant funding. Questionnaires should be standard across all services, including in terms of common response scales, question ordering and layout.

If data collection is to remain a key part of the Physical Activity Behaviour Change Care Pathway, this needs to be appropriately resourced. Staffing models need to include dedicated and specialist time for supporting service users to complete the questionnaire, for chasing follow-up and for entering, cleaning and analysing the data. Alternatively, Macmillan may wish to outsource data collection to an independent data collection agency.

Macmillan and future funders should consider whether there is scope for providing further guidance to services on the rationale behind the questionnaire and on how they should communicate this rationale to service users.

Macmillan and future funders should ensure that all services understand that the questionnaire should be self-administered by service users. Services should be supported and encouraged to use the online version of the questionnaire with service users completing the questionnaire on a tablet device if necessary.

Services should be supported and encouraged to make use of the data generated by the questionnaires for planning, improving and sustaining their services, as this is likely to lead to services valuing data collection more. Services that have effectively used the data should be facilitated to share their approaches and their results with others who have yet to exploit the data to provide ideas and inspiration. Services will require access to analytical expertise in order to effectively use the data.

Robust data security policies and practices should be pre-requisite for funded services in future.

The evidence for the Physical Activity Behaviour Change Care Pathway could be strengthened with more robust longitudinal data and a controlled trial or quasi-experimental evaluation with a comparison group.

## For services

### Referrals for professionals

The referral process should be made as easy and efficient as possible. Access should be provided to an NHS email where possible to enable professionals to transfer referral details electronically.

Services should focus on building trust with key HCPs through on-going and face-to-face engagement. This should include engagement with Macmillan Information Centres. Services should use the Macmillan referral tactics tool as appropriate.

Services should explore ways to provide feedback on service user progress to those who provide referrals. This could be in the form of case studies of service users.

Services should continue to target GPs and, where possible, work with them to include the service as an option as part of the cancer care review.

Services should broker relationships with a range of potential sources of referrals including other charities, private health providers and other Macmillan services.

The responsibility for generating relationships with and referrals from HCPs and partner organisations should be shared by senior staff, champions and steering group members as well as Practitioners. Steering groups should include suitable senior members who can help to remove blockages to progress and effectively advocate for the service.

### Self referrals

Move More Practitioners should present at health and wellbeing days in order to promote the service to PABC and HCPs. Offering short bursts of taster activity and getting current or former service users to attend as ambassadors for the service should be considered.

Services should promote the wider benefits of physical activity to potential service users and their families.

The language used to promote physical activity should be accessible, appealing and inclusive – to reflect a wide as possible concept of what physical activity involves.

Make self-referral easy with methods such as postcards or tear-off slips.

### Behaviour change interventions

If BC interventions are to be delivered by telephone, appointments should be made in advance so that the service user is aware of the purpose of the call and the estimated length of the call so that they are prepared and have the time for a meaningful conversation that lasts a minimum of 30 minutes. Practitioners need to be trained with the same level of competency and skills for telephone as for face-to-face interventions.

Practitioners should not undertake interventions unless they have completed training in MI.

Services should ensure that Practitioners devote the whole intervention to discussing behaviour change. Any requirements for data collection should be completed prior/post the intervention.

Healthcare based services in particular should consider whether greater flexibility in the location of interventions could be offered in order to ensure that the varying preferences of potential service users are met whilst maintaining sufficient levels of confidentiality and openness.

### Physical activity offer

Service users who express a desire to change behaviour should be encouraged to identify an activity that suits them. No matter what preference they have, Practitioners should do as much as possible to facilitate the service user's choice. All decision-making should be service user led.

Services should seek to facilitate access to as wide a range of physical activities as possible, including closed and open sessions, group and individual activities and activities undertaken as part of daily living. Services should review the profile of service users and consider how the activities available may need to be adjusted in order to ensure that they meet the diverse interests of the participants – for example, by ensuring there are activities likely to appeal to men and that cover a wide geographical area. Services should identify local activity providers first before deciding if there is a need for directly delivered activity to fill gaps.

Services that deliver activities directly need to ensure that the intervention explores service users' physical activities preferences and interests and does not focus on promoting the particular activities that the service offers. This undertaking should include the negotiation of support activity between supervised sessions and the continuation of activity following the end of free sessions.

All services, when signposting, need to consider the appropriateness of the activity for PLWC. If required, Practitioners should work with external providers to ensure that they are appropriately trained and feel sufficiently supported to provide activities for PLWC.

Where activities are directly delivered, it is important that instructors provide personalised exercises for each service user and consider whether some need more advanced exercises than others.

Services should consider how they can build opportunities for social interaction into activities. Services should also consider how they might encourage the family and/or carers of PLWC to participate with them in physical activity.

### Ongoing Behaviour Change Support

Where possible, support should be provided by the same staff member at all stages, in order to ensure continuity of care. There may be benefit in front loading this support in order to establish a relationship with the service user.

### Service management

We recommend services separate the Move More Practitioner role from other, more administrative, tasks such as data entry and data collection.

Healthcare based services and those that mainly signpost service users, may benefit from there being more representatives of the leisure and/or community sectors on their steering group in order to ensure that they can link effectively with a wide range of activity providers. Community and leisure based services may wish to focus on recruiting members that are most likely to help generate referrals.

### Data collection

Services should consider using the online version of the questionnaire. This could involve service users self-completing the survey on a tablet provided by the service as part of initial interventions or follow-up sessions.

Services should consider adopting a more strategic approach to reminding service users to complete follow-up questionnaires. This should include calling service users at different times and on different days in order to boost response rates.

# Glossary

| | |
|---|---|
| **AC** | Average Cost |
| **activPal™ accelerometers** | The activPAL™ accelerometer is a research tool that quantifies sedentary, upright and ambulatory activities in order to provide evidence for treatment interventions and disease related risks. |
| **BC** | Behaviour Change |
| **BCRP** | Berkshire Cancer Rehabilitation Programme |
| **BDA** | The Bowls Development Alliance is a body incorporating Bowls England and the English Indoor Bowling Association Ltd. |
| **BECCI** | Behaviour Change Counselling Index. This is a research instrument designed to score practitioners' use of behaviour change counselling in consultations. |
| **CaPASEF** | Cancer and Physical Activity Standard Evaluation Framework. This framework is a tool, developed by Macmillan's Physical Activity Behaviour Change Expert Advisory Group, which is used to standardise evaluation-data collection. It is also known as the minimum dataset. This builds on Public Health England's Standard Evaluation Framework for Physical Activity. |
| **CCG** | Clinical Commissioning Groups are clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services in a local area in England. |
| **CNS** | Cancer Nurse Specialist |
| **Completers only analysis** | The completers-only approach analyses data only from those service users who complete the programme. For example, average changes in outcome, from baseline to 3 months, would use outcome data *only* from those service users who provide data at both baseline and 3 months. |

| | |
|---|---|
| **CSP** | County Sports Partnerships are networks of local agencies in England committed to working together to increase the number of people taking part in sports and physical activities. |
| **(E)HNA** | The (Electronic) Holistic Needs Assessment. This is an assessment tool used to understand the needs of a person living with cancer as part of an Assessment and Care Plan consultation. It is typically presented in the form of a questionnaire and it identifies the issues which are most important to the individual concerned. The results are used to inform the development of a care and support plan, produced by a healthcare professional. It is available in both paper format and electronically. |
| **EQ-5D** | The EQ-5D is a standardised measure of health status using five dimensions of health: mobility, ability to self-care, ability to undertake usual activities, pain and discomfort. |
| **FACIT** | The Functional Assessment of Chronic Illness Therapy questionnaire is comprised of a collection of health-related quality of life questionnaires targeted at the management of chronic illness. |
| **GSE** | The General Self Efficacy scale is a 10 item psychometric scale that is designed to assess optimistic self-beliefs which can help to cope with a variety of difficult demands in life. |
| **GSTT** | Guys' and St Thomas' NHS Foundation Trust – one of the services included in the evaluation |
| **HCP** | Healthcare Professional – an umbrella term which represents a range of job roles associated with cancer treatment. The term encompasses cancer nurse specialists, consultants, oncologists, physiotherapists, GPs and occupational therapists. |
| **HOPE** | HOPE (Help to Overcome Problems Effectively) is a licensed programme developed jointly by both Macmillan and Coventry University to help people that have had/or have cancer to get on with their lives |

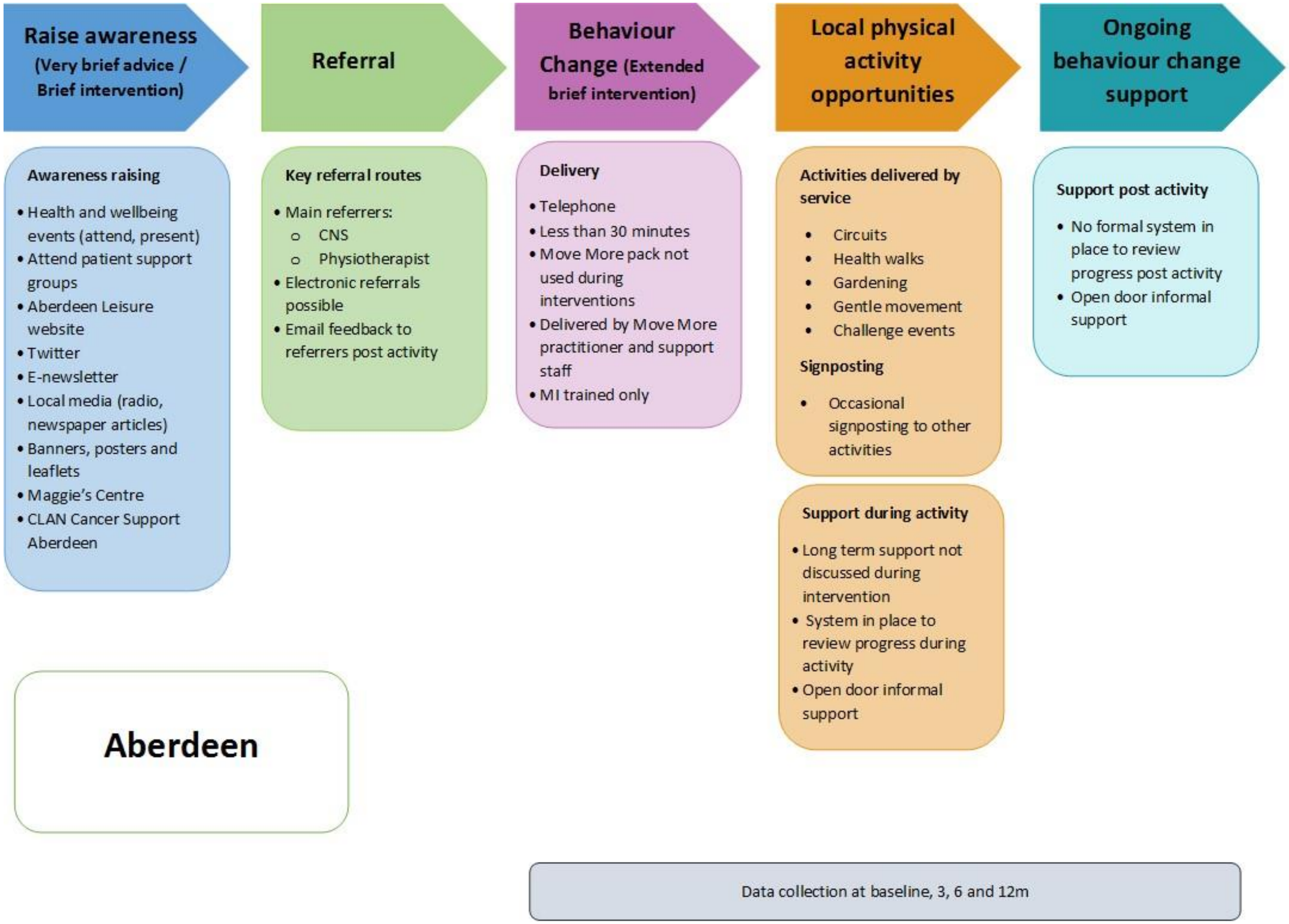
| | |
|---|---|
| **HRQoL** | Health Related Quality of Life is a measure calculated using EQ-5D (see above) which provides an overall assessment score of the impact someone's health status has on their quality of life. |
| **IPAQ** | The International Physical Activity Questionnaire is a research tool used to obtain internationally comparable data on health-related physical activity. |
| **ITT analysis** | Intention to Treat analysis assesses outcomes for all service users who have enrolled on the programme (i.e., provided baseline data), regardless of whether they dropped out at any stage. |
| **LEAP** | Local Exercise Evaluation Pilots, an initiative funded by the Department of Health, Sport England and the Countryside Alliance in England in 2005, of locally run pilot programmes which test and evaluate new ways of encouraging people to take up more physical activity. |
| **Likert Scale** | This is a research tool that is widely used to represent people's attitudes to a topic. |
| **Macmillan Physical Activity Behaviour Change Care Pathway** | This is a model of care, developed by Macmillan, based on NICE public health guidance 49 and additional insight and learning, which enables health and social care professionals to raise the importance of moving more and signpost people who are interested to tailored behaviour-change services. These services support people in choosing to become and stay active, or maintain a level of activity, in an activity and at an intensity that's right for them. |
| **Metastatic cancer** | When cancer has spread to other parts of the body it is called metastatic cancer. |
| **MI** | Motivational Interviewing is a counselling approach developed by clinical psychologists. It focuses on a goal-oriented, client-centred approach which is intended to help achieve behaviour change. |
| **Minimum Data Set** | Also known as the CaPASEF, the minimum dataset is a tool, developed by Macmillan's physical activity and behaviour change expert advisory group, which is used to standardise evaluation data |

| | |
|---|---|
| | collection. This builds on Public Health England's Standard Evaluation Framework for Physical Activity. |
| **Move More Practitioner** | A Move More Practitioner is an individual who co-ordinates and runs a local Move More service. The practitioner raises awareness for the programme, conducts the behaviour change sessions and also sources, recruits and liaises with leisure providers and health care professionals. |
| **NCSI** | The National Cancer Survivorship Initiative was a partnership in England between Macmillan Cancer Support, the Department of Health and NHS Improvement. It seeks to improve the quality and effectiveness of the service delivery that is intended to improve the quality of life of those living with and beyond cancer. |
| **NGB** | National Governing Bodies of sports. |
| **NICE** | National Institute for Health and Care Excellence |
| **NVivo™** | Software used for managing and analysing qualitative data – for example, interview transcripts |
| **OT** | Occupational therapy/therapists |
| **Palliative** | Palliative treatment is designed to relieve symptoms, and improve quality of life. It can be used at any stage of an illness, however it is often associated with end of life care |
| **PABC** | People affected by cancer – this includes a person with cancer, as well as their family and friends |
| **PAR - Q** | The Physical Activity Readiness Questionnaire is a research tool used before physical activity is undertaken in order to identify whether there are any medical barriers to participation. This tool helps ensure that potential activities are suitable for the service user. |

| | |
|---|---|
| **Patient Activation Measure (PAM)** | This is a tool that analyses the knowledge, skills and confidence a person has in managing their own health and care. |
| **PLWC** | Person living with or beyond cancer. Someone who has had a diagnosis of cancer but can be at any stage of their cancer journey. |
| **Prehab** | Shortened from Pre-habilitation. Exercise or other interventions which are intended to build a person's capacity and fitness before they undergo surgery. |
| **Primary care** | Primary health care is the first point of contact, in terms of health care, for most people. It is mainly provided by GPs (general practitioners) but the term can include services provided by practice nurses, pharmacists and dentists. |
| **QALY** | Quality adjusted life years. A generic measure of disease burden, including both the quality and the quantity of life lived. This measure is used in economic evaluations to assess the value for money of medical interventions. One QALY equates to one year in perfect health. |
| **Recovery Package** | The recovery package refers to a core group of four interventions used to support individuals affected by cancer: Assessment and Care Planning (using the Holistic Needs Assessment), Treatment Summary, the Cancer Care Review and Health and Wellbeing Events. These are used to then refer or signpost into support services to help meet unmet need, including physical activity. |
| **SP** | A Sampling Point refers to a specific time at which data is collected for the purposes of an evaluation. |
| **SPAQ** | Scottish Physical Activity Questionnaire, this is a tool developed and validated by NHS Health Scotland, in partnership with the University of Edinburgh, that records data on the number of minutes of 'moderate and vigorous' exercise per week engaged in by service users. This tool is used in physical activity interventions. |

| | |
|---|---|
| **TC** | Total cost |
| **TCAT** | The Transforming Care After Treatment programme is a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland and local authorities which supports a redesign of care following active treatment of cancer. Its aim is to support and enable cancer survivors to live as healthy a life as possible for as long as possible. |
| **Very Brief Advice (VBA)** | Very brief advice describes a short intervention (usually from 30 seconds to three minutes) delivered opportunistically to improve an individual's health and wellbeing. |

# Appendix 1: Pathway implementation for each service



**Raise awareness (Very brief advice / Brief intervention)**

**Awareness raising**

- Health and wellbeing events (attend, present)
- Attend patient support groups
- Aberdeen Leisure website
- Twitter
- E-newsletter
- Local media (radio, newspaper articles)
- Banners, posters and leaflets
- Maggie's Centre
- CLAN Cancer Support Aberdeen

**Referral**

**Key referral routes**

- Main referrers:
  - CNS
  - Physiotherapist
- Electronic referrals possible
- Email feedback to referrers post activity

**Behaviour Change (Extended brief intervention)**

**Delivery**

- Telephone
- Less than 30 minutes
- Move More pack not used during interventions
- Delivered by Move More practitioner and support staff
- MI trained only

**Local physical activity opportunities**

**Activities delivered by service**

- Circuits
- Health walks
- Gardening
- Gentle movement
- Challenge events

**Signposting**

- Occasional signposting to other activities

**Support during activity**

- Long term support not discussed during intervention
- System in place to review progress during activity
- Open door informal support

**Ongoing behaviour change support**

**Support post activity**

- No formal system in place to review progress post activity
- Open door informal support

**Aberdeen**

Data collection at baseline, 3, 6 and 12m

**Raise awareness (Very brief advice / Brief intervention)**

**Awareness raising**

- Health and wellbeing events (attend, present)
- YouTube
- Website
- Council newsletter
- Banners, posters and leaflets
- Taster exercise session
- Engagement with Macmillan Information Centres

**Referral**

**Key referral routes**

- Main referrers:
  - CNS
  - Physiotherapist
  - Macmillan Information Centres
- Electronic referrals not possible
- Informal feedback to HCPs

**Behaviour Change (Extended brief intervention)**

**Delivery**

- Face to face
- Session length varies
- Community setting - leisure centres
- Move More pack used
- Delivered by Move More practitioner
- MI & level 4 CanRehab trained

**Local physical activity opportunities**

**Activities delivered by service**

- Circuits
- Nordic walking
- Leisure centre activities
- Walking football

**Signposting**

- Gardening

**Support during activity**

- Long term support not discussed at intervention
- No system in place to review progress during activity
- Open door informal support

**Ongoing behaviour change support**

**Support post activity**

- No formal system in place to review progress post activity
- Open door informal support

## Antrim and Newtownabbey

Data collection at baseline, 3, 6 and 12m

## Raise awareness (Very brief advice / Brief intervention)

**Awareness raising**

- Health and wellbeing events (attend, present)
- Council website
- Council Facebook
- Council newsletter
- Local press articles
- Banners, posters and leaflets
- Engagement with Macmillan Information Centres

## Referral

**Key referral routes**

- Main referrers:
  - PLWC
  - Macmillan Information Centres
- Electronic referrals possible

## Behaviour Change (Extended brief intervention)

**Delivery**

- Face to face
- Session length varies
- Community setting – leisure centres, coffee shops, home
- Move More pack used
- Delivered by Move More practitioner
- MI & level 4 CanRehab trained

## Local physical activity opportunities

**Activities delivered by service**

- Circuits
- Range of leisure centre activities

**Signposting**

- Walking football
- Active Ageing classes

**Support during activity**

- Long term support not discussed at intervention
- No system in place to review progress during activity
- Open door informal support

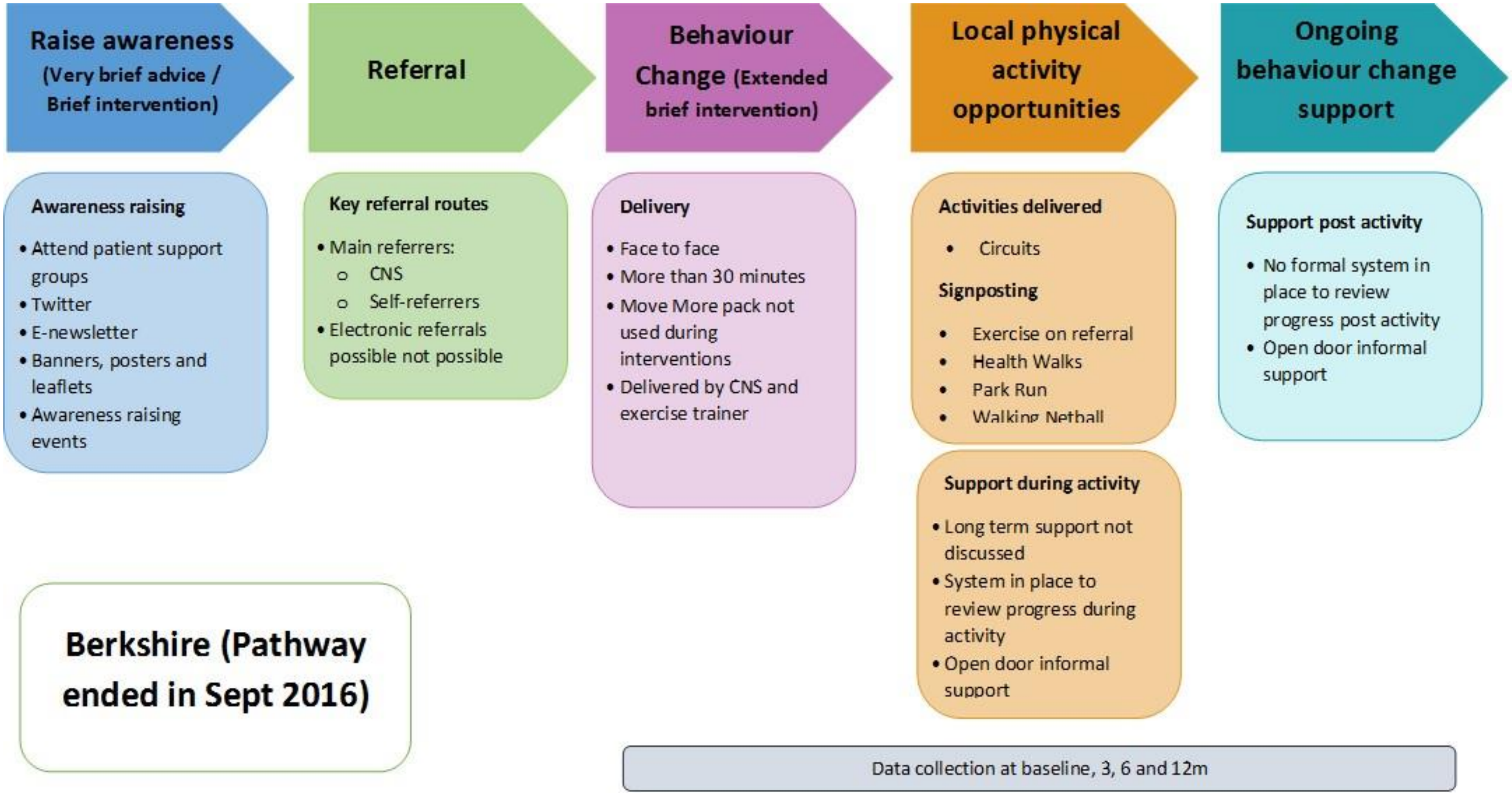
## Ongoing behaviour change support

**Support post activity**

- No formal system in place to review progress post activity
- Open door informal support

## Ards and North Down

Data collection at baseline, 3, 6 and 12m



**Raise awareness (Very brief advice / Brief intervention)**

**Awareness raising**

- Attend patient support groups
- Twitter
- E-newsletter
- Banners, posters and leaflets
- Awareness raising events

**Referral**

**Key referral routes**

- Main referrers:
    - CNS
    - Self-referrers
- Electronic referrals possible not possible

**Behaviour Change (Extended brief intervention)**

**Delivery**

- Face to face
- More than 30 minutes
- Move More pack not used during interventions
- Delivered by CNS and exercise trainer

**Local physical activity opportunities**

**Activities delivered**

- Circuits

**Signposting**

- Exercise on referral
- Health Walks
- Park Run
- Walking Netball

**Support during activity**

- Long term support not discussed
- System in place to review progress during activity
- Open door informal support

**Ongoing behaviour change support**

**Support post activity**

- No formal system in place to review progress post activity
- Open door informal support

**Berkshire (Pathway ended in Sept 2016)**

Data collection at baseline, 3, 6 and 12m

## Raise awareness (Very brief advice / Brief intervention)

**Awareness raising**

- Health and wellbeing events (attend, present)
- Living well Active days
- Website
- Twitter
- Hospital forum
- E-newsletter
- Banners, posters and leaflets
- Direct mail shot

## Referral

**Key referral routes**

- Main referrers:
  - PLWC
  - CNS
- Electronic referrals possible
- Occasional feedback to HCPs

## Behaviour Change (Extended brief intervention)

**Delivery**

- Group setting
- Community setting - Bournemouth University
- Move More pack not used during interventions
- Delivered by Move More practitioner
- MI & level 4 CanRehab trained

## Local physical activity opportunities

**Activities delivered by service**

- No activities delivered by Move More practitioner

**Signposting**

Wide range of up to 30 activities including:

- Walking football,
- Dragon boat racing
- Table tennis
- Ambling

**Support during activity**

- Long term support not discussed at intervention
- No system in place to review progress during activity
- Open door informal support

## Ongoing behaviour change support

**Support post activity**

- No formal system in place to review progress post end of activity
- No system in place to review progress post activity
- Open door informal support

# Dorset

Data collection at baseline, 3, 6 and 12m

## Raise awareness (Very brief advice / Brief intervention)

**Awareness raising**

- Edinburgh Leisure Website
- Edinburgh Leisure twitter
- Banners, posters and leaflets

## Referral

**Key referral routes**

- Main referrers are:
    - CNS
- Electronic referrals possible
- Provides feedback to HCPs

## Behaviour Change (Extended brief intervention)

**Delivery**

- Telephone
- Less than 30 minutes
- Move More pack not used during interventions
- Delivered by Move More practitioner & support staff
- MI trained and shortly to receive level 4 CanRehab

## Local physical activity opportunities

**Activities delivered by service**

- Circuits
- Gentle Movement
- Gardening
- Walking

**Signposting**

- Occasional signposting to other activities

**Support during activity**

- Long term support not discussed during intervention
- System in place to review progress during activity

## Ongoing behaviour change support

**Support post activity**

- No formal system in place to review progress post activity
- Open door informal support

# Edinburgh

Data collection at baseline, 3, 6 and 12m

## Raise awareness (Very brief advice / Brief intervention)

**Awareness raising**

- Health and wellbeing events (attend, present)
- Website
- Hospital Facebook
- Hospital twitter
- Hospital newsletter
- Hospital TV screens
- Banners, posters and leaflets

## Referral

**Key referral routes**

- Main referrers are:
    - CNS
    - Physiotherapists
- Electronic referrals possible
- Informal feedback to HCPs
- Included in HNA

## Behaviour Change (Extended brief intervention)

**Delivery**

- Telephone (now option of face to face as well)
- Clinical setting - GSTT cancer centre
- Session length varies
- Move More pack referred to during interventions
- Delivered by Move More practitioner
- MI & level 4 CanRehab

## Local physical activity opportunities

**Activities delivered by service**

- Circuits
- Bowls

**Signposting**

- Exercise on referral
- Range of activities across 6 London Boroughs

**Support during activity**

- Long term support not discussed during intervention
- System in place to review progress during activity
- Open door informal support

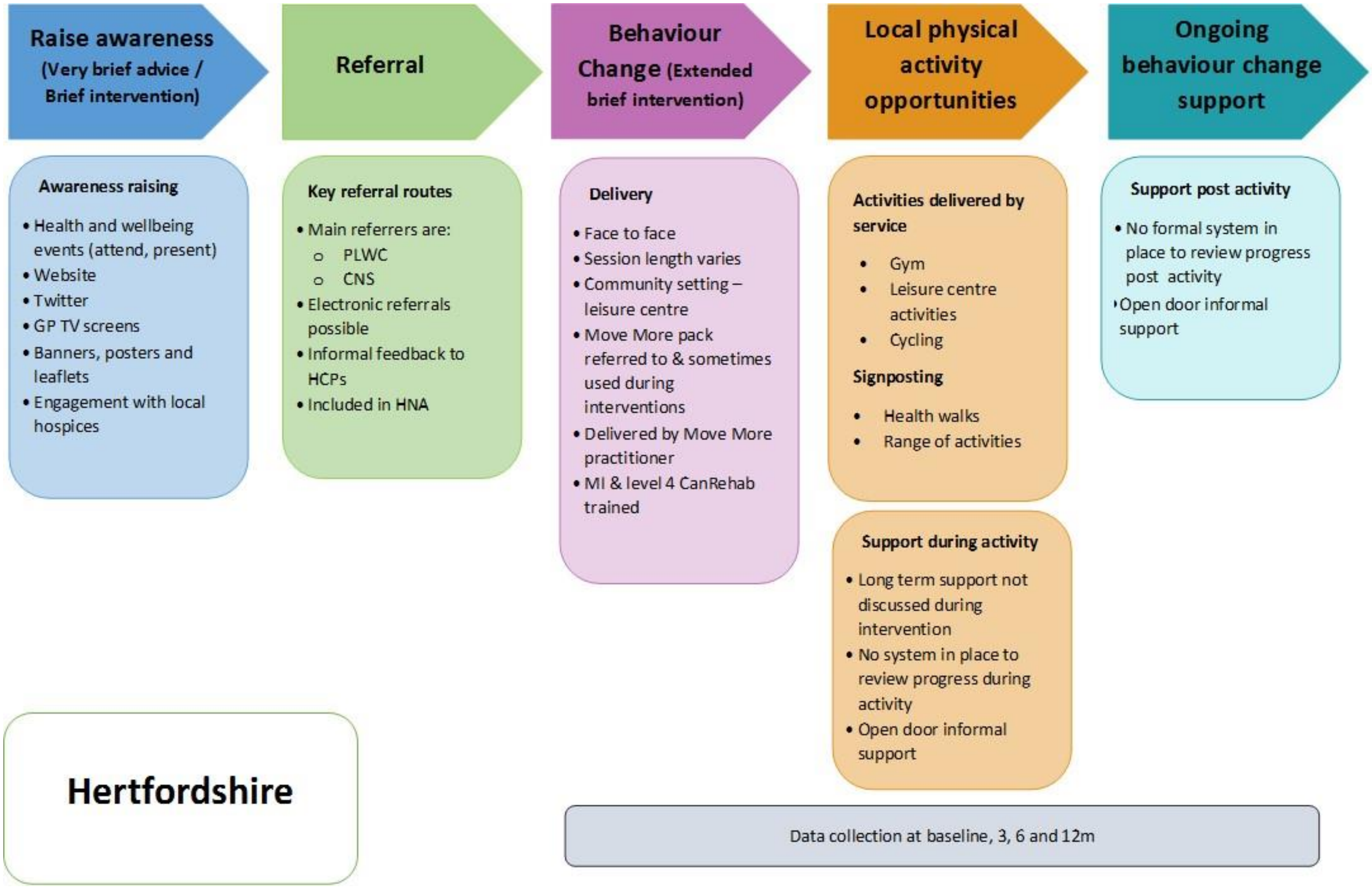
## Ongoing behaviour change support

**Support post activity**

- No formal system in place to review progress post activity
- Open door informal support

**GSTT**

Data collection at baseline, 3, 6 and 12m



**Raise awareness (Very brief advice / Brief intervention)**

**Awareness raising**

- Health and wellbeing events (attend, present)
- Website
- Twitter
- GP TV screens
- Banners, posters and leaflets
- Engagement with local hospices

**Referral**

**Key referral routes**

- Main referrers are:
  - PLWC
  - CNS
- Electronic referrals possible
- Informal feedback to HCPs
- Included in HNA

**Behaviour Change (Extended brief intervention)**

**Delivery**

- Face to face
- Session length varies
- Community setting – leisure centre
- Move More pack referred to & sometimes used during interventions
- Delivered by Move More practitioner
- MI & level 4 CanRehab trained

**Local physical activity opportunities**

**Activities delivered by service**

- Gym
- Leisure centre activities
- Cycling

**Signposting**

- Health walks
- Range of activities

**Support during activity**

- Long term support not discussed during intervention
- No system in place to review progress during activity
- Open door informal support

**Ongoing behaviour change support**

**Support post activity**

- No formal system in place to review progress post activity
- Open door informal support

**Hertfordshire**

Data collection at baseline, 3, 6 and 12m

**Raise awareness (Very brief advice / Brief intervention)**

**Awareness raising**

- Health and wellbeing events (attend, present)
- Website
- Twitter
- GP TV screens
- Banners, posters and leaflets

**Referral**

**Key referral routes**

- Main referrers are:
    - CNS
    - Physiotherapists
    - Occupational therapists
- Electronic referrals not possible
- Provides feedback to HCPs

**Behaviour Change (Extended brief intervention)**

**Delivery**

- Face to face
- More than 30 minutes
- Service user home
- Move More pack referred to & sometimes used during interventions
- Delivered by Move More practitioner and service staff
- MI & level 4 CanRehab trained

**Local physical activity opportunities**

**Activities delivered by service**

- Challenge events

**Signposting**

- Health walks
- Move More DVD
- Range of activities

**Support during activity**

- Long term support often discussed during intervention
- Regular patient centred reviews
- Open door informal support

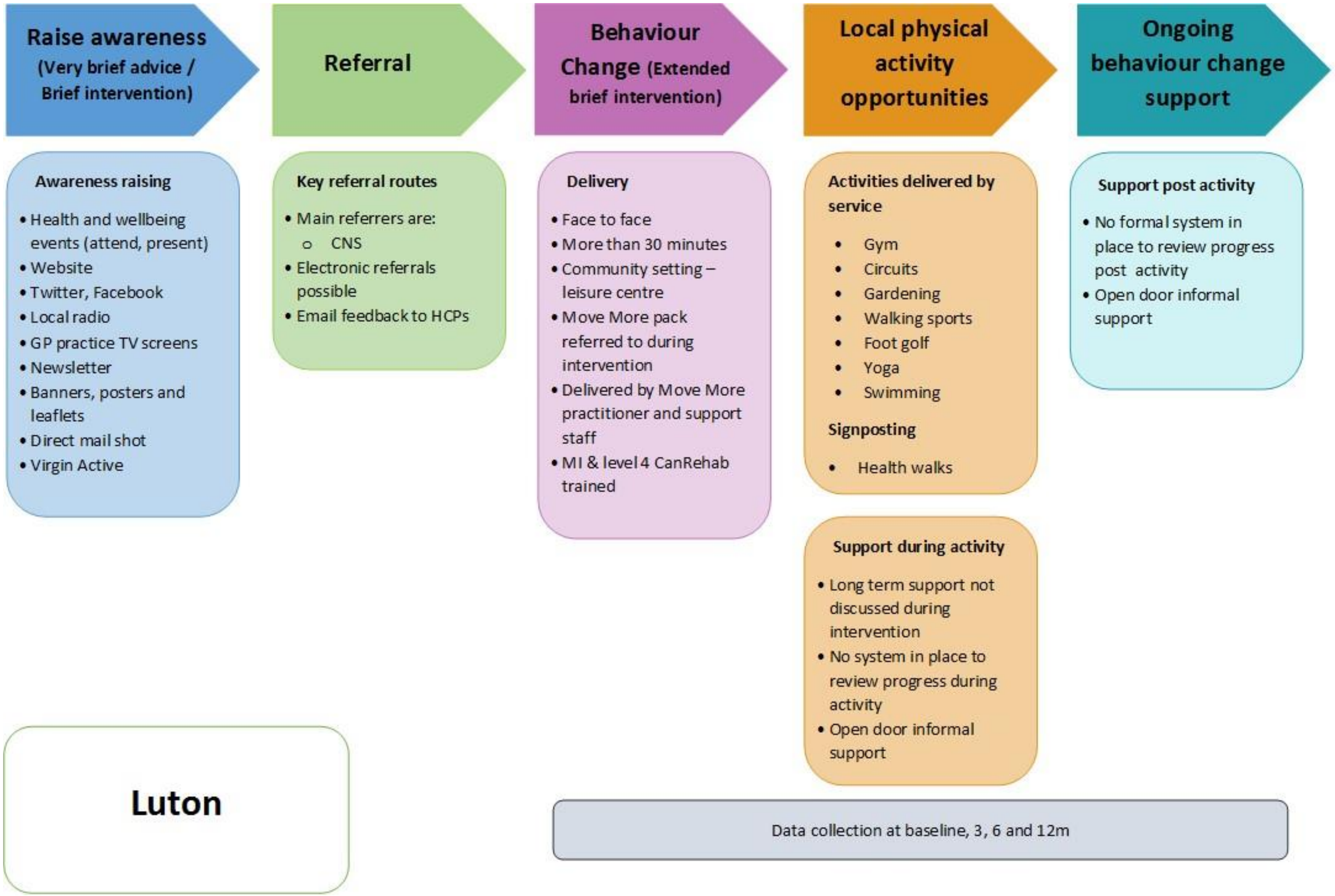
**Ongoing behaviour change support**

**Support post activity**

- Regular patient centred reviews
- Open door informal support

## Lincolnshire

Data collection at baseline, 3, 6 and 12m



**Raise awareness (Very brief advice / Brief intervention)**

**Awareness raising**

- Health and wellbeing events (attend, present)
- Website
- Twitter, Facebook
- Local radio
- GP practice TV screens
- Newsletter
- Banners, posters and leaflets
- Direct mail shot
- Virgin Active

**Referral**

**Key referral routes**

- Main referrers are:
    - CNS
- Electronic referrals possible
- Email feedback to HCPs

**Behaviour Change (Extended brief intervention)**

**Delivery**

- Face to face
- More than 30 minutes
- Community setting – leisure centre
- Move More pack referred to during intervention
- Delivered by Move More practitioner and support staff
- MI & level 4 CanRehab trained

**Local physical activity opportunities**

**Activities delivered by service**

- Gym
- Circuits
- Gardening
- Walking sports
- Foot golf
- Yoga
- Swimming

**Signposting**

- Health walks

**Support during activity**

- Long term support not discussed during intervention
- No system in place to review progress during activity
- Open door informal support

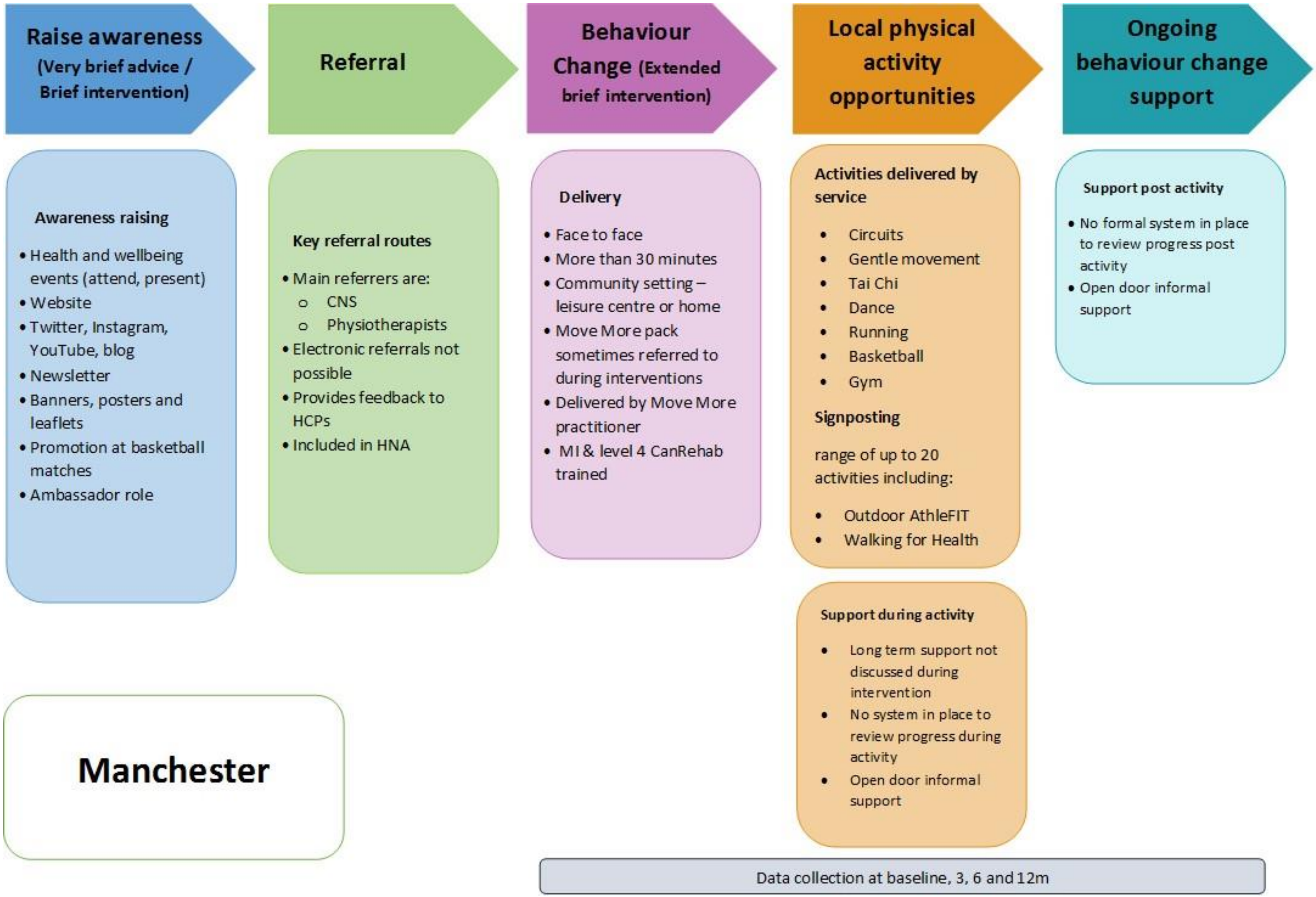
**Ongoing behaviour change support**

**Support post activity**

- No formal system in place to review progress post activity
- Open door informal support

**Luton**

Data collection at baseline, 3, 6 and 12m



**Raise awareness (Very brief advice / Brief intervention)**

**Awareness raising**

- Health and wellbeing events (attend, present)
- Website
- Twitter, Instagram, YouTube, blog
- Newsletter
- Banners, posters and leaflets
- Promotion at basketball matches
- Ambassador role

**Referral**

**Key referral routes**

- Main referrers are:
  - CNS
  - Physiotherapists
- Electronic referrals not possible
- Provides feedback to HCPs
- Included in HNA

**Behaviour Change (Extended brief intervention)**

**Delivery**

- Face to face
- More than 30 minutes
- Community setting – leisure centre or home
- Move More pack sometimes referred to during interventions
- Delivered by Move More practitioner
- MI & level 4 CanRehab trained

**Local physical activity opportunities**

**Activities delivered by service**

- Circuits
- Gentle movement
- Tai Chi
- Dance
- Running
- Basketball
- Gym

**Signposting**

range of up to 20 activities including:

- Outdoor AthleFIT
- Walking for Health

**Support during activity**

- Long term support not discussed during intervention
- No system in place to review progress during activity
- Open door informal support

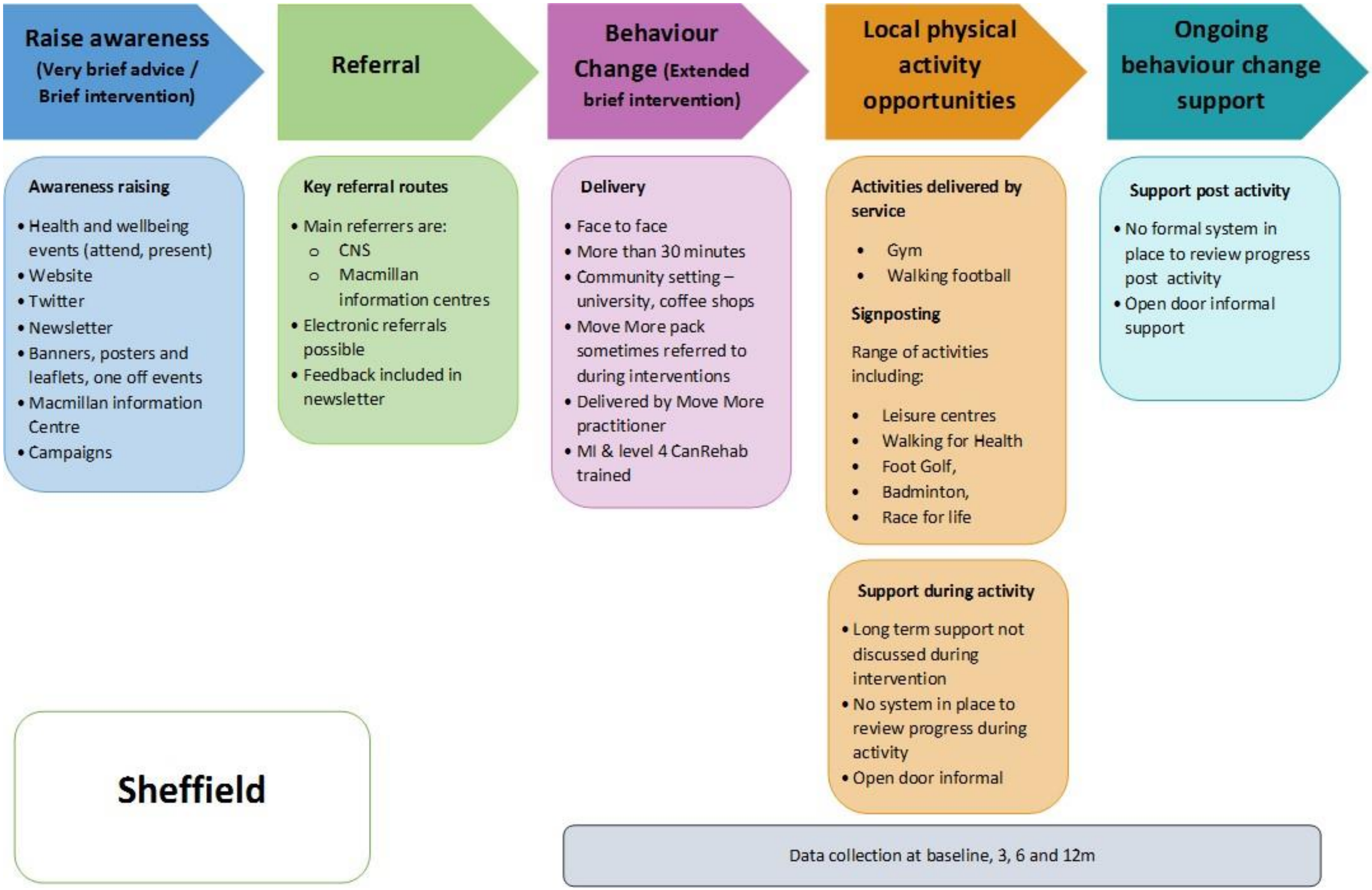
**Ongoing behaviour change support**

**Support post activity**

- No formal system in place to review progress post activity
- Open door informal support

**Manchester**

Data collection at baseline, 3, 6 and 12m



**Raise awareness (Very brief advice / Brief intervention)**

**Awareness raising**

- Health and wellbeing events (attend, present)
- Website
- Twitter
- Newsletter
- Banners, posters and leaflets, one off events
- Macmillan information Centre
- Campaigns

**Referral**

**Key referral routes**

- Main referrers are:
  - CNS
  - Macmillan information centres
- Electronic referrals possible
- Feedback included in newsletter

**Behaviour Change (Extended brief intervention)**

**Delivery**

- Face to face
- More than 30 minutes
- Community setting – university, coffee shops
- Move More pack sometimes referred to during interventions
- Delivered by Move More practitioner
- MI & level 4 CanRehab trained

**Local physical activity opportunities**

**Activities delivered by service**

- Gym
- Walking football

**Signposting**

Range of activities including:

- Leisure centres
- Walking for Health
- Foot Golf,
- Badminton,
- Race for life

**Support during activity**

- Long term support not discussed during intervention
- No system in place to review progress during activity
- Open door informal

**Ongoing behaviour change support**

**Support post activity**

- No formal system in place to review progress post activity
- Open door informal support

**Sheffield**

Data collection at baseline, 3, 6 and 12m

## Shropshire

### Raise awareness (Very brief advice / Brief intervention)

**Awareness raising**

- Health and wellbeing events (attend, present)
- Website
- Twitter
- Newsletter
- Banners, posters and leaflets
- Macmillan information Centre
- Hamar Centre

### Referral

**Key referral routes**

- Main referrers are:
  - CNS
- Electronic referrals possible
- Provides a league table of referrers

### Behaviour Change (Extended brief intervention)

**Delivery**

- Face to face
- More than 30 minutes
- Clinical setting – Hamar Centre
- Move More pack used during interventions
- Delivered by Move More practitioner
- MI & level 4 CanRehab trained

### Local physical activity opportunities

**Activities delivered by service**

- Walking

**Signposting**

Range of 17 activities including:

- Move More DVD
- Walking for Health
- Back to Ballroom
- Parkrun

**Support during activity**

- Long term support not discussed during intervention
- No system in place to review progress during activity
- Open door informal support

### Ongoing behaviour change support

**Support post activity**

- No formal system in place to review progress post activity
- Open door informal support

Data collection at baseline, 3, 6 and 12m

# Appendix 2: Sporting activities offered by Sport England funded services

| **Service** | **Sporting activities signposted to/delivered by sites part-funded by Sport England** |
|---|---|
| Luton | Foot golf, walking football men, women's football, tennis, table tennis, indoor bowls, martial arts, Nordic walking , archery, swimming, aqua aerobics, boxing, gym, dance, Pilates, Parkrun, walking cricket , badminton, walking for health, gym, golf, tai-chi, circuits |
| Shropshire | Back to Ballroom, swimming, cycling, hockey skills, rowing, gym, running, netball, walking for health, rowing, coracle, orienteering, cancer specific circuit class, Pilates. |
| Berkshire | Bowls, AthleFIT, hockey, badminton, walking netball, walking football, fishing, Nordic walking, Run England, Parkrun, swimming, cycling, table tennis, equestrian, canoeing, rowing, walking basketball, circuits, gym, walking for health |
| Dorset | Run England, badminton, dragon boat racing, cycling, orienteering, dance, Nordic walking, walking football, Parkrun, Bollywood dance, swimming, walking jive, table tennis, golf, gym, Tripudio, martial arts, sailing, walking for health, walking netball, tai chi, qi gong, rock climbing, free guided rides with British Cycling Sky Ride Local. |
| Manchester | Outdoor AthleFIT, 321 routes, Run England, basketball, bowls, cycling, rowing, dragon boat racing, boxing, circuits, tai chi, green gym, dance, gym, walking for health, Zumba, walking football, foot golf, yoga, gardening |
| Sheffield | Race for life, sky ride, sports photo booth, foot golf, Sheffield Sharks basketball, equestrian, body building, walking football, badminton, gym, walking for health, archery |

# Appendix 3: Data tables

## Tables to support outcomes analysis in Chapter 8

Asterisks indicate significance level of the two-sided t-test of the difference in means for a paired sample. *** P<1%, ** p<5%.

SPAQ - all service users with an overall SPAQ score greater than 1400 have been excluded from the analysis

**Table 8.5: Mean changes in physical activity as reported using SPAQ by service sub-group (national)**

| | | N | Mean Start | Difference M |
|---|---|---|---|---|
| **Those who gave data at Start and 3 months** | **England & Wales** | 858 | 342.95 | 137.79*** |
| | **Scotland** | 56 | 286.03 | 136.89*** |
| | **Northern Ireland** | 68 | 346.78 | 55.03 |
| **Those who gave data at start and 6 months** | **England & Wales** | 465 | 340.98 | 170.69*** |
| | **Scotland** | 38 | 301.95 | 178.97*** |
| | **Northern Ireland** | | | |
| **Those who gave data at start and 12 months** | **England & Wales** | 237 | 368.58 | 163.37*** |
| | **Scotland** | | | |
| | **Northern Ireland** | | | |

### Table 8.6: Mean changes in physical activity (SPAQ) by service sub-group (healthcare/community based)

| | | N | Mean Start | Difference M |
|---|---|---|---|---|
| **Those who gave data at Start and 3 months** | **Healthcare** | 379 | 326.23 | 118.53*** |
| | **Community** | 603 | 348.61 | 140.48*** |
| **Those who gave data at start and 6 months** | **Healthcare** | 178 | 312.76 | 97.08*** |
| | **Community** | 341 | 354.64 | 205.89*** |
| **Those who gave data at start and 12 months** | **Healthcare** | 84 | 412.87 | 58.17 |
| | **Community** | 176 | 341.09 | 210.81*** |

### Table 8.7: Mean changes in physical activity (SPAQ) by service sub-group (signposting/direct delivery model)

| | | N | Mean Start | Difference M |
|---|---|---|---|---|
| **Those who gave data at Start and 3 months** | **Signposting** | 321 | 292.57 | 130.12*** |
| | **Non signposting** | 661 | 362.99 | 132.92*** |
| **Those who gave data at start and 6 months** | **Signposting** | 229 | 328.7 | 142.61*** |
| | **Non signposting** | 290 | 349.41 | 189.08*** |
| **Those who gave data at start and 12 months** | **Signposting** | 120 | 335.38 | 230.88*** |
| | **Non signposting** | 140 | 389.06 | 102.03*** |

### Table 8.10: Mean changes in health related quality of life (EQ5D) by service sub-group (nation)

| | | N | Mean Start | Difference M |
|---|---|---|---|---|
| **Those who gave data at Start and 3 months** | **England & Wales** | 718 | 0.71 | 0.06*** |
| | **Scotland** | 61 | 0.74 | 0.03 |
| | **Northern Ireland** | 72 | 0.73 | 0.05** |
| **Those who gave data at start and 6 months** | **England & Wales** | 408 | 0.7 | 0.12*** |
| | **Scotland** | 44 | 0.78 | 0.03 |
| | **Northern Ireland** | | | |
| **Those who gave data at start and 12 months** | **England & Wales** | 182 | 0.69 | 0.14*** |
| | **Scotland** | 30 | 0.77 | 0.04 |
| | **Northern Ireland** | | | |

### Table 8.11: Mean changes in health related quality of life (EQ5D) by service sub-group (signposting/direct delivery)

| | | N | Mean Start | Difference M |
|---|---|---|---|---|
| **Those who gave data at Start and 3 months** | **Signposting** | 336 | 0.69 | 0.1*** |
| | **Non signposting** | 515 | 0.74 | 0.02*** |
| **Those who gave data at start and 6 months** | **Signposting** | 240 | 0.69 | 0.15*** |
| | **Non signposting** | 228 | 0.73 | 0.06*** |
| **Those who gave data at start and 12 months** | **Signposting** | 129 | 0.68 | 0.18*** |
| | **Non signposting** | 83 | 0.74 | 0.04* |

Table 8.12: Mean changes in health related quality of life (EQ5D) by service sub-group (community/healthcare based)

| | | N | Mean Start | Difference M |
|---|---|---|---|---|
| **Those who gave data at Start and 3 months** | **Healthcare** | 162 | 0.73 | 0.03 |
| | **Community** | 689 | 0.71 | 0.06*** |
| **Those who gave data at start and 6 months** | **Healthcare** | 76 | 0.72 | 0.1*** |
| | **Community** | 392 | 0.7 | 0.11*** |
| **Those who gave data at start and 12 months** | **Healthcare** | | | |
| | **Community** | 202 | 0.7 | 0.12*** |

Table 8.14: Mean changes in fatigue (FACIT) by service sub-group (national)

| | | N | Mean Start | Difference M |
|---|---|---|---|---|
| **Those who gave data at Start and 3 months** | **England & Wales** | 791 | 30.01 | 2.35*** |
| | **Scotland** | 555 | 35.99 | 2.73 |
| | **Northern Ireland** | 62 | 33.34 | 2.5** |
| **Those who gave data at start and 6 months** | **England & Wales** | 445 | 30.4 | 3.18*** |
| | **Scotland** | 40 | 34.7 | 2.95 |
| | **Northern Ireland** | | | |
| **Those who gave data at start and 12 months** | **England & Wales** | 240 | 28.55 | 3.73*** |
| | **Scotland** | | | |
| | **Northern Ireland** | | | |

Table 8.15: Mean changes in fatigue (FACIT) by service sub-group (signposting / direct delivery)

| | | N | Mean Start | Difference M |
|---|---|---|---|---|
| **Those who gave data at Start and 3 months** | **Signposting** | 306 | 31.8 | 3.17*** |
| | **Non signposting** | 603 | 30.01 | 1.98*** |
| **Those who gave data at start and 6 months** | **Signposting** | 226 | 32.24 | 4.8*** |
| | **Non signposting** | 274 | 29.85 | 1.62*** |
| **Those who gave data at start and 12 months** | **Signposting** | 127 | 32.23 | 7.17*** |
| | **Non signposting** | 141 | 27.18 | -0.2 |

Table 8.16: Mean changes in fatigue (FACIT)) by service sub-group (community/healthcare based)

| | | N | Mean Start | Difference M |
|---|---|---|---|---|
| **Those who gave data at Start and 3 months** | **Healthcare** | 320 | 25.15 | 0.90 |
| | **Community** | 589 | 33.58 | 3.19*** |
| **Those who gave data at start and 6 months** | **Healthcare** | 137 | 23.77 | -1.36 |
| | **Community** | 363 | 33.63 | 4.73*** |
| **Those who gave data at start and 12 months** | **Healthcare** | 744 | 20.04 | -2.42** |
| | **Community** | 193 | 33.27 | 5.51*** |

Table 8.19: Mean changes in general self-efficacy (GSE) by service sub-group (nation)

| | | N | Mean Start | Difference M |
|---|---|---|---|---|
| **Those who gave data at Start and 3 months** | **England & Wales** | 5388 | 29.9 | 0.48** |
| | **Scotland** | 45 | 30.2 | 0.02 |
| | **Northern Ireland** | 66 | 27.3 | 0.38 |
| **Those who gave data at start and 6 months** | **England & Wales** | 290 | 29.76 | 1.24*** |
| | **Scotland** | 36 | 31 | 0.06 |
| | **Northern Ireland** | | | |
| **Those who gave data at start and 12 months** | **England & Wales** | 94 | 29.71 | 1.80*** |
| | **Scotland** | | | |
| | **Northern Ireland** | | | |

### Table 8.20: Mean changes in general self-efficacy (GSE) by service sub-group (community/healthcare)

| | | N | Mean Start | Difference M |
|---|---|---|---|---|
| **Those who gave data at Start and 3 months** | **Healthcare** | 220 | 29.85 | 0.3 |
| | **Community** | 430 | 29.57 | 0.51** |
| **Those who gave data at start and 6 months** | **Healthcare** | 89 | 29.48 | 0.58 |
| | **Community** | 2544 | 30 | 1.76*** |
| **Those who gave data at start and 12 months** | **Healthcare** | | | |
| | **Community** | 97 | 29.55 | 1.68*** |

### Table 8.21: Mean changes in general self-efficacy (GSE) by service sub-group (signposting/direct delivery)

| | | N | Mean Start | Difference M |
|---|---|---|---|---|
| **Those who gave data at Start and 3 months** | **Signposting** | 214 | 28.59 | 0.77** |
| | **Non signposting** | 539 | 29.9 | 0.48** |
| **Those who gave data at start and 6 months** | **Signposting** | 138 | 28.96 | 1.22*** |
| | **Non signposting** | 290 | 29.76 | 1.24 |
| **Those who gave data at start and 12 months** | **Signposting** | 388 | 29.72 | 2.15** |
| | **Non signposting** | 933 | 29.71 | 1.8*** |

# Tables to support economic analysis

### Table 9.2: Average change in outcomes by service, ITT analysis

| | FACIT | | | EQ-5D Index | | | GSE | | | SPAQ | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Mean Start | Diff. M3 | | Mean Start | Diff. M3 | | Mean Start | Diff. M3 | | Mean Start | Diff. M3 | |
| **Aberdeen** | 31.5 | 1.9 | ** | 0.69 | -- | | 30.0 | -- | | 291 | 53 | ** |
| **Ant. & Newtown.** | 35.8 | 0.8 | | 0.79 | -- | | 26.1 | -- | | 208 | -- | |
| **Ards & N. Down** | 31.1 | 0.8 | | 0.70 | -- | | 29.1 | 0.2 | | 387 | 27 | |
| **Berkshire** | 32.4 | 1.2 | ** | 0.70 | -- | | 29.9 | -- | | 254 | 26 | *** |
| **Cardiff** | 29.3 | 2.9 | *** | 0.62 | 0.00 | | 29.7 | 0.5 | | 252 | 143 | *** |
| **Dorset** | 36.4 | 1.8 | *** | 0.78 | 0.01 | ** | 31.6 | 0.3 | | 554 | 71 | *** |
| **Edinburgh** | 35.4 | -0.4 | | 0.72 | -- | | 30.2 | -0.3 | | 400 | 24 | |
| **Guys** | 20.0 | -1.0 | *** | N/A | -- | | 30.9 | 0.1 | | 391 | 47 | *** |
| **Herts** | 34.9 | 0.4 | *** | 0.77 | 0.00 | | 30.7 | -0.1 | | 456 | 4 | |
| **Lincolnshire** | 30.7 | 3.1 | *** | 0.66 | 0.06 | *** | 27.5 | 0.9 | ** | 280 | 112 | *** |
| **Luton** | 36.0 | -0.1 | | 0.78 | 0.01 | | 33.2 | -0.6 | *** | 454 | 18 | |
| **Manchester** | 31.9 | 0.8 | *** | 0.64 | -- | | 26.5 | 0.6 | *** | 299 | 94 | *** |
| **Sheffield** | 31.0 | 0.9 | ** | 0.72 | 0.02 | *** | 29.7 | 0.1 | | 323 | 61 | *** |
| **Shropshire** | 30.8 | -1.8 | | 0.77 | 0.02 | *** | 26.7 | -0.2 | | 223 | -3 | |

Notes: Asterisks indicate significance level of the two-sided t-test of the difference in means for a paired sample. *** P<0.01, ** p<0.05.

In ITT analysis, outcomes are assessed for all service users who provide baseline data, regardless of whether they dropped out at any stage. For service users not present at follow up their baseline value is assessed at follow up, which is equivalent to the assumption that there is no change in outcome for that service user.

FACIT scores are reverse coded to be increasing in health. SPAQ distributions are truncated to omit the top 5% of values.

The two services in Northern Ireland (Antrim & Newtownabbey and Ards. & North Down) have only been established for 12 months and only receiving referrals for between 8 and 10 months whereas all other services have been established for at least 24 months.

-- Represents a cell size < 30.

### Table 9.3a Average changes in outcomes, by service subgroup (National), ITT analysis.

| | | Mean Start | Difference M3 |
|---|---|---|---|
| **FACIT** | **England & Wales** | 30.6 | 0.9*** |
| | **Scotland** | 33.3 | 0.8 |
| | **Northern Ireland** | 33.0 | 0.8** |
| **EQ5D** | **England & Wales** | 0.72 | 0.01*** |
| | **Scotland** | 0.71 | 0.01 |
| | **Northern Ireland** | 0.74 | 0.03*** |
| **GSE** | **England & Wales** | 29.7 | 0.2** |
| | **Scotland** | 30.2 | -0.00 |
| | **Northern Ireland** | 28.1 | 0.1 |
| **SPAQ** | **England & Wales** | 356 | 53*** |
| | **Scotland** | 343 | 40*** |
| | **Northern Ireland** | 324 | 26** |

Notes: Asterisks indicate significance level of the two-sided t-test of the difference in means for a paired sample. *** P<0.01, ** p<0.05.

In ITT analysis outcomes are assessed for all service users who provide baseline data, regardless of whether they dropped out at any stage. For service users not present at follow up their baseline value is assessed at follow up, which is equivalent to the assumption that there is no change in outcome for that service user.

FACIT scores are reverse coded to be increasing in health. SPAQ distributions are truncated to omit the top 5% of values.

The two services in Northern Ireland have only been established for 12 months whereas all other services have been established for at least 24 months.

### Table 9.3b Average changes in outcomes, by service subgroup (Delivery Model), ITT analysis

| | | Mean Start | Difference M3 |
|---|---|---|---|
| **FACIT** | **Direct delivery** | 31.0 | 0.7*** |
| | **Signposting only** | 30.1 | 1.9*** |
| **EQ5D** | **Direct delivery** | 0.73 | 0.01*** |
| | **Signposting only** | 0.70 | 0.04*** |
| **GSE** | **Direct delivery** | 29.9 | 0.1 |
| | **Signposting only** | 28.4 | 0.4** |
| **SPAQ** | **Direct delivery** | 378 | 44*** |
| | **Signposting only** | 276 | 68*** |

Notes: Asterisks indicate significance level of the two-sided t-test of the difference in means for a paired sample. *** P<0.01, ** p<0.05.

In ITT analysis outcomes are assessed for all service users who provide baseline data, regardless of whether they dropped out at any stage. For service users not present at follow up their baseline value is assessed at follow up, which is equivalent to the assumption that there is no change in outcome for that service user.

FACIT scores are reverse coded to be increasing in health. SPAQ distributions are truncated to omit the top 5% of values.

### Table 9.3c Average changes in outcomes, by service subgroup (Setting), ITT analysis

| | | Mean Start | Difference M3 |
|---|---|---|---|
| **FACIT** | **Community** | 33.2 | 1.1*** |
| | **Healthcare** | 25.6 | 0.4 |
| **EQ5D** | **Community** | 0.72 | 0.02*** |
| | **Healthcare** | 0.71 | 0.01 |
| **GSE** | **Community** | 29.5 | 0.2** |
| | **Healthcare** | 29.9 | 0.2 |
| **SPAQ** | **Community** | 374 | 52*** |
| | **Healthcare** | 310 | 43*** |

Notes: Asterisks indicate significance level of the two-sided t-test of the difference in means for a paired sample. *** P<0.01, ** p<0.05.

In ITT analysis outcomes are assessed for all service users who provide baseline data, regardless of whether they dropped out at any stage. For service users not present at follow up their baseline value is assessed at follow up, which is equivalent to the assumption that there is no change in outcome for that service user.

FACIT scores are reverse coded to be increasing in health. SPAQ distributions are truncated to omit the top 5% of values.

Table 9.4: Cost information by service

| Service | No. Mths | Total cost £ | Monthly costs £ | Set-up costs £ | % set-up costs | Staff costs £ | % staff costs | In-kind costs £ | % in-kind costs | Macmillan funding £ | % Macmillan funding |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **Aberdeen** | 35 | 229,028 | 6,544 | 16,621 | 7 | 117,978 | 52 | 55,939 | 24 | 142,464 | 62 |
| **Ant. & N' town.** | 12 | 39,059 | 3,255 | 3,494 | 9 | 33,321 | 85 | 5,739 | 15 | 33,321 | 85 |
| **Ards & N. Down** | 12 | 43,346 | 3,612 | 3,506 | 8 | 34,140 | 79 | 5,206 | 12 | 38,140 | 88 |
| **Dorset** | 24 | 163,075 | 6,795 | 26,182 | 16 | 80,750 | 50 | 30,000 | 18 | N/A | N/A |
| **Edinburgh** | 24 | 96,978 | 4,041 | 7,895 | 8 | 61,928 | 64 | 5,323 | 5 | 91,044 | 94 |
| **Guys** | 24 | 139,582 | 5,816 | 2,800 | 2 | 118,941 | 85 | 0 | 0 | 133,590 | 96 |
| **Herts$^{\$}$** | 24 | 151,809 | 6,325 | 12,144 | 8 | 91,491 | 60 | 0 | 0 | 152,100 | 100 |
| **Lincolnshire** | 29 | 237,970 | 8,206 | 11,124 | 5 | 161,824 | 68 | 0 | 0 | 237,970 | 100 |
| **Luton** | 47 | 273,269 | 5,814 | 9,031 | 3 | 161,536 | 59 | 0 | 0 | 94,356 | 35 |
| **Manchester** | 24 | 182,220 | 7,593 | 11,766 | 6 | 85,645 | 47 | 20,080 | 11 | 172,140 | 94 |
| **Sheffield** | 24 | 171,537 | 7,147 | 25,800 | 15 | 78,214 | 46 | 42,437 | 25 | N/A | N/A |
| **Shropshire** | 24 | 171,030 | 7,126 | 21,280 | 12 | 47,840 | 28 | 89,950 | 53 | £59,800 | 35 |
| **Overall Mean** | | **£158,242** | **£6,023** | **£11,625** | **8%** | **£89,467** | **60%** | **£25,467** | **16%** | **£115,493** | **79%** |

Notes: Cardiff and Berkshire are omitted from the analysis of costs because the cost information provided was not comparable.

$^{\$}$Set-up costs were imputed for Herts at the average % for all other services (8%) as this service was unable to provide this information.

N/A = not available.

## Table 9.5: Mean costs per service user

| | | | | | | | | Excluding set-up costs | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Service** | **Mths** | **No. starters** | **No. 3 mth completers** | **Total cost £** | **Total costs 3 mths £** | **cost per starter £** | **cost per completer £** | **Total costs 3 months £** | **cost per starter £** | **cost per completer £** |
| **Aberdeen** | 35 | 96 | 37 | 229028 | 19631 | 204 | 531 | 18206 | 190 | 492 |
| **Antrim & Newtownabbey** | 12 | 72 | 26 | 39059 | 9765 | 136 | 376 | 8891 | 123 | 342 |
| **Ards & N. Down** | 12 | 136 | 47 | 43346 | 10837 | 80 | 231 | 9960 | 73 | 212 |
| **Dorset** | 24 | 152 | 95 | 163075 | 20384 | 134 | 215 | 17112 | 113 | 180 |
| **Edinburgh** | 24 | 85 | 42 | 96978 | 12122 | 143 | 289 | 11135 | 131 | 265 |
| **Guys** | 24 | 396 | 274 | 139582 | 17448 | 44 | 64 | 17098 | 43 | 62 |
| **Herts$** | 24 | 249 | 43 | 151809 | 18976 | 76 | 441 | 17458 | 70 | 406 |
| **Lincolnshire** | 29 | 292 | 207 | 237970 | 24618 | 84 | 119 | 23467 | 80 | 113 |
| **Luton** | 47 | 275 | 73 | 273269 | 17443 | 63 | 239 | 16866 | 61 | 231 |
| **Manchester** | 24 | 202 | 70 | 182220 | 22778 | 113 | 325 | 21307 | 105 | 304 |
| **Sheffield** | 24 | 176 | 75 | 171537 | 21442 | 122 | 286 | 18217 | 104 | 243 |
| **Shropshire** | 24 | 162 | 56 | 171030 | 21379 | 132 | 382 | 18719 | 116 | 334 |
| **Total** | | **2,293** | **1,045** | | | | | | | |
| **Mean** | | | | **£158242** | **£18068** | **£111** | **£291** | **£16536** | **£101** | **£265** |

Notes:

Cardiff and Berkshire are omitted from the analysis of costs because the cost information provided was not comparable.

$Set-up costs were imputed for Herts at the average % for all other services (8%) as this service was unable to provide this information.

Number of 3 month completers is defined here are provision of SPAQ response (primary outcome measure) at 3, months follow-up.

Highlighted cells emphasise estimates of mean costs based on sample sizes of < 30.

### Table 9.6: Mean costs per service user by service sub-groups

| | | Start | Month 3 |
|---|---|---|---|
| ***National Models*** | | | |
| **Northern Ireland** | No of service users | 208 | 73 |
| | Mean cost per service user | £99 | £282 |
| **Scotland** | No of service users | 181 | 79 |
| | Mean cost per service user | £175 | £401 |
| **England** | No of service users | 1904 | 893 |
| | Mean cost per service user | £86 | £184 |
| ***Delivery Models*** | | | |
| **Signposting only** | No of service users | 630 | 338 |
| | Mean cost per service user | £107 | £199 |
| **Direct Delivery & Signposting** | No of service users | 1663 | 707 |
| | Mean cost per service user | £89 | £211 |
| ***Setting*** | | | |
| **Healthcare** | No of service users | 558 | 330 |
| | Mean cost per service user | £69 | £118 |
| | No of service users | 1735 | 715 |
| **Other** | Mean cost per service user | £102 | £249 |

Note: Cardiff and Berkshire are omitted from the analysis of costs.

**Table 9.7 Average changes in EQ5D index outcomes, by project, ITT analysis.**

| | Mean Start | Difference M3 | Difference M6 | Difference M12 |
|---|---|---|---|---|
| **Aberdeen** | 0.69 | -- | -- | -- |
| **Ards & N. Down** | 0.70 | -- | -- | -- |
| **Berkshire** | 0.70 | -- | -- | -- |
| **Cardiff** | 0.62 | -0.00 | 0.02** | -- |
| **Dorset** | 0.78 | 0.01** | 0.01 | -- |
| **Edinburgh** | 0.72 | -- | 0.00 | -- |
| **Guys** | Not collected | -- | -- | -- |
| **Herts** | 0.77 | 0.00 | -- | -- |
| **Lincolnshire** | 0.66 | 0.06*** | 0.1*** | 0.07*** |
| **Luton** | 0.78 | 0.01* | -- | -- |
| **Manchester** | 0.64 | -- | 0.03*** | -- |
| **Newtownabbey** | 0.79 | -- | -- | -- |
| **Sheffield** | 0.72 | 0.02*** | 0.02*** | -- |
| **Shropshire** | 0.77 | 0.02*** | 0.03*** | -- |

Notes: Asterisks indicate significance level of the two-sided t-test of the difference in means for a paired sample. *** P<0.01, ** p<0.05.

In ITT analysis outcomes are assessed for all participants who provide baseline data, regardless of whether they dropped out at any stage. For participants not present at follow up their baseline value is assessed at follow up, which is equivalent to the assumption that there is no change in outcome for that participant.

-- Represents a cell size < 30.