



MOVE  
MORE

## Integrating physical activity into cancer care

Evidence and guidance

**MACMILLAN**  
CANCER SUPPORT

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## Purpose of this document

This document builds on extensive research and evidence from Macmillan's work with pilot physical activity behaviour change projects. It aims to:

- provide decision makers with the evidence for integrating physical activity into cancer care
- describe effective intervention models
- demonstrate the connection to national policy and targets
- outline the economic implications of investing in physical activity for people living with cancer
- enable providers to decide on the right model and to implement it effectively as an integrated part of cancer care.

This document is designed to be read in conjunction with:

- *Physical Activity and Cancer: the Underrated wonder drug*<sup>1</sup>
- *Physical activity and cancer: a concise evidence review*<sup>2</sup>

Published 2018

This document updates and replaces Macmillan Cancer Support's document *How to run a physical activity project guide*.

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## Foreword

One in two of us will have a cancer diagnosis during our lifetime. Differences in our type of cancer and when we are diagnosed will mean our outcomes will be different.

Whilst improvements in cancer diagnosis and treatments mean many people are living longer, they are not necessarily living well. Also, many people are living with disabling consequences of cancer treatment and multiple-health conditions.

Physical activity from the moment of diagnosis has been called a ‘wonder drug’ as it plays a crucial role in both ‘pre-habilitation’ (before treatment) and rehabilitation. Not only does it help improve clinical outcomes, it can also help people take control of their lives, reduce social isolation, and enable them to live independently.

Macmillan has identified and developed ways to support people with cancer to be physically active. Through our pilot work in partnership across the UK with the NHS and local and national governments, we have identified and developed models which

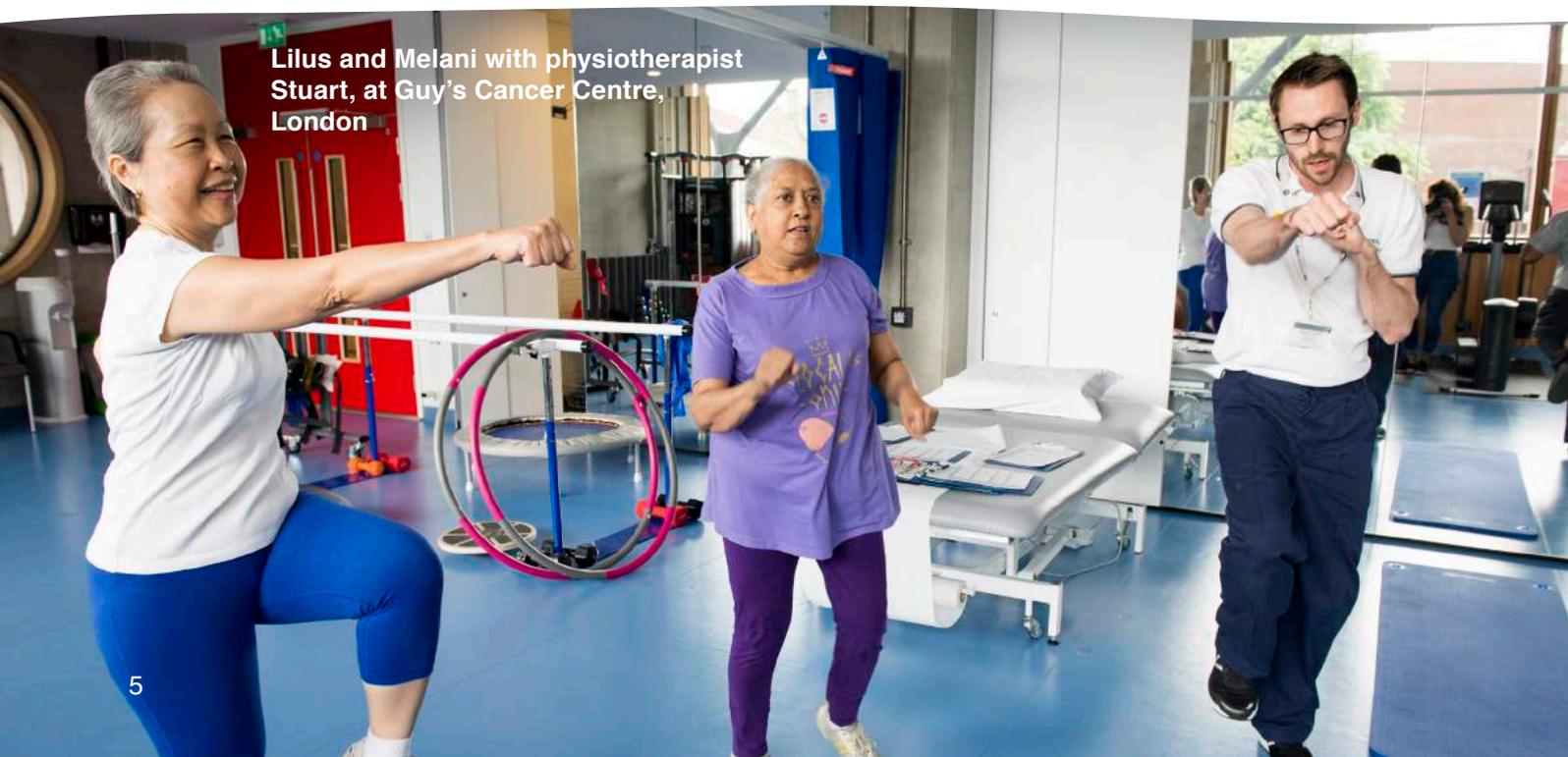
support behaviour change and can support people with a range of long-term conditions.

Macmillan’s evaluation and this guidance document show that the promotion of physical activity can be integrated into cancer care and people can be supported to become and stay more active at all stages of their cancer journey.

This guidance document has been produced to provide health and social care professionals with the evidence and insight they need to support and influence the inclusion of physical activity in commissioning or reviewing services in cancer care.

I hope you will join us in our mission to help people with cancer enjoy the benefits of moving more.

James Austin, Director of Specialist Advisory  
Fay Scullion, Director of UK Partnership  
Services



Lilus and Melani with physiotherapist Stuart, at Guy’s Cancer Centre, London

## Executive summary

Physical activity can help to improve clinical and quality-of-life outcomes from diagnosis through to end of life. It has been called the underrated 'wonder drug'.

A cancer diagnosis is a teachable moment, when people are more inclined to make positive changes to their behaviour. However, despite this, people become less active during cancer treatment and remain inactive.

Evidence shows a healthcare professional can trigger this teachable moment and help motivate people to understand the importance of moving more and inspire them to make a change, no matter their circumstances and barriers to change.

Macmillan has identified and developed ways to support people with cancer to be physically active, recognising the health benefits of moving more. We have identified and developed models which have the potential to support people with a range of long-term conditions and support behaviour change.



A motivational interview with Susan, delivered by her physiotherapist, Isla

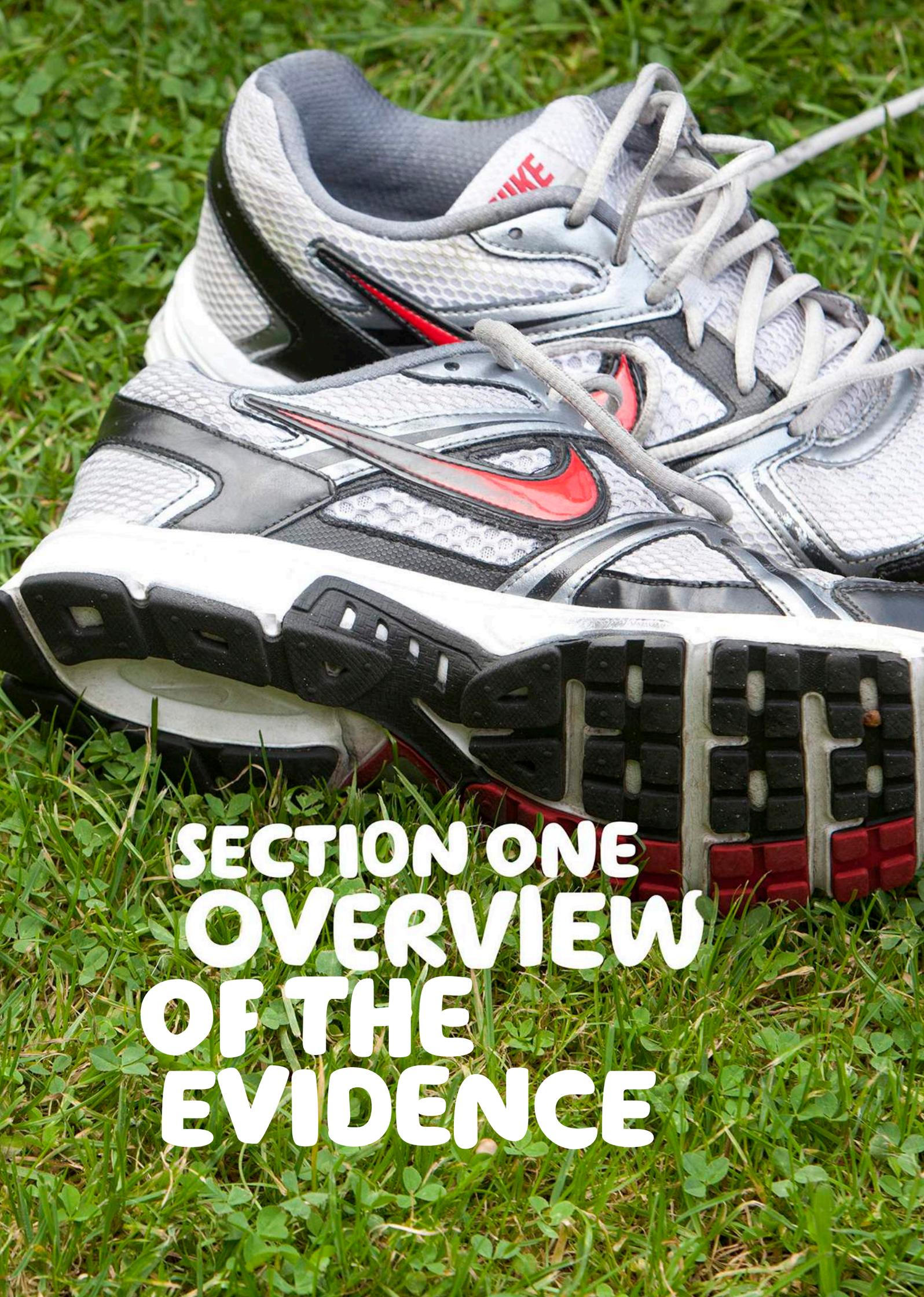
Macmillan has developed a model of care that can be integrated into the cancer care pathway to support people to become and stay more active. This is based on recommendations from NICE guidelines PH44, PH49 and PH55, the NHS Physical Activity Care Pathway *Let's Get Moving*, as well as additional evidence reviews and insight research.

Macmillan's approach is part of the Recovery Package – a UK-wide series of key interventions which, when delivered together, can greatly improve outcomes for people living with and beyond cancer. It is important that the promotion of physical activity is integrated into the recovery package at all stages, from 'prehabilitation' (before treatment) to rehabilitation afterwards.

Macmillan's approach is based on assessing someone's individual need and providing regular ongoing motivational support, with access to a wide variety of physical activities based on their personal preference and need. This helps to support long-term change, including for those during treatment and with incurable and advanced cancers,

A range of different approaches were piloted in a variety of settings and populations. As a minimum, healthcare professionals should advocate physical activity by raising the importance of moving more to patients and their carers, and signposting to Macmillan's *Move More* guide as a supported self-management tool to support change. If resources and partnerships allow, patients can be referred to a multi-stage, behaviour-change based intervention, usually based in the community, supporting the individual to make a sustained behaviour change to become and stay active.

This guidance document provides a comprehensive overview of the evidence, insight and testing of the approach with detailed guidance on how to implement locally, with case study examples of implementation in different health landscapes. Section one covers the evidence, Section two covers how to implement it.



**SECTION ONE  
OVERVIEW  
OF THE  
EVIDENCE**

# 1. Background: physical activity and cancer

## 1.1 Cancer prevalence, trends, and outcomes

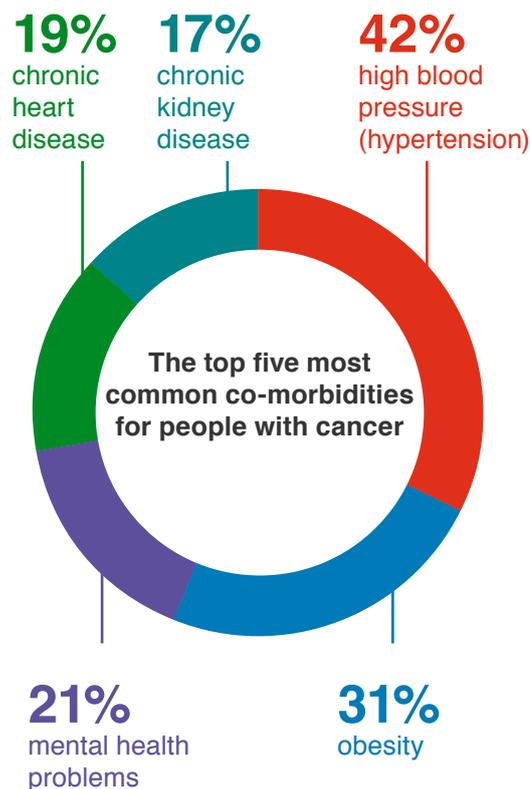
Improved cancer survival rates, the prevalence of unhealthy lifestyle behaviours, and a growing and ageing population are contributing to an increasing cancer incidence. By 2040 it is estimated that a total of 5.3 million adults in the United Kingdom will be living with or beyond a cancer diagnosis, representing 6.2% of the male and 8.5% of the female population.<sup>3</sup>

Different survivorship outcomes are seen in different cancers. The cancer journey that patients go through and their outcomes will vary depending on elements such as tumour type and the stage of the cancer at the point of diagnosis. Generally, survivorship can be categorised into three types: limited survival; limited to moderate survival; and on-going survival. For example, breast and prostate cancer patients have a higher proportion of patients classified as on-going survival, whereas a large proportion of lung cancer patients have only limited survival.<sup>4</sup>

Survival rates vary for each cancer type. For those diagnosed with cancer from 2011–2015 in England<sup>5</sup>:

- The one-year survival rate for prostate cancer was at 96.3% and female breast cancer was 95.6%. The lung cancer one-year survival rates were much lower with an average rate of 38.7%.
- The five-year net survival rate for prostate cancer was 88.3% and for female breast cancer it was 86%. Lung cancer had an average 15.3% five-year net survival rate.
- Estimated ten-year survival rates show that prostate cancer (82.9%) and female breast cancer (80.5%) had the highest survival rates.

Macmillan research<sup>6</sup> shows that an estimated 1.8 million people are living with one or more other potentially serious long-term health condition in addition to cancer.



Additionally, around 2 in 3 people living with cancer (64%) have practical or personal support needs, and 4 in 5 (78%) have emotional support needs. Around 2 in 5 people living with cancer (42%) have social care needs that are estimated as serious enough to be eligible for formal support from local authorities or health and social care trusts.<sup>7</sup>

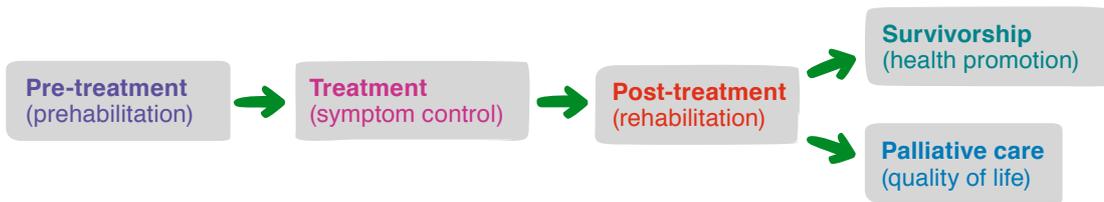
Some people may live longer, but they are not necessarily well. One in four people struggle with the consequences of treatment including heart damage, arthritis, depression and chronic fatigue.<sup>8</sup>

This burden of disease places significant pressure on the NHS, social care systems and the economy. For example, in 2009–2010, the NHS spent £5.86 billion on cancer care, which is 5.6% of the UK's total health spend.<sup>9</sup>

### 1.2 Physical activity improves clinical and quality-of-life outcomes

Evidence is growing to support the integration of physical activity promotion into cancer care. Enabling people to be physically active at all stages of their cancer journey can improve both clinical and quality-of-life outcomes. This includes ‘prehabilitation’ (before surgery or treatment) as well as rehabilitation afterwards.<sup>10,11</sup>

**Figure 1: Key stages of the cancer care pathway where physical activity has potential benefit**



Stage	Outcomes	Evidence
<b>Pre-treatment</b>	Increased cardiorespiratory fitness, fewer post-operative complications and shorter hospital admissions	Preliminary evidence
<b>Treatment</b>	Helps to preserve cardiorespiratory and muscular fitness, and to control cancer-related fatigue	Promising evidence
<b>Post-treatment</b>	Increased cardiorespiratory and muscular fitness, reduced fatigue, and improved body composition and wellbeing outcomes	Promising evidence
<b>Palliative</b>	Exercise is feasible, and may help maintain physical function, control fatigue, and improve bone health	Preliminary evidence
<b>Survivorship</b>	Associated with longer survival and a lower risk of recurrence or disease progression	Preliminary evidence

**Table 1: Key stages of the cancer care pathway where physical activity can improve outcomes**

Compelling	Promising	Preliminary
High-quality body of evidence with no uncertainty over the effects demonstrated	Moderate-quality body of evidence with some uncertainty over the effects demonstrated	Low or very low-quality evidence with considerable uncertainty over the effects demonstrated

**Physical activity is safe during and after cancer treatment**

Traditionally, people have been encouraged to rest during cancer treatment. However, this advice has now been shown to be outdated. A review of evidence-based physical activity guidelines for cancer populations in Australia, Europe, and the United States now concludes that physical activity is safe and should be an integral and continuous part of care for all individuals.<sup>12</sup>

General recommendations common to all published guidelines<sup>13</sup> include:

- Avoid inactivity and return to usual activities as soon as possible after surgery.
- Aim to continue physical activity as far as possible while undergoing treatment.
- Build up to age-appropriate guidelines for health-enhancing physical activity after treatment (typically aerobic exercise for two and a half hours per week, resistance exercise twice a week, and balance/ coordination exercises twice a week), heeding key safety principles).

**Figure 2: UK Chief Medical Officer’s Guidelines for adults and older adults<sup>14</sup>**



This builds on the 2010 American College of Sports Medicine round table guidelines (scheduled for update in 2018) that advocate physical activity during and after cancer treatment.<sup>15</sup>

For more information on the evidence for physical activity and cancer, see *Physical activity and cancer: a concise evidence review*.<sup>16</sup>



### Patient case study: pre-treatment ('prehabilitation')

In 2005 Richard was diagnosed with bladder cancer. The cancer was successfully eradicated. However, his overall fitness declined. Richard decided to take part in the 'Macmillan Move More' project to improve his wellbeing and fitness. He consulted his doctor about 'Move More' who made the referral.

Less than a year later, 2013, he was very thankful for participating in 'Move More' when diagnosed with stomach cancer. The decision was made to remove his stomach if it was considered he was fit enough for the operation. Richard, who has a heart condition, passed the fitness tests reasonably well and the operation was planned with an anaesthetist on hand who specialised on people with a heart condition.

The gastrectomy went well, made all the easier because his general fitness had been maintained by his participation in 'Move More'. Recovery took over eighteen months before returning to the project. He is now back enjoying light exercise under the supervision of his *Move More* Activator, Stephanie. Richard completed the first three-month period of 'Macmillan Move More' and hopes to continue the scheme in the future.

In 2015 he was diagnosed with Myelodysplastic Syndrome (MDS) which means he needed to maintain a good state of fitness and health to give any treatments the best chance of success.

What Richard likes about the 'Macmillan *Move More*' scheme is that his fitness goals are regularly assessed and set to be within his capabilities, inspiring him to move forward without putting pressure on or to overstretch himself. Perhaps most noteworthy is that the project has prepared him for the unforeseen health issues that have come along.



### Patient case study: during treatment

John, 63, was diagnosed with diffuse large B-cell lymphoma in 2015. Before cancer, John lived an active lifestyle: he regularly walked the dog and taught exercise classes at the leisure centre. The seriousness of his illness was a complete surprise and he went from being ok to being unable to walk in a couple of weeks.

'My illness shook both my wife and me. In fact, I think in the first weeks it was harder on my wife. All I had to do was lie in a hospital bed and get better. She had to do everything else.'

John spent three months in hospital. For many weeks he was unable to move his lower body without help as the cancer had impacted his spinal cord. The first round of chemotherapy hit John badly and he had many side effects. Recovery was very slow, but he could see minor improvements in hospital towards the end.

During John's recovery, he received physiotherapy and support from the *Move More* Eastleigh service. As a result, his strength, coordination, control, balance, mobility and stamina have all improved. This helps make the tasks of day-to-day living easier to accomplish and the level of pain has reduced, especially during and immediately after exercise.

Exercise has helped John maintain a positive approach to life. John is now able to cycle 20 miles and walk with poles for 4 to 5 miles. He is setting further targets for 2017 with support from the *Move More* service and resources.

**🔍 Patient case study: post-treatment**

Clare, 52, was diagnosed with breast cancer in 2011. Clare now lives with lymphoedema, osteoporosis and mild asthma as a consequence of her treatment. Clare heard about the benefits of physical activity through the Macmillan website and a poster put up in her local cancer centre. She found out where the service was running in her area, and was referred by her cancer nurse onto the Get Active Feel Good service.

Prior to Clare's cancer diagnosis she gardened and had an allotment, but otherwise hadn't done much activity since school, where she had played for the hockey and badminton teams. Since joining Get Active Feel Good, Clare has been introduced to a new way of life.

'Being involved in Get Active Feel Good has changed my whole outlook, my career, my whole everything. It's not just about being a sick person. It's not about the cancer. It's about more than that. Having a positive attitude and being mentally well, as well as physically well, helps you combat what has gone on before and after the cancer.'

**🔍 Patient case study: advanced cancer**

Paul, 73, was diagnosed with advanced follicular lymphoma in July 2010. Following his diagnosis and treatment, Paul felt his general state of fitness to have fallen. Paul heard about the *Move More* service through attending a local support group.

As his general fitness improved, he found increased energy and improved balance, co-ordination and flexibility. Paul was so impressed with the results that he began exercising at home. This has resulted in a quantifiable improvement that he is determined to maintain.

Taking part in the service has enabled Paul to take control of his own personal fitness. The programme is provided with support at a level that is right for him and the benefits are quantifiable. Previously inactive, he now feels lighter, fitter, more flexible and empowered.



Clare, diagnosed with breast cancer in 2011

'The Active Luton programme really has changed my life. My cancer was treated with surgery, which has left me currently unable to walk. After such drastic treatment I felt very low emotionally, but taking part in the exercise programme has given me focus and motivation as well as being a huge physical help. I have hydrotherapy once a week and also lift weights in the gym to keep my upper body strong. This has been very beneficial as it means I am able to self-propel my wheelchair, which helps me to stay independent and mobile. I have a great support network in the gym with other regular gym-goers, giving me moral and physical support with my workouts.'

Roy, Luton

'Physical activity helped me get over the extreme fatigue I had from medication. To stay on the medication – to stop the cancer coming back – I need to keep active so the fatigue is manageable. Physical activity is a positive thing you can do for yourself, even during treatment when you may not feel in control.'

Nicki, Luton

'The Radiotherapist at The Christie told me about Manchester Active and *Move More* Practitioner. I emailed and an appointment was arranged for him to meet me for an initial assessment. The way he conducted the meeting encouraged me to attend my first class the following week. It was his matter-of-fact approach and the certainty with which he explained how it didn't matter how much or how little I could manage, he would tailor the exercises to my requirements, which gave me confidence. I then began to attend the Tuesday morning class at Beechwood Cancer Care centre.

I have been a regular attendee since September 2016 and it has been instrumental in changing my lifestyle for the better. I now do yoga and tai chi and have started swimming for the first time in twenty years. The changes to routine have helped change my attitude towards food and as a result of the combination of regular exercise and healthy eating, I have lost two and a half stone. I have more energy and stamina than for some years before my diagnosis, and my family and friends can see this and take heart that the diagnosis of cancer does not mean that all changes have to be for the worst. The first step in my healthier lifestyle was taken as a direct result of my first meeting with Ambokile and my starting the Manchester Active class at Beechwood. I will always be grateful for this and I hope that many more patients in the future will be able to benefit in the same way.'

Kathryn, Manchester

**'After such drastic treatment I felt very low emotionally, but taking part in the exercise programme has given me focus and motivation.'**

Roy, Luton

### 1.3 Physical activity participation trends, barriers, and motivators

Despite the evidence that being physically active can improve clinical and quality-of-life outcomes, the evidence also shows that most people with cancer reduce their physical activity levels during cancer treatment, and do not start being active again without support.<sup>17,18</sup> This is most likely due to a combination of the impact of cancer-related fatigue, concerns about safety, and the traditional message of rest.

The Patient Reported Outcomes Measures (PROMS) survey in 2012 shows that only 33%<sup>19</sup> of people living with and beyond cancer in England are active at recommended levels. This is significantly lower than the general population in England and Scotland: 67% of men and 55% of women in England and Scotland report physical activity at this level.<sup>20</sup>

Macmillan has carried out research to understand the barriers and motivators for people of all demographics, types of cancer and stages of the cancer journey. This found four core predictors of whether someone is likely to become active during and after their cancer diagnosis. These are:

- **Individual drivers:** the person's emotional state including their level of confidence, response to cancer, mental wellbeing, and their self-identity.
- **Social drivers:** the strength of a person's social network and the support of family and friends.
- **Physical symptoms:** the side effects of the cancer and its treatments. These were identified as barriers to physical activity, notably fatigue and pain, incontinence (for bowel and prostate cancers), scars from surgery affecting certain muscle groups and breathlessness in those suffering from lung cancer. People may not know what

type or level of exercise is safe for their particular cancer type or treatment stage. People with cancer want to know what is safe and appropriate for their situation, cancer type and treatment stage.

- **Physical environment:** the availability of facilities and opportunities for physical activity. Proximity of facilities is important, as is the potential for social stigma: some people might feel uncomfortable in public places.

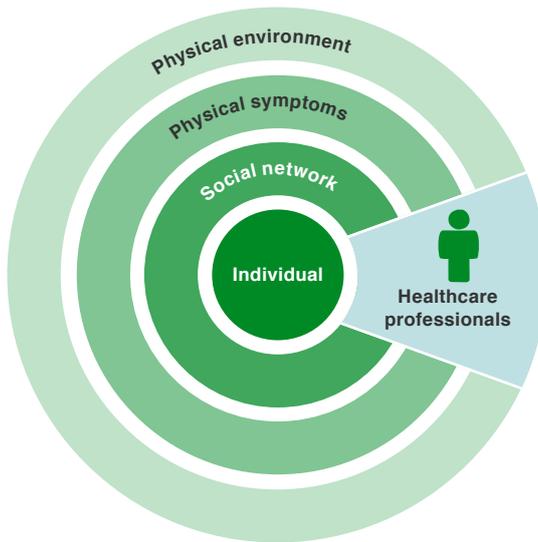
It is the individual drivers and social network that are the key determinants of physical activity across all the sub-groups involved in this research. If an individual is motivated, confident, focusing on positive achievements and regaining control, with a social network in place, then they are likely to find ways to become active and overcome any physical symptoms and limitations in their physical environment.

Conversely, if they are not motivated, confident or suffering from anxiety or depression with no social network, even with few physical symptoms and plenty of opportunities within their physical environment, they are unlikely to become active.

People living with and beyond cancer need to know it is safe to become and stay active, at a level that is right for them, listening to their body, starting slowly, building gradually, and planning around treatment cycles and physical limitations.

These messages need to come from trusted healthcare professionals, who have the power to cut across all barriers to change.

**Figure 3: Healthcare professionals can have a strong impact on the drivers of physical activity in people living with cancer.**



People tend to be motivated to do physical activity with family, friends, and pets (i.e. getting back to the routine of walking the dog). They want it to be part of family time rather than competing with it. Family members and friends would benefit from receiving advice along with their loved one on physical activity, encouraging their involvement in discussions, planning and taking part.

For more information see Macmillan's report *What Motivates people with cancer to get active?*<sup>22</sup>



Sonia, diagnosed with bowel cancer in 2009



Healthcare professional, Shelagh, delivering a 'very brief advice' session

#### 1.4 Opportunities to intervene: the teachable moment and the Recovery Package

A cancer diagnosis provides a 'teachable moment': a time when an individual is more inclined to change their behaviour.<sup>23,24,25,26,27</sup>

Cancer patients, have been shown to demonstrate an enhanced motivation to change lifestyle behaviours, especially within the year after diagnosis.<sup>28</sup>

These teachable moments however, will not bring about a change in behaviour on their own. They need to be deliberately created as part of the patient consultation.<sup>29,30</sup> Despite frequent views to the contrary, there is evidence that most cancer survivors are keen to receive information or advice about exercise at some point during the cancer experience.<sup>31,32</sup> It is important that this counselling is delivered by a qualified health professional, and is individually tailored to each patient. Macmillan's insight research shows that it is more important how this conversation is delivered than when.<sup>33</sup>

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, given in less than two minutes, to motivate

people to make a lifestyle change.<sup>34</sup> 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.<sup>35,36</sup>

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<sup>37</sup> 89% of patients have a named clinical nurse specialist in charge of their care.<sup>38</sup> Nurses often see the same patients many times and can build a strong relationship, meaning patients may be more receptive to their advice.<sup>39,40</sup> For example, in one study, patients who recalled being given advice about physical activity were 9% more likely to be active than those who did not.<sup>41</sup>

The Recovery Package core interventions provide an excellent opportunity for healthcare professionals to raise awareness of the importance of being active during and after cancer treatment. This can be done during assessment and care planning using the holistic needs assessment or at a health and wellbeing event.<sup>42</sup>

## The Recovery Package



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The Recovery Package is a series of key interventions which, when delivered together, can greatly improve outcomes for people living with and beyond cancer.<sup>43</sup>

These include:

- A holistic needs assessment (HNA) and care plan
- A treatment summary
- A cancer care review, and
- A health and wellbeing event.<sup>44</sup>

These interventions provide opportunities for patients, supported by their healthcare professional, to identify their needs at each stage of their cancer journey, and be supported to access additional support. This includes where physical activity can help to meet an unmet need such as managing fatigue, living independently, or returning to work.

### **Treatment summary**

The treatment summary is the apex of the Recovery Package. It documents the cancer and reviews the treatment a patient has undertaken, including 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 patient should also receive a copy in order to help improve their understanding of their treatment. It is used to inform the GP's cancer care review, which is also part of the Recovery Package.

### **Cancer care review**

Informed by the treatment summary, this is a discussion between a patient and their GP or practice nurse about their cancer journey. It should help the person living with cancer 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. It aims to identify and support the individual's unmet needs and signpost to more support. This can be delivered using a holistic needs assessment to ensure the conversation is person-centred.

### **Holistic needs assessment (HNA) and care plan**

The HNA helps the person living with and beyond cancer (PLWC) and their healthcare professional to identify the needs of the person and ensure they are met. It is a questionnaire completed by the PLWC that 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 the changing needs of the PLWC are met, a HNA should be undertaken at each different stage of a patient's treatment journey: at diagnosis; at end of treatment; whenever the patient's needs change; or at the patient's request. Effective assessment and care planning can lead to early interventions, diagnosis of consequences of treatment, improved communication and better equity of care. The HNA and care plan ensure that people's physical, emotional and social needs are met in a timely and appropriate way, and that resources are targeted to those who need them most.

### **Health and wellbeing events**

Health and wellbeing events are designed to help people living with cancer and their families to access the support 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, generic (covering all tumour types), or delivered as an appointment.

The full Recovery Package was tested through the National Cancer Survivorship Initiative. This showed that if delivered well, it will help people living with cancer increase their wellbeing, and reduce their demand for services. This depends on them getting the support that's relevant to their needs, and which promotes healthier lifestyles and independence.<sup>45</sup>

## 2. An evidence-based approach to integrating the promotion of physical activity into cancer care

The evidence and insight has shown that physical activity can improve clinical and quality-of-life outcomes at all stages of the cancer journey, and that people living with and beyond cancer are receptive to advice from healthcare professionals about physical activity at all stages of cancer care. They want support in becoming more active and want this to be tailored to their needs whilst being active participants in choosing the right approach for them.

NICE guideline PH49 *Behaviour change: individual approaches* recommends that support is provided for at least a year to bring about long-term behaviour change. The regularity and format of support need to be based on the individual's personal needs and preferences.<sup>46</sup>

Macmillan has worked with clinicians, service users, local decision makers, service providers and academics to develop an intervention based on the best available evidence. It builds on learning from the adult physical activity care pathway *Let's Get Moving*<sup>47</sup> and recommendations and evidence from NICE Public Health Guidelines *Physical activity: brief advice for adults in primary care* PH44 and *Behaviour change: individual approaches* [PH49].



Bei, diagnosed with colorectal cancer in 2014

NICE PH44 concludes that brief interventions are effective at increasing physical activity levels, in the short term (six to 12 weeks), the long term (over 12 weeks), and in the very long term (12 months or more). For the effect to be sustained for one year, the evidence suggested that several follow-up sessions over a period of three to six months are required after the initial consultation episode.<sup>48</sup>

NICE PH49 found that for an increase in physical activity levels to be sustained until the one-year mark, there should be an initial consultation using a behaviour change technique such as motivational interviewing, with regular follow-up sessions over the course of the year. The regularity of these should be based on the need of the individual.

Based on this evidence and insight, Macmillan has developed a model that is delivered as an integrated care pathway. This initiates in healthcare and is followed by a multi-stage, behaviour change-based intervention, usually based in the community.

This physical activity behaviour change care pathway – also known as the *Move More* service – has been tested in over 50 sites across the UK, taking into account a wide variety of geographies and health landscapes. In addition to learning from a community of practice from all of these sites, an independent process and impact evaluation of 14 of these test sites was conducted.

The *Move More* service evaluation report<sup>49</sup> is available here: [www.macmillan.org.uk/assets/evaluation-of-macmillan-physical-activity-behaviour-change-care-pathway-2018.pdf](http://www.macmillan.org.uk/assets/evaluation-of-macmillan-physical-activity-behaviour-change-care-pathway-2018.pdf) and the summary document: *Physical Activity and Cancer: the underrated wonder drug*.

## 2.1 A physical activity behaviour change care pathway: an overview of the best practice model

Figure 4: A physical activity behaviour change care pathway



### Raising awareness

Macmillan’s model starts with the Recovery Package. Professionals delivering holistic needs assessments as part of assessment and care planning, cancer care reviews and health and wellbeing events are encouraged to advocate physical activity to improve their outcomes.

Promotional materials are available to help promote physical activity in clinical and other settings. These combine user-tested messages with the trusted Macmillan brand, on banners, posters and leaflets, as well as through social media, local media, radio and printed press.

Awareness of the importance of physical activity can also be raised by healthcare

through direct mail. Early testing suggests that a letter advocating physical activity signed by a lead clinician and sent by hospitals to their patient list increases self-referrals to the local *Move More* service by an average 20% increase per mail-out.

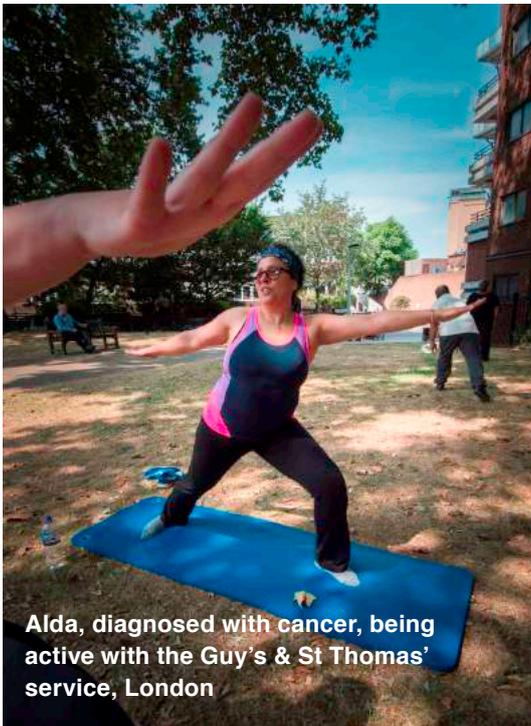
Many community-based services also raise awareness and signpost patients to further support, including pharmacies, information, support centres and libraries.

### Referral

Patients either self-refer, or are referred by a health or allied healthcare professional into a *Move More* service. Where there are no services available, patients are signposted to Macmillan’s *Move More* guide – a supported self-management resource pack.

### Holistic needs assessment (HNA) and care plan

Guy's and St Thomas' are an early adopter of the eHNA process and hundreds are conducted each month. The *Move More* service have placed physical activity as a concern on the eHNA, which automatically triggers a request for the service to contact the individual and support them onto the programme. The service has attracted over 744 service users since its launch and receives over 30 referrals from healthcare professionals per quarter.



Alda, diagnosed with cancer, being active with the Guy's & St Thomas' service, London

Bournemouth, Poole and Dorchester Hospital has used the eHNA database to send a letter to patients about the importance of moving more. This direct mail approach from the hospital led to an increase in monthly referrals of over 20%.

### Health and wellbeing events

In Manchester, there is a fortnightly health and wellbeing event targeting different tumour groups. The Manchester *Move More* service attends and the *Move More* practitioner delivers an interactive, informative presentation, which leads to people self-referring to the service.

Guy's and St Thomas' have increased attendance at their health and wellbeing events. The *Move More* team (in this case physiotherapists) deliver a session at every health and wellbeing event, which has boosted numbers to their programme further. They link with the hospital survivorship days offering taster activities including Just Bowl, Wii Fit, yoga and a Step Up Challenge to encourage new referrals onto the service.

Move More Luton and Dorset Living Well Active work with their NHS Hospital Trusts to host health and wellbeing events in community facilities including leisure centres and universities. Some of these events are generic, and some are specific to a cancer site. The hospital Cancer Nurse Specialists (CNSs) attend the events at the community facilities, service users present their experiences of the cancer journey, and they also incorporate a series of physical activity taster sessions. Approximately 60 people living with and beyond cancer attend these events, leading to an average of 14 new referrals.

### Cancer care reviews

In Dudley, the service is testing an opt-out process in collaboration with GPs delivering the cancer care reviews. By embedding a pop-up, simple referral form within the patient record system used at a key part of the cancer care review, the GP and patient have to physically discard (or opt-out of) the automated form. The system electronically sends a pre-populated contact form over to the service for them to contact the patient and engage in the 12-month behaviour change support programme. This system of simple, electronic referrals has resulted in the Dudley service receiving a large uplift in referrals from primary care, even though the physical activity service is based within a secondary care hospital setting. This results in approximately 14 GP referrals per quarter.



### **Move More service**

#### **First appointment: behaviour change intervention and needs assessment**

The first appointment is a 30- to 60-minute, person-centred behaviour change intervention, undertaken by a *Move More* Practitioner. This person requires strong behaviour change skills and competencies such as motivational interviewing, with good empathy and listening skills and knowledge of cancer rehabilitation.

In this appointment, the practitioner undertakes a needs assessment including: the cancer; its treatment; co-morbidities and any safety considerations; previous and current levels of physical activity; and a discussion of social support available.

The next stage is to use motivational interviewing to discuss the individual's motivations and barriers to taking part in physical activity, and support them to build confidence and motivation. Those who are ready are supported to set achievable goals,

and decide on an activity they will enjoy that is right for their needs – whether independently or in a group. How much and the type of physical activity will depend on their personal preference and the impact of their cancer, its treatment, co-morbidities, and current fitness levels.

It is important to note that for many, this is about maintaining a level of gentle activity or trying to reduce the amount of time spent sedentary. For some it may be about managing a decline as opposed to increasing physical activity levels, particularly for those during treatment or with advanced cancer. A close friend or family member can be encouraged to provide support and take part.

The most effective behaviour change techniques to encourage physical activity are reviewed in NICE PH49, and *Behaviour Change Taxonomy*.<sup>50</sup> These are included within the *Move More* guide to support a motivational interviewing style intervention.

### Physical activities

Macmillan's insight research<sup>51</sup> shows that in terms of physical activities, some people would like group-based activities, some individual. Some people want the activities to be cancer-specific, while others do not want to be associated with cancer and would like to 'get back to a new normal'.

Macmillan encourages providers to have a variety of local physical activities available for people to choose from. These include specialist cancer rehabilitation, walking groups, and dance, programmes focused on getting back into sport, gentle movement classes such as chi gung or adapted tai chi, or home-based activities such as Macmillan's exercise-to-music DVD.



Where services signpost to existing local physical activity opportunities, it is important that there is an element of quality control and that the physical activity group leaders have an awareness of the impact of cancer.

### Long-term behaviour change support and follow-up

This is based on the NICE Public Health guideline *Behaviour change: individual approaches* PH49, which recommends that feedback and monitoring is provided for a minimum of one year in order to bring about long-term behaviour change.

The *Move More* professional provides tailored support and encouragement at regular intervals that is appropriate for an individual. The NICE Guidance suggests that

this should be for at least 12 months. There is no specific frequency of appointment. One person may need support more regularly than another and for a different length of time. Not all people will need support for 12 months. Feedback from test sites is that some service users choose to opt out of ongoing behaviour change support as they no longer need it whilst remaining active. However, they will need the ability to re-enter the service should their circumstances change – as is the nature of living with cancer.

At each follow-up appointment, it is important to: re-evaluate changes to the person's condition; discuss safety considerations; review progress and possible setbacks; review goals and activity types; review the level of support; and agree ongoing follow-up.

The strongest evidence for the delivery of behaviour change support is in a one-to-one, face-to-face environment. This is the model that the majority of Macmillan's test sites followed.

There is also evidence from the general population, and from NICE PH49, to suggest that when done well, this behaviour change support can also be provided in a group environment.<sup>52</sup> There is also a growing body of strong, positive evidence that behaviour change can be delivered effectively when done remotely by telephone<sup>53,54,55,56,57,58</sup> and through digital support mechanisms.<sup>59,60,61,62,63</sup> The evidence for the use of telephone support in helping to support people living with cancer to become and stay more active has typically been used in conjunction with a healthcare consultation. This has been shown to be effective in breast and colorectal cancer survivor populations.

This can be supported by other mechanisms such as motivational newsletters, text message prompts and reminders, volunteer peer support, informal drop-in support sessions, and by professional and peer support within physical activity groups.

**Volunteers** can be a key resource in supporting behaviour change. Evidence suggests that having a supportive individual (a role model, peer supporter or someone from ones' own community) who understands the journey the patient is on, and facilitates and joins in with their physical activities has the potential to increase levels of self-efficacy and perceived social support. This in turn can motivate, empower and enable people living with and after cancer to choose to become and stay active at a level that is right for them.<sup>64,65,66,67,68,69</sup>

Evidence suggests that a peer-support volunteer role increases perceived social support, targets social stigma, and alleviates loneliness and isolation, removing the barriers of exercising alone.<sup>70,71</sup> The effective physical activity buddy model includes social skills, self-esteem and social responsibility. If the buddy is a natural, friendly support, chances of effectiveness are higher. Familiarity of peers increased self-efficacy.<sup>72,73</sup>

Peers are more accessible than staff and work better in smaller groups. Encouragement should be via weekly emails, text, phone or in person. Peer mentors are effective in supporting individuals making changes and better equipped than professionals to support others who face similar challenges, life experiences and barriers.<sup>74,75</sup> Peer mentors lead to increased retention, adherence and improved fitness, which is a cost-effective approach for services.<sup>76,77</sup>

'Spending time with people was the key motivation for me, helping my mood and confidence is something that in turn makes me happy. *Move More* is a fantastic programme and I would recommend it to other volunteers. I have met so many great people, improved my physical and mental fitness while helping others.'

**Scotland *Move More* volunteer**

Linda, diagnosed with non-Hodgkin lymphoma in 2010



## 2.2 Types of delivery model

The UK is not a uniform landscape. The needs of people living with and beyond cancer, and the health and social care landscape vary by geography. A delivery model that works for an inner-city community will need to be adapted to work in a rural location. Macmillan has worked in partnership with a vast range of localities across the UK in testing the overarching model of care and understand what works, for whom and in what circumstances.

Two delivery-model settings for behaviour change have been identified: community, and healthcare. The two types of delivery models will signpost to existing opportunities in the area and may also directly deliver physical activity services. This is dependent upon their organisation's set-up, facilities and resources. It must be noted that utilising existing physical activity services and leisure provision, rather than creating new sessions adds to the financial sustainability of the service. However, if budgets permit and service users require and request it, tailored group sessions may be created.

### Community

These services are based in the community, with provider organisations including County Sports Partnerships (in England), Universities and Football Clubs. These services deliver behaviour change support in community venues, or an individual's home. They tend not to provide any (or very few) physical-activity opportunities themselves, instead focusing their efforts on signposting to existing activities across the area covered.



### Spotlight on community setting signposting to physical activity

The *Move More* programme in Lincolnshire is delivered by Active Lincolnshire, who are the County Sports Partnership (CSP). They host and support the two *Move More* practitioners, who deliver the service in a remote fashion, covering half of the county each.

The *Move More* practitioners deliver behaviour change interventions within a service user's home, and in agreed public venues such as coffee shops, libraries, community centres and other community venues. The behaviour change intervention identifies which activities would most suit the individual, which they are then signposted to and supported to engage in. These could be anything from a wide range of activities, including home-based activities, or sports. Each individual service user is followed up and supported by their dedicated *Move More* practitioner over a period of 12 months and in a way that's best suited for the service user. For more information, visit [activelincolnshire.com/get-active-feel-good](https://activelincolnshire.com/get-active-feel-good)

**‘Being active with Walking for Health has helped reduce my fatigue which is a side effect of my treatment.’**

Mike



### Spotlight on community settings with direct delivery

*Move More Luton* is run by the Active Luton sport and leisure trust. It was one of the first *Move More* pilots working in partnership with Macmillan and the Luton and Dunstable Hospital. During the pilot phase, a dedicated CNS was funded to champion the programme, which led to increased referrals from secondary care. The service received funding from Sport England as part of the Get Healthy Get Active portfolio to recruit two new members of staff – one with a sporting opportunities focus and one with a palliative care remit. The sessions are available to anyone with a cancer diagnosis – either curative or palliative – and at any stage of the journey, whether currently in active treatment, recovering from surgery or in remission. The first 12 sessions are free within any Active Luton leisure facility including Inspire Sports Village – a world class, state-of-the-art, multi-sports facility. There are a wide variety of sports and activities to suit all tastes, which are all led by cancer rehabilitation specialists. Activities range from swimming, exclusive Macmillan classes, walking for health, one-to-one sessions in the gym and walking football.

### Healthcare

These are services that are embedded within a healthcare setting, typically secondary care linked to a physiotherapy or wider therapies team, and associated with cancer. Individuals are able to access these services directly from clinical treatment.



### Spotlight on a service

The *Move More* programme at *Guy's and St Thomas'* trust is delivered by the physiotherapy department within the hospital trust, from the dedicated Guy's Cancer Centre. The hospital trust provides cancer treatment for patients across six south-east London boroughs and the *Move More* service replicates this. The physiotherapists take referrals directly from healthcare professionals or patients and are risk stratified based on their capabilities and consequences of treatment. This service is led by a physiotherapy team and consists of specialist oncology physiotherapists and technical instructors trained to deliver cancer exercise and rehabilitation.

Patients receive an initial assessment using behavior change techniques which results in being triaged into the most appropriate physical activity – from one-to-one physiotherapy support (for severe and complex cases) to exercise in the community such as health walks. They are followed up at regular intervals, regardless of their activity choice and they are invited to participate in further behaviour-change interventions over the subsequent 12-month period.



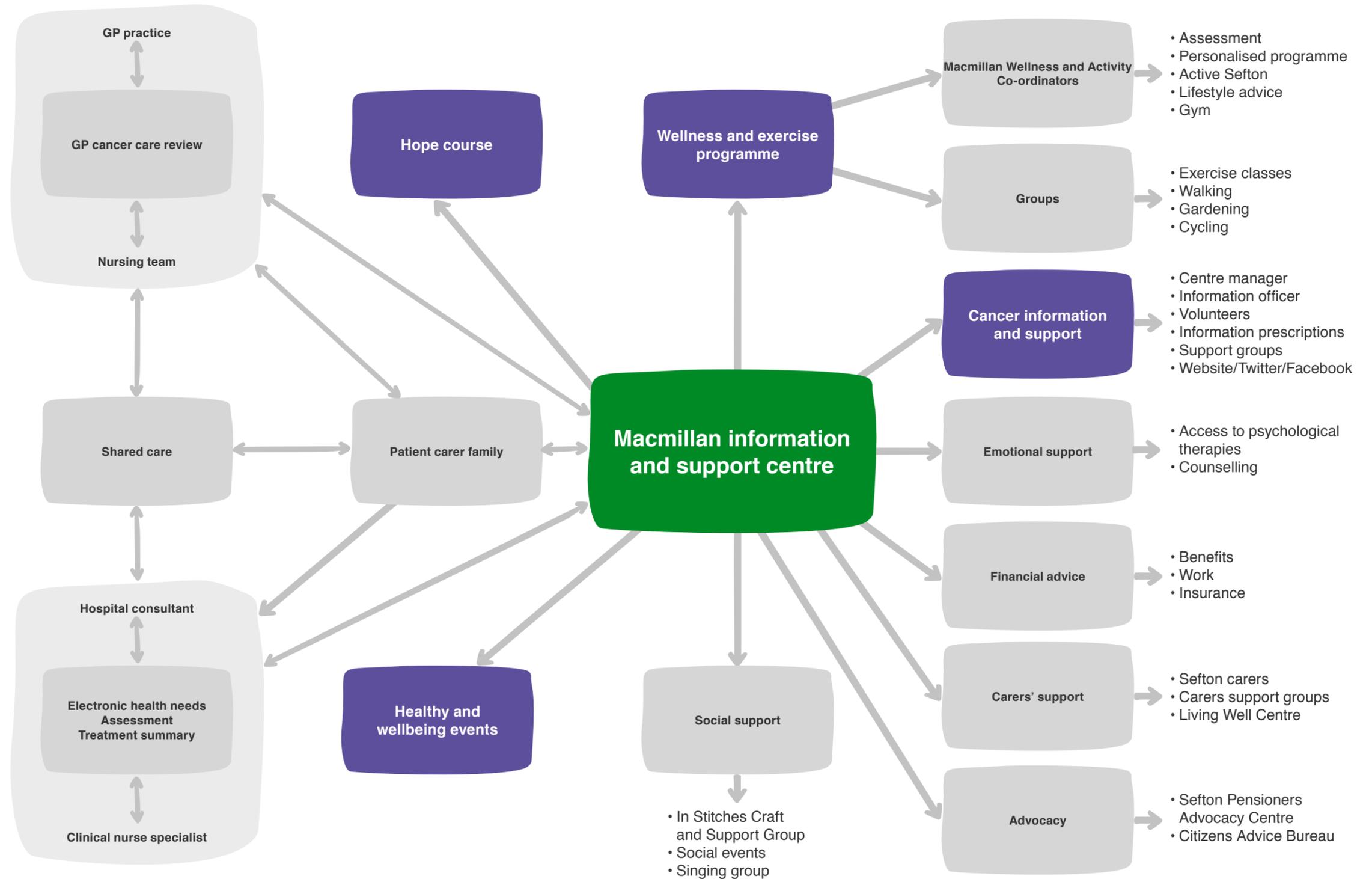
Isla, Macmillan Oncologist Physiotherapist, and Stephen, diagnosed with cancer

**‘Promoting exercise and physical activity really enables those with a cancer diagnosis at any point throughout someone’s cancer journey including curative and palliative stages. It helps cancer survivors to not only live but to live well and have meaning if their life.’**

Isla Veal, Highly Specialist Macmillan Oncology Physiotherapist.

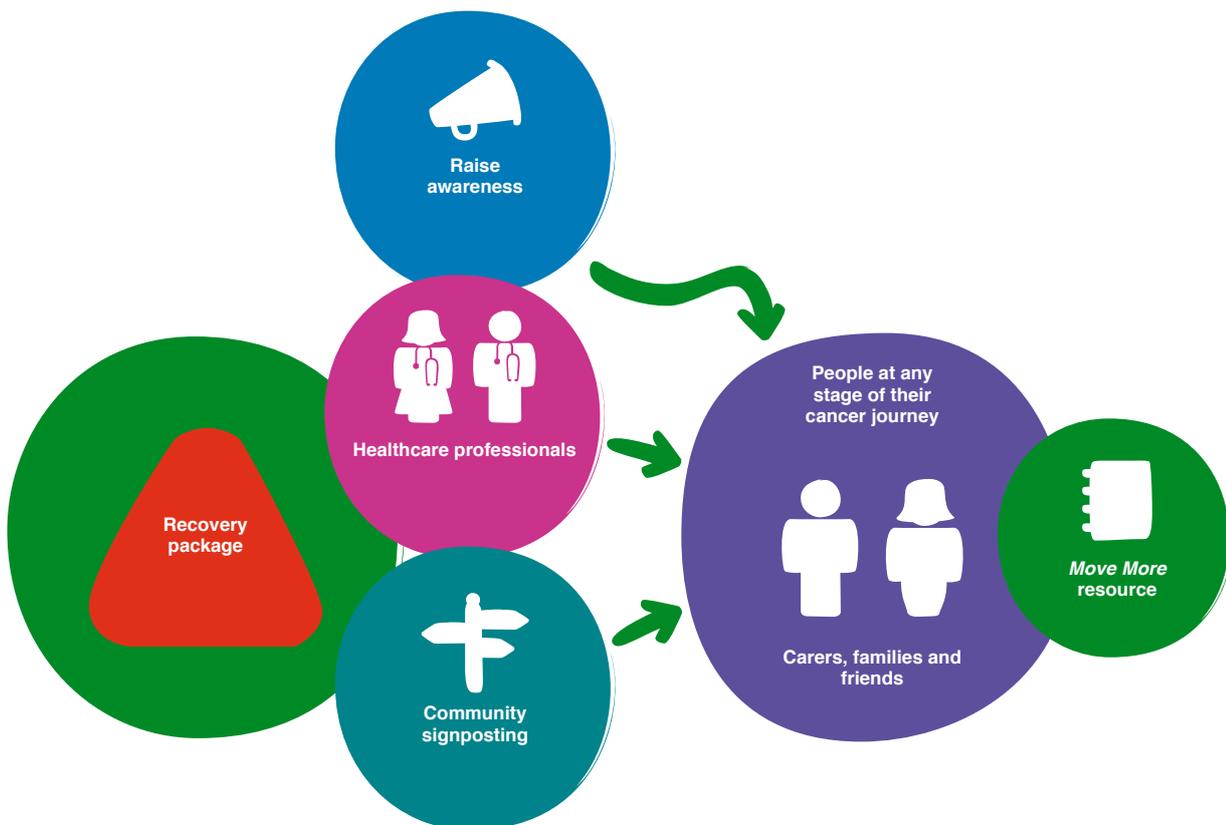
Southport and Formby rehabilitation programme

Southport and Formby have integrated physical activity into the Recovery Package as a whole system approach. The Southport Macmillan Information and Support Centre acts as a hub, a team comprising members from various health and social care organisations, work together to provide person-centred support to help individuals identify their personal needs and access support. The service was successful in attracting more than 200 patients to their health and wellbeing events. Patients receive a specially designed information pack detailing the support they can access, including the *Move More* service. The service received the Macmillan Integration Excellence Award 2016 for their work around improving the quality and experience of care for people affected by cancer.



### 2.3 Minimum viable product

Where it is not possible to provide a full behaviour-change service as an integrated care pathway with cancer care, at the very least there is the opportunity for healthcare professionals to raise the importance of physical activity with their cancer patients and to signpost to Macmillan’s *Move More* resource pack – a supported self-management tool.



#### Raising awareness

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 wellbeing events to advocate physical activity in order to improve their patients’ outcomes.

#### Supported self-management

Where there is no service available, patients are signposted to Macmillan’s supported self-management resource pack, *Move More*.

*Move More* guide This patient information resource combines print and digital to provide: information about physical activity and cancer outcomes; behaviour-change tools; an activity diary; an exercise-to-music DVD; case studies and videos; and an online Ask the Expert forum and online community as well as motivational emails. **The *Move More* guide was ‘highly commended’ in the 2017 BMA Patient Information Awards and won the award for self-care.**

A randomised controlled trial of this resource is ongoing. Early findings indicate statistically significant increases in physical activity

levels over six months, with the biggest improvements seen in those who were classified as inactive prior to cancer diagnosis. This will be published in 2018.

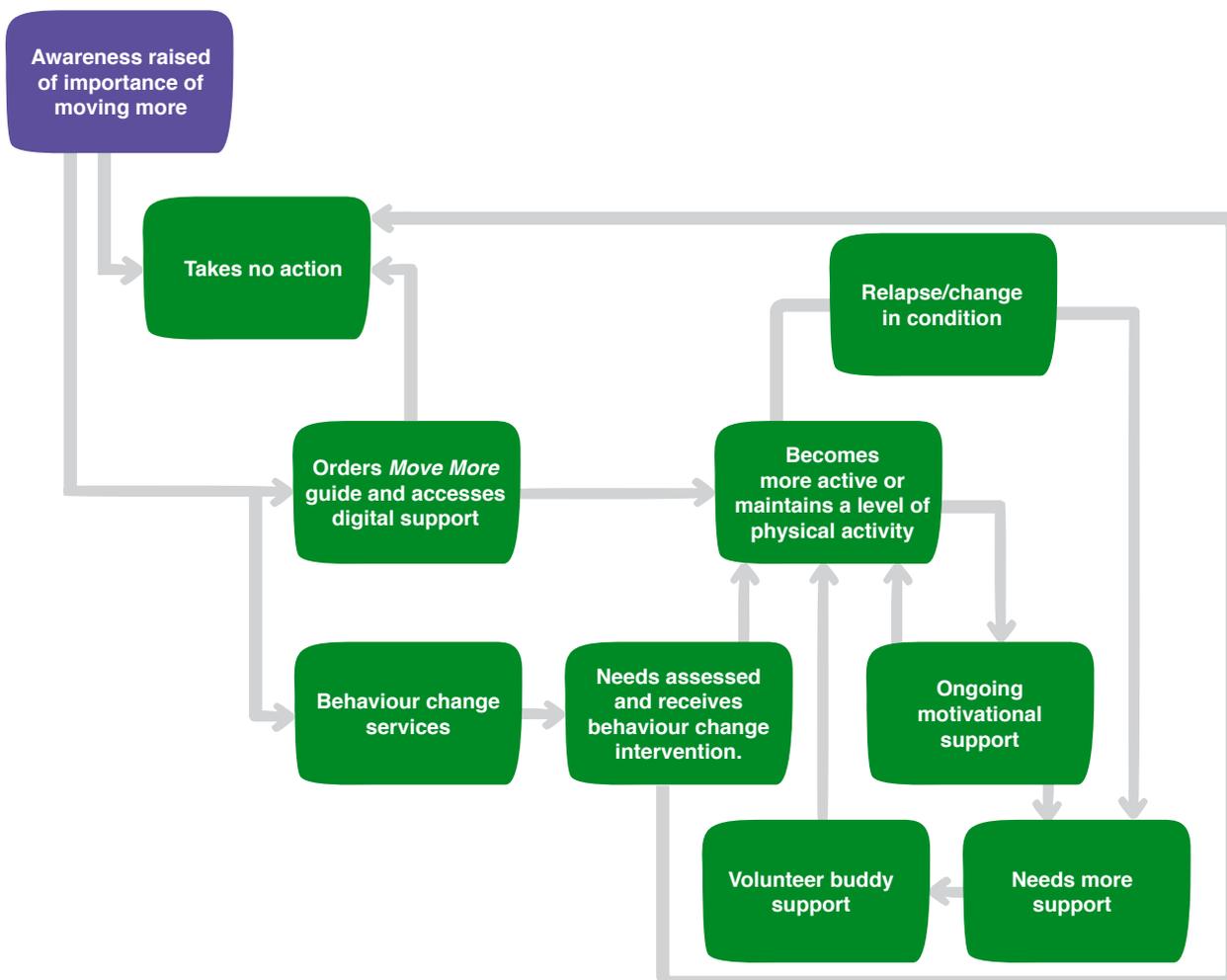
Order or download the *Move More* resource pack from [macmillan.org.uk/beactive](http://macmillan.org.uk/beactive)

**Proportionate universalism**

With increasing constraints on budgets, there is the potential to apply the principle of ‘proportionate universalism’ to service design. This is the principle of providing a universal service, that is also tailored to provide specific support for populations with differing needs.

According to Macmillan’s insight research<sup>78</sup> those with the highest level of self efficacy, who were active prior to treatment and have good social support, should require less motivational support to make a sustained behaviour change. For these people it is likely to be enough to provide the *Move More* guide, alongside telephone and digital behaviour change interventions. Those with lowest self efficacy, who were inactive prior to diagnosis, and have little social support may need more intensive support, such as face-to-face motivational support and peer support volunteers. This approach thus allows resources to be focused on those with the greatest need, whilst still supporting all to become and stay more active.

**Figure 4: Physical Activity Behaviour Change Care Pathway, flow diagram**



## 3. Evidence from the national evaluation

Macmillan has worked in partnership with over 55 localities to test this model of care. Each service has participated in a 'community of practice' to share action learning and collected standardised data from across their programmes. This has been underpinned by an independent process and impact evaluation of 14 test sites across the UK.

This section presents a summary of findings from the evaluation, which can be used to help make the case for investment and help decide on the right delivery model for an area.<sup>79</sup>

The full move more evaluation report can be found here [www.macmillan.org.uk/assets/evaluation-of-macmillan-physical-activity-behaviour-change-care-pathway-2018.pdf](http://www.macmillan.org.uk/assets/evaluation-of-macmillan-physical-activity-behaviour-change-care-pathway-2018.pdf) and the summary report here [www.macmillan.org.uk/assets/physical-activity-and-cancer-the-underrated-wonder-drug.pdf](http://www.macmillan.org.uk/assets/physical-activity-and-cancer-the-underrated-wonder-drug.pdf)

### 3.1 Impact evaluation

The quantitative outcomes from Macmillan's national evaluation provide indicative data on the overall outcomes and differences by delivery model. It is important to note there are limitations with this data which reduce the levels of certainty that can be drawn from the outcomes.<sup>a</sup> Where possible comparisons are drawn to the published evidence including the NICE public health guideline on brief advice, exercise on referral and individual behaviour change.

#### Physical activity

32% of questionnaire respondents said that prior to joining the service they did 'very little' sport or exercise prior to diagnosis, and 13% were classed as inactive, undertaking less than 30 minutes of activity per week.

Macmillan's insight research<sup>80</sup> shows that people are more likely to see themselves as an 'active person' and believe they can make a change to their lifestyle if they were previously active. This in turn makes them more likely to be able to increase their activity levels.

Evaluation data indicates statistically significant increases in physical activity levels for all *Move More* service delivery models that provided data. Of those who completed questionnaires at the start and 12 months later, none who were inactive at the start remained so by 12 months.

The aim of a service should not just be to increase physical activity, but also to help manage any decline in activity levels, particularly for those during treatment, with advanced cancer or at the end of life.

Service users were from all stages of the cancer journey: 3% were pre-treatment; 25% during treatment; 48% post treatment; 9% had advanced cancer; and 1% were palliative. Among such a diverse group, significant declines in physical activity levels could have been expected. This was not the case, making the results from this model of care even more significant.

These findings indicate that it is feasible to embed the promotion of physical activity into cancer care at all stages of the cancer journey.

<sup>a</sup> For more information on quantitative analysis, refer to the evaluation report. Limitations include test sites commencing at different time points, so some had been running for longer than others, and sites varying in their data collection quality and quantity.

Figure 5: Change in physical activity levels reported by service users

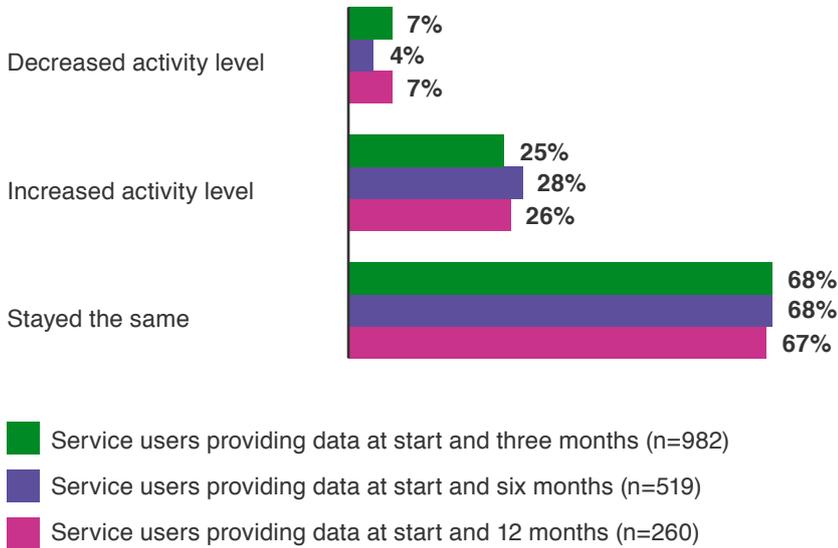
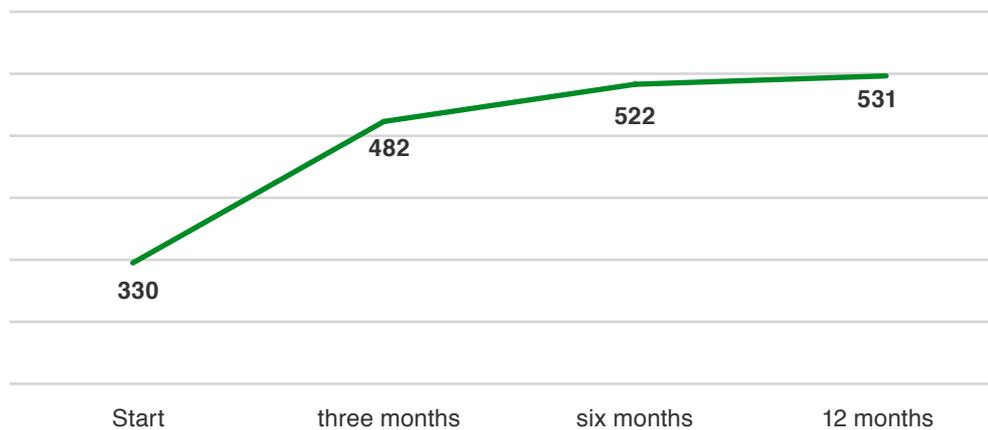


Figure 6: Average (mean) minutes of activity per week for service users providing data at all 4 sampling points (n=160)



### **Quality of life, self-assessed health and fatigue outcomes**

There were statistically significant improvements to quality of life, self-assessed health and fatigue. These factors are all important as they counter the potential debilitating consequences of treatment, and increase the individual's ability to take control back of their lives and create a 'new normal'. This could include being able to live independently or work.

### **Health-related quality of life (using EQ-5D)**

There were statistically significant ( $p < 0.01$ ) increase in overall quality of life between start and three, start and six and start and 12 months. The largest increase is between start and three months.

### **Self-assessed health**

There were statistically significant improvements in service user perceived state of health between baseline and three months ( $p < 0.01$ ), three and six months ( $p < 0.01$ ) and six and 12 months ( $p < 0.01$ ). The largest increase is observed between start and three months, with more modest increases thereafter.

### **Fatigue**

The evaluation found statistically significant ( $p < 0.01$ ) increases in FACIT score (meaning a decrease in levels of fatigue) between start and three months and between three months and six months, with minimal change between six and 12 months.

**Cathy, diagnosed with ovarian cancer in 2007. Sadly, Cathy died December 2014. We'd like to thank her family for allowing us to continue sharing her story, so others can benefit from Macmillan's support**



### 3.2 Quantitative outcomes by model

#### Healthcare and community settings model

Poor data collection for certain indicators meant that sub-group analysis by setting and delivery model was challenging. 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 necessarily reflect changes in the mean outcome levels.

	Healthcare setting model	Community setting model
Physical activity (measured by Scottish Physical Activity Questionnaire SPAQ)	Statistically significant improvements in physical activity levels between start and three months, start and six months and start and 12 months ( $p < 0.01$ for all).	Statistically significant improvements in physical activity levels between start and three months, start and six months and start and 12 months ( $p < 0.01$ for all).
Physical activity (measured by Functional Assessment of Chronical Illness Therapy FACIT)	<p>No statistically significant changes in fatigue between start and three months, and start and six 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 (<math>n=74</math>, <math>p &lt; 0.05</math>).</p> <p>Note there was insufficient data to further analyse by stage of cancer pathway to understand whether this increase in fatigue was due to a higher proportion of people in treatment in comparison to the community setting model.</p>	Statistically significant decreases in feelings of fatigue between start and three months, six months and 12 months ( $p < 0.01$ ).
Quality of life (measured by EQ-5D)	<p>A significant difference in mean scores for those who provided data at start and six months (<math>p &lt; 0.001</math>).</p> <p>The difference in mean scores for those who provided data at start and three months was very small and not significant.</p> <p>The sample size for those at start and 12 months was too small for analysis.</p>	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 three months, start and six months and start and 12 months ( $p < 0.01$ ).

**Direct provision and signposting to physical activity delivery model**

	<b>Direct provision</b>	<b>Signposting</b>
Physical activity (measured by SPAQ)	Statistically significant improvements in physical activity levels between start and three months, start and six months, and start and 12 months (p<0.01 for all)	Statistically significant improvements in physical activity levels between start and three months, start and six months, and start and 12 months (p<0.01 for all)
Quality of life (measured by EQ-5D)	Statistically significant increases in quality-of-life scores between start and three months and start and six months (all significant at p<0.01) although the increases for direct delivery were very small.	Statistically significant increases in quality-of-life scores between start and three months and start and six months (all significant at p<0.01).  Only the signposting model had statistically significant improvements in quality-of-life scores which were statistically significant between start and 12 months (p<0.001, n=129).
Fatigue (measured by FACIT)	Small but significant increases in scores between start and three months, and start and six months.  No real change for those completing questionnaires at start and 12 months – the mean score remained at about 27 (n=141).	Statistically significant decrease in fatigue between start and three months, six months and 12 months (p<0.01).  For those completing questionnaires at start and 12 months (n=126), the mean score increased from 32 to 39.

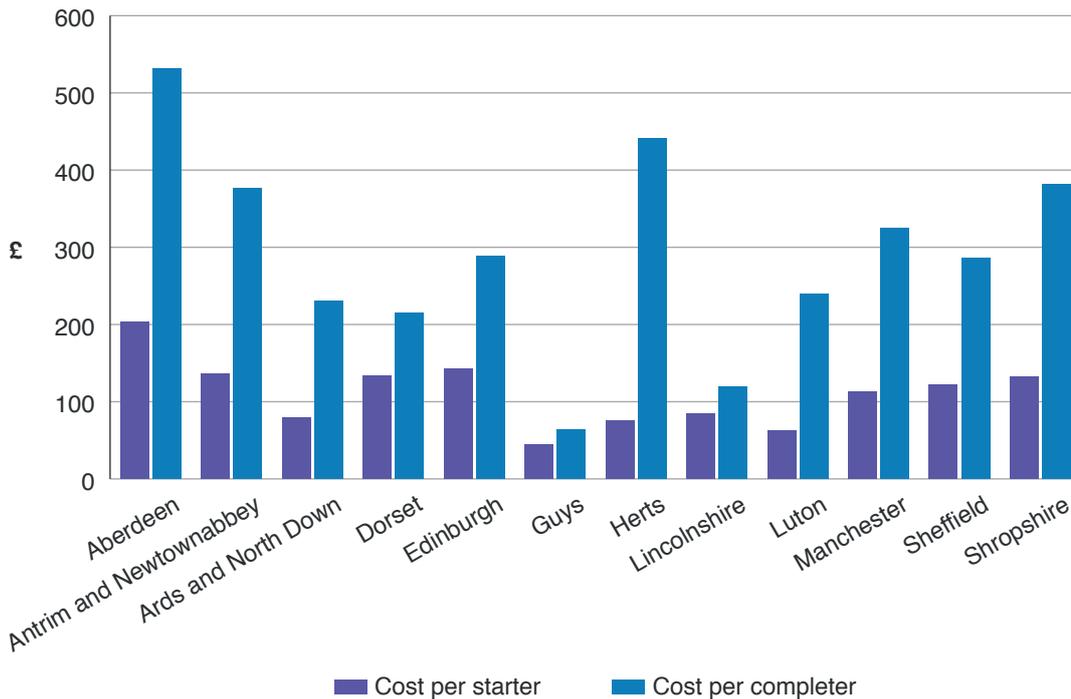
### 3.3 Cost per service user and cost per completer

If costs are averaged across all starters<sup>b</sup>, 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-up costs). There are alternative ways to average costs and further information can be found in the *Evaluation of the Macmillan Physical Activity Behaviour Change Care Pathway*

This cost estimate is similar to that found in previous studies. **The *Let's Get Moving* feasibility study found a mean cost per participant of between £124 and £630<sup>81</sup>.** Also, a recent systematic review of exercise referral schemes (which underpins the NICE Public Health guideline: Physical activity: exercise referral schemes (PH54) found an average cost per service user of £225.<sup>82</sup>

Mean costs per completer vary substantially across services. These are also shown in Figure 7 (together with costs averaged across all starters).

**Figure 7: Cost per service user (starters and three-month completers) based on three-month running costs**



In terms of delivery models, the costs for signposting only and direct delivery are similar.

In terms of setting, 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% compared to 41% for the community setting.

<sup>b</sup> A starter is a service user who has enrolled onto the programme. A completer is a service user who has participated in the programme for at least three months. Further information on this analysis can be found in the evaluation.

### 3.4 Cost per QALY

The economic analysis within the evaluation provides estimates of cost per quality-adjusted life year (QALY) based on two different assumptions: (a) that the behaviour-change effects of the programme last for three months and (b) that they last for 12 months.

**Table 2: Cost per outcome by sub-group using Intention to Treat approach and cost per completer<sup>c</sup>**

		Cost per outcome					
		FACIT	EQ-5D	GSE	SPAQ	QALYs(a)	QALYs(b)
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

NICE consider that interventions costing the NHS less than £20,000 per QALY gained are cost effective.<sup>83</sup> Those costing between £20,000 and £30,000 per QALY gained may also be deemed cost effective, if certain conditions are satisfied.<sup>84</sup>

The community and healthcare settings service models achieve a similar cost per QALY. Assuming the duration of intervention effect lasts for 12 months (column b table 2 [above]), both models fall below the £20,000 threshold. This is the assumption made in the economic modelling for NICE PH44 on which the recommendations of PH49 are also based. This suggests both the community and the health-care setting models are cost effective.

#### Comparative data

Economic modelling for NICE PH4<sup>85</sup> *Physical activity: brief advice for adults in primary care* equates to a QALY gain of 0.0047 per person. The incremental cost per QALY of brief advice compared with usual care is £1,730 and thus can be considered cost-effective at the NICE threshold of £20,000.

Economic modelling for NICE Public Health guideline *Physical activity: exercise referral schemes* (PH54).<sup>86</sup> Using the base case assumptions, the incremental intervention cost of £217 led to an incremental cost-effectiveness ratio (ICER) between £72,748 and £113,931 per QALY gained. Even in the best-case scenario, the estimated incremental cost effectiveness ratio was £31,009 per QALY gained.<sup>d</sup>

<sup>c</sup> Two conservative assumptions have been 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 (three months). In QALYS (b) the intervention effect is assumed to last for 12 months.

<sup>d</sup> NICE normally considers that any interventions over a threshold of £20,000–£30,000 per QALY are not cost effective. However, because current evidence to inform the assumptions in the model was insufficient, members did not feel they could recommend disinvestment in such schemes. Furthermore, some schemes may be cost effective, or may only be cost effective for some subgroups. Again, there was insufficient evidence to make recommendations on this, hence data collection has been made a condition for any exercise referral scheme that is commissioned.

The signposting-to-physical-activity model achieves a much lower cost per QALY than the direct delivery model of physical activities within the service.<sup>9</sup>

This indicates that a model that focuses on providing long-term person-centred behaviour change support, with access to a wide variety of physical activity opportunities that meet the needs of the cancer population, is cost-effective. However, as

already indicated, the strength of recommendation that can be drawn from Macmillan's independent evaluation analysis is limited. Ongoing data collection and further research is recommended.

Recommendation two of the NICE Public Health guideline Physical activity: exercise referral schemes (PH54) appears to be relevant here:

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NICE Public Health guideline *Physical activity: exercise referral schemes* (PH54)

**Recommendation two:**

Policy makers and commissioners should only fund exercise-referral schemes for people who are sedentary or inactive and have existing health conditions or other factors that put them at increased risk of ill health if the scheme incorporates the core techniques outlined in recommendations 7–10 of NICE PH49 Behaviour change: individual approaches. This includes:

- recognising when people may or may not be more open to change (recommendations 8 and 9)
- agreeing goals and developing action plans to help change behaviour (recommendation 7)
- advising on and arranging social support (see recommendations 7 and 10)
- tailoring behaviour change techniques and interventions to individual need (recommendation 8)
- monitoring progress and providing feedback (recommendations 7 and 10)
- developing coping plans to prevent relapse (recommendations 7 and 8).

Every funded service collects data in line with the 'essential criteria' outlined in the Standard Evaluation Framework for physical activity interventions. This includes specifically: programme details, evaluation details, demographics of individual participants, baseline data, follow-up data (impact evaluation) and process evaluation.

Makes the data collected available for analysis, monitoring and research to inform future practice.

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<sup>9</sup> The service models advocated within this guidance document are for the most clinically and cost effective, based on the evaluation. Models that are not cost effective have not been included here. For further information on these and other models tested this please refer to the Move More services [\*Evaluation report\*](#).

### 3.5 Models of delivery: learning from the test sites

One of the key issues investigated during the evaluation was comparing the different models of care. This section outlines the benefits and challenges in operating each type of delivery model.

#### **Community-based provider model: benefits and limitations**

For the purposes of the evaluation, the external evaluators grouped community and leisure models together under the banner 'community'.

##### **Benefits**

- Able to draw from their portfolio of community and leisure facilities.
- Provide access to a wide range of facilities and classes, with reduced membership or fees, and trained instructors
- Offer activities from a range of locations, making the offer more accessible to service users.
- Provide access to Cancer and Exercise Rehabilitation professionals (Level 4) in the community.
- Help the person living with cancer transition to being active in the community
- Have close links to other sports and leisure providers including, for example, County Sports Partnerships (CSPs) in England and National Governing Bodies of Sport (NGBs).
- Useful for those who want to access a gym or pool to work out individually, but would like some initial one-to-one support from trainers who understand their condition and can advise on appropriate exercise.

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 a healthcare setting have a more limited offer.

##### **Limitations**

- Can be more difficult to establish relationships with healthcare professionals and generate referrals.

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

#### **Hospital-based provider model: benefits and limitations**

##### **Benefits**

- Better able to engage healthcare professionals.
- Likely to be based in the same location as healthcare professionals and often with other Macmillan services such as information centres and counselling services. Therefore, more accessible and visible to healthcare professionals. In areas where the service is delivered by members of the physiotherapy team, the service staff have successfully encouraged their colleagues to refer patients thus increasing the volume of referrals.
- Able to access patient health updates and notes from healthcare professionals 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 healthcare professionals more easily than those in a community setting.
- Better integrated within the local healthcare system. The service is more embedded within the Recovery Package and engagement with healthcare professionals is more straightforward.

- Easier to embed the service as an exit route from the Recovery Package core interventions.
- Opportunity for generating ‘walk-ins’. Potential service users show an interest in signing up after seeing the sessions in action.

#### Limitations

- The range of direct delivery on offer is usually limited to circuit-style activities for people living with cancer. This restricts the offer available making it less appealing to many people.

#### Provision of physical activity opportunities

There are benefits and limitations to both signposting to existing physical activities and direct provision. Ideally, a delivery model should include: signposting of activities for the individual’s needs in order to influence the quality of this provision; and direct delivery of cancer-specific opportunities, as long as the organisation is able to deliver this and it is a preference of local service users.

#### Signposting to physical activity model: benefits and limitations

##### Benefits

- Achieves significant changes in all measured outcomes across the 12 months.
- Potentially frees up practitioner time that can be used in ways other than delivering sessions. For example, providing the on-going, formal behaviour change support, without the temptation to ‘sell’ activities which are directly delivered.
- Potential to provide a genuinely tailored and personalised service.
- Lower costs per QALY than direct delivery and it falls within the NICE cost effectiveness threshold for public health interventions<sup>f</sup>

#### Limitations

- 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).
- Participants do not benefit from the social element of classes and the mutual support to be gained from group activities targeted at people living with cancer. The qualitative findings show that, for many, these are valued aspects of the programme.
- Requires practitioners to have a good understanding of the availability and quality of local activities.
- Difficult to control the quality of the physical activities to which service users are signposted.

#### Direct delivery of physical activity model: benefits and limitations

##### Benefits

- Direct delivery enables the provision of, circuit-style activities. These are particularly popular for many people with cancer and service users value activities delivered by trained instructors who are knowledgeable about cancer rehabilitation.
- Much easier 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.
- Provide a useful opportunity for practitioners to engage with and support service users. In the best examples, this can reduce the need for more formal follow-up sessions.

<sup>f</sup> 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.



### Limitations

- Resources required can be significant and could become unsustainable as popularity grows.
- Tendency to promote own activities rather than provide a personalised offer.
- Significant changes were found in physical activity levels between commencement and three, six and 12 months. However, significant changes for some of the other outcome measures were less consistent across time and were often smaller.
- Cost per QALY is more than for the signposting model.<sup>9</sup>
- 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 and suitability of venues available.
- Many believe 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.
- Likely to be a limit to the extent to which service users' needs can be catered for by directly delivered activities as services grow.

<sup>9</sup> The reasons for these differences are unclear. The signposting model may be more effective, or the differences may be due to larger sample sizes for the signposting model thus making it more statistically significant.

## 4. UK-wide levers for change

This section describes key national level policies and targets which can be supported through the integration of physical activity into cancer care.

### 4.1 Quality and Outcomes Framework (QOF)<sup>87</sup>

Cancer Care Review: the percentage of patients with cancer diagnosed within the preceding 15 months who have a review recorded as occurring within three months of the practice receiving confirmation of the diagnosis. This review represents an initial opportunity to address patients' needs for individual assessment, care planning and ongoing support and information requirements.

### 4.2 NICE clinical guidelines

#### CG175 Prostate cancer: diagnosis and management<sup>88</sup>

1.4.19: Offer men who are starting or having androgen deprivation therapy supervised resistance and aerobic exercise at least twice a week for 12 weeks to reduce fatigue and improve quality of life.

#### CG81 Advanced breast cancer: diagnosis and treatment<sup>89</sup>

1.5 Managing complications  
Lymphoedema

1.5.1 Discuss with people who have or who are at risk of breast cancer-related lymphoedema that there is no indication that exercise prevents, causes or worsens lymphoedema. [2014]

1.5.2 Discuss with people who have or who are at risk of breast cancer-related lymphoedema that exercise may improve their quality of life. [2014]

Cancer-related fatigue

1.5.8 Offer all patients with advanced breast cancer for whom cancer-related fatigue is a significant problem an assessment to identify any treatable causative factors, and offer appropriate management as necessary. [2009]

1.5.10 Provide information about and timely access to an exercise programme for all

patients with advanced breast cancer experiencing cancer-related fatigue. [2009]

### 4.3 NICE public health guidance

NICE guidance relevant to physical activity and cancer care:

PH44 Physical activity: brief advice for adults in primary care (2013)

PH49 Behaviour change: individual approaches (2014)

PH16 Mental wellbeing in over 65s: occupational therapy and physical activity interventions (2008)

PH54 Physical activity: exercise referral schemes (2014)

NG44 Community engagement: improving health and wellbeing and reducing health inequalities (2016)

### 4.4 NICE Quality Standards

#### QS137 Mental wellbeing and independence for older people (2016)

Quality statement two: older people most at risk of a decline in their independence and mental wellbeing are offered tailored, community-based physical activity programmes.

#### QS148 Community engagement: improving health and wellbeing (2017)

Quality statement four: members of the local community are actively recruited to take on peer and lay roles for health and wellbeing initiatives.

### 4.5 Relevant national policy England

- NHS England. *Five Year Forward View*.<sup>90</sup>
- Sport England. *Towards an Active Nation*.<sup>91</sup>
- Public Health England. *Everybody active, every day*.<sup>92</sup>
- Independent Cancer Taskforce. *Achieving world-class cancer outcomes: a strategy for England 2015–2020*.<sup>93</sup>
- NHS England. *Implementing the Cancer Taskforce Recommendations: Commissioning person centred care for people affected by cancer*.<sup>94</sup>

The Recovery Package has been recognised in key national strategy documents, including the NHS England *Five Year Forward View* and the *Cancer Taskforce Strategy*. The latter outlines a commitment to ensure that 'every person with cancer has access to the elements of the Recovery Package by 2020'. There are three specific recommendations within the taskforce report (8, 9, 65) that include physical activity, its integration into cancer care as part of the Recovery Package and active promotion by the NHS.

NHS cancer transformation funding, underpinned by local sustainability and transformation plans, offers an opportunity for the NHS and local government to achieve roll out of the Recovery Package, including integration of physical activity.

### Wales

- Wales Cancer Network. *Cancer Delivery Plan for Wales 2016–2020*.<sup>95</sup>
- Welsh Assembly Government. *Creating an Active Wales*<sup>96</sup>
- Wellbeing of Future Generations (Wales) Act 2015.<sup>97</sup>

In November 2016, the Wales Cancer Network, working with the Welsh Government, published a Cancer Delivery Plan for the NHS to 2020. The key action in the plan is that the Wales Cancer Network is to lead on the consistent application of elements of the Recovery Package across Wales. 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

- Scottish Government. *The Healthcare Quality Strategy for NHS Scotland*.<sup>98</sup>
- Scottish Government. *Beating Cancer: Ambition and Action*<sup>99</sup>
- Scottish Parliament Health and Sport Committee. *Strategic Plan and Vision 2016–2021*<sup>100</sup>
- Scottish Government. *Active Scotland Outcomes Framework*<sup>101</sup>

In Scotland, the NHS Scotland Quality Strategy underpins the development of the NHS in Scotland. The strategy was published in 2010 and sets out three ambitions relating to quality, of which two are relevant to holistic needs assessment and care planning. These are: 'people are able to live well at home or in the community' and 'everyone has a positive experience of healthcare'.

The Transforming Care After Treatment (TCAT) programme is being delivered by the Scottish Government in partnership with Macmillan. Assessment and care planning are a major part of this programme.

In 2014, Macmillan launched the Improving the Cancer Journey service. This service offers people living with and beyond cancer 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.

Scottish Government's Cancer Plan 2016 Beating Cancer: Ambition and Action includes: 'In an effort to improve health and reduce the risk of secondary disease or a second primary cancer, we will ensure that physical activity advice and services (described in the earlier chapter on cancer prevention) are available for people recovering from cancer.'

### Northern Ireland

- Department of Health. *Service Framework for Cancer Prevention, Treatment and Care*.<sup>102</sup>

The Department of Health, Social Services and Public Safety established a set of Service Frameworks in 2011, which set out standards of care to be used by patients and their wider families in relation to prevention, diagnosis, treatment, rehabilitation and care. Several standards include performance indicators regarding holistic needs assessment and care planning.

#### 4.6 NHS England and Public Health Outcome Frameworks

There are a number of indicators where physical activity for cancer patients can support meeting outcomes using national outcomes frameworks.

##### NHS Outcomes Framework: list of outcomes and indicators, 2016–17<sup>103</sup>

###### Domain 1: Preventing people from dying prematurely

Overarching indicators

1a Potential years of life lost (PYLL) from causes considered amenable to healthcare i Adults ≠ ii Children and young people

1b Life expectancy at 75 i Males ≠ ii Females ≠

Reducing premature mortality from the major causes of death

1.4 Under 75 mortality rate from cancer (PHOF 4.5\*) ≠

i One- year survival from all cancers

ii Five-year survival from all cancers

iii One- year survival from breast, lung and colorectal cancer

iv Five-year survival from breast, lung and colorectal cancer

v One-year survival from cancers diagnosed at stage 1 and 2 (PHOF 2.19\*\*)

vi Five-year survival from cancers diagnosed at stage 1 and 2 (PHOF 2.19\*\*)

###### Domain 2: Enhancing quality of life for people with long-term conditions

2.1 Proportion of people feeling supported to manage their condition Improving functional ability in people with long-term conditions

2.2 Employment of people with long-term conditions (ASCOF 1E\*\*, PHOF 1.8\*)

Reducing time spent in hospital by people with long-term conditions

Enhancing quality of life for carers

2.4 Health-related quality of life for carers (ASCOF 1D\*\*)

2.6 ii A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life (ASCOF 2F\*\*) Improving quality of life for people with multiple long-term conditions

2.7 Health-related quality of life for people with three or more long-term conditions (ASCOF 1A\*\*)

##### Domain 3: Helping people to recover from episodes of ill health or following injury

3.5 ii 120 days Helping older people to recover their independence after illness or injury

3.6 i Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation service (ASCOF 2B[1]\*) ii Proportion offered rehabilitation following discharge from acute or community hospital (ASCOF 2B[2]\*)

##### Key:

Indicators in italics are in development

\* Indicator is shared

\*\* Indicator is complementary

≠ Indicator is for health inequalities assessment

##### Public Health Outcome Framework: list of outcomes, 2016–17<sup>104</sup>

1.16 Percentage of people using outdoor space for exercise/health reasons

2.13i Proportion of adults achieving at least 150 minutes of physical activity per week in accordance with UK CMO recommended guidelines on physical activity

2.13ii Proportion of adults classified as 'inactive'

2.23i The percentage of respondents scoring 0-4 to the question "Overall, how satisfied are you with your life nowadays?"

2.23ii The percentage of respondents scoring 0-4 to the question "Overall, to what extent do you feel the things you do in your life are worthwhile?"

2.23iii The percentage of respondents who answered 0-4 to the question "Overall, how happy did you feel yesterday?"

2.23iv The percentage of respondents scoring 6-10 to the question "Overall, how anxious did you feel yesterday?"

4.03 Mortality rate from causes considered preventable considered preventable per 100,000 population

4.05 Under 75 mortality rate from cancer

4.05i Age-standardised rate of mortality from all cancers in persons less than 75 years of age per 100,000 population

4.05ii Age-standardised rate of mortality that is considered preventable from all cancers in persons less than 75 years of age per 100,000 population

4.13 Average health status score for adults aged 65 and over



**SECTION TWO  
HOW-TO  
GUIDE**



## 1. Introduction

This section provides detailed guidance to local decision makers and service providers on the setting-up and running of a physical activity behaviour change care pathway, or 'Move More service', as an integrated part of the Recovery Package in cancer care.

The overarching model of a person-centred behaviour change service, that supports the individual to become and stay active, can be implemented in a number of different ways depending on the needs of the local area in question. These include: the cancer population, geography and health landscape, and the resources available.

All models start with the Recovery Package. The minimum viable product includes healthcare professionals advocating physical activity as part of the Recovery Package and signposting to the supported self-management resource – the *Move More* pack.

The comprehensive person-centred physical activity behaviour change service can be implemented in a healthcare, community or leisure setting. Physical activities can be either signposted to or delivered directly, but ideally a combination of the two.

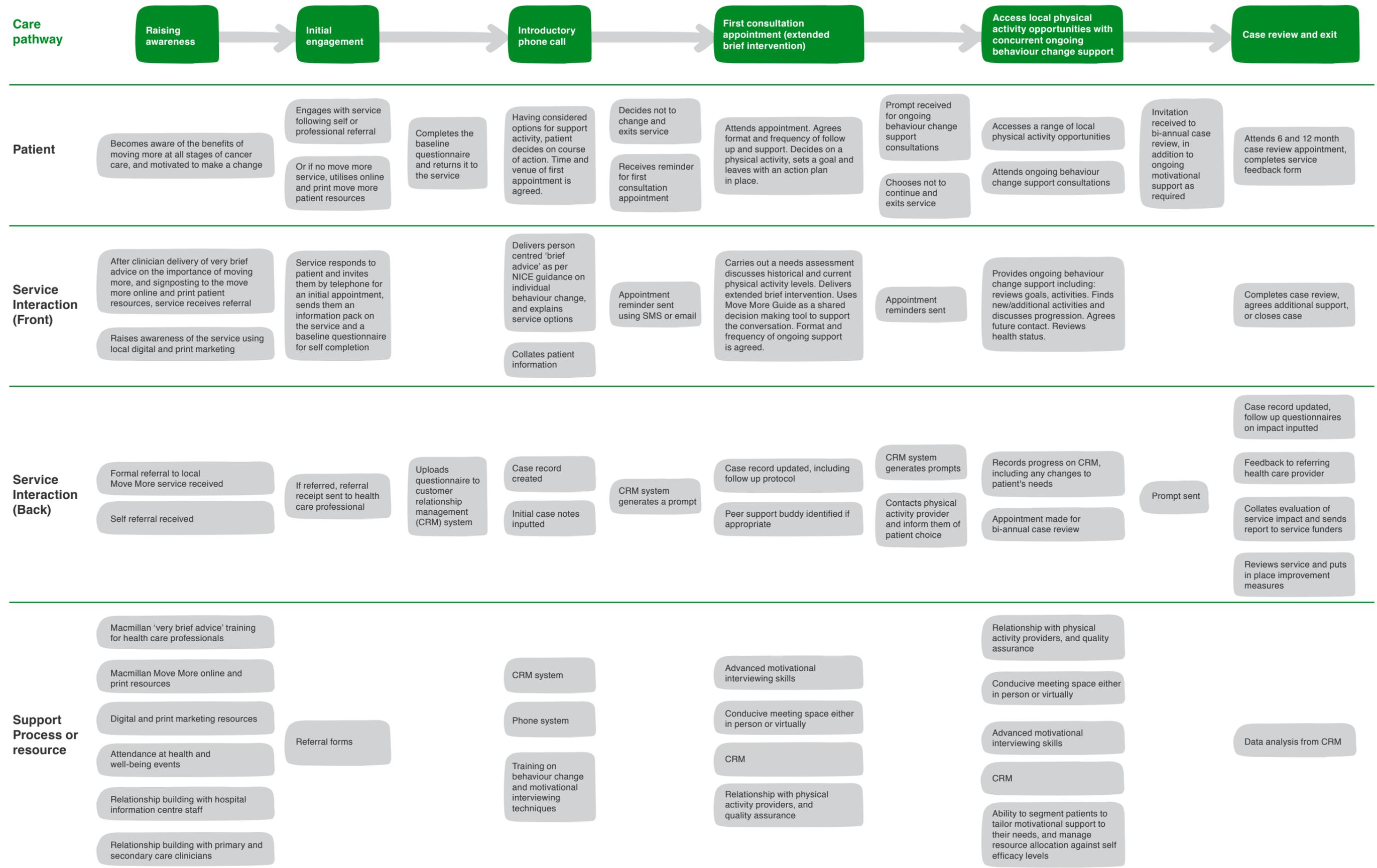
For setting up the minimum viable product, refer to section 8.

For setting up the *Move More* service, refer to all sections.



Lilus, diagnosed with cancer

Twelve month behaviour change service blueprint



## 2. Governance

### 2.1 Macmillan's service development teams

Macmillan's service development teams have a wealth of experience in developing health and social care services throughout the UK in partnership with the NHS and local government. They can help in many ways: engaging with key stakeholders to support set-up and sustainability; identifying gaps in service provision; offering advice on the development of new posts based on their previous experience; and developing innovative solutions to meet the needs of people affected by cancer.

### 2.2 Stakeholder engagement

It is important to engage with key stakeholders during the development stage of a service. This helps to make sure the service meets key local priorities, including referrals from healthcare, and increases its chances of becoming sustainable. Partners should include:

- potential funders, such as local government, leisure or sports organisations, health and social care, Public Health, and commissioning groups

- referrers, for example, clinical nurse specialists, oncologists, radiologists, physiotherapists, and local cancer charities
- community organisations and services that can promote and signpost people to your service, including Macmillan Cancer Information and Support centres, cancer support groups, libraries, councils, and leisure organisations
- physical activity providers and co-ordinators, including leisure providers, National Governing Bodies of Sport (NGBs) and local clubs, health walk schemes
- local evaluation organisations such as local universities.

Establishing partnerships at regional and local level requires time and resource, but is vital to the success and sustainability of the programmes. By ensuring the engagement of key partners locally, services are able to embed a plan for sustainability across the life of the service and increase the likelihood of further funding or commissioning in the future. This partnership working is very time intensive and cannot be rushed, but will lead to better outcomes at the end of the project.



Macmillan Gynae  
Oncology Team



**Top tip:** Ask to present your service at a potential partner's team or board meeting, enabling you to engage partners collectively. This increases the likelihood of senior level buy-in. It is also good practice to develop basic information sheets that can be left with potential partners following a meeting.

### 2.3 Steering groups

An effective way of involving stakeholders on a long-term basis is to form a steering group. This group acts as a voice for key stakeholders and provides a 'critical friend' to the service.

The steering group can also provide vital governance during the development and delivery stages of a service. Initially, the group may need to meet quite regularly as the service finds its feet, but once the service has moved into delivery, it could meet quarterly. Some sites have found if they are having regular meetings and have strong relationships with healthcare, then 2–3 meetings a year are adequate. A regular meeting provides an opportunity to review progress and decide if any improvements need to be made. It is important to understand what outcomes key stakeholders want to see from the service; this may include some additional targets for the service. Incorporating this at an early stage will enable you to build a stronger case for the service towards the end of the funding.

An example [terms of reference for a steering group](#) is available.



### Spotlight on steering groups

The public health manager with the strategic lead for physical activity chairs the quarterly Manchester Active steering group. Other attendees include:

- representatives from the Manchester Giants basketball team (provider organisation)
- Macmillan information centre managers
- clinical champions from Wythenshawe and Stockport NHS Trust
- project ambassador
- Macmillan partnership manager
- Walking for Health lead
- Sport England regional lead
- representatives from Manchester Physical Activity Referral Service (PARS)
- Manchester University evaluators
- Greater Sport – Greater Manchester's County Sports Partnership.

In addition to the steering group, an action group has been formed to implement decisions made at the steering group.

### 3. Service delivery models

Your local structures are likely to determine which organisation is best suited to be the operational lead. There are three settings with which Macmillan has worked in partnership to test the delivery of behaviour change services:

- Healthcare: led by healthcare providers such as an NHS Trust or a Cancer Centre.
- Community: includes services led by organisations such as local authorities, County Sports Partnerships, sports trusts, universities and leisure trusts.
- Leisure: including leisure trusts.

You then need to decide whether you are:

- signposting to existing physical activity opportunities; or
- working in partnership to ensure that the existing physical activity opportunities meet the needs of people living with and beyond cancer; or
- providing physical activities directly; or
- a combination of the above.

You will need to work with your partners to decide on what is the right model for you, taking into account the different benefits and challenges. Section one of this document and the national evaluation may help guide your decision.



**Top tip:** The evaluation indicates that services are most effective when they align closely to the evidence on providing ongoing person-centred behaviour change support. This indicates moving away from traditional rehabilitation delivery models.

**The following page demonstrates an end-to-end customer journey for a community and healthcare model.**

**‘Beside the huge benefit of reducing my weight, my physical activities have enabled me to meet new people. I feel less isolated, less hard done by and I feel much, much better in myself...’.**

Daniel

# END TO END CUSTOMER JOURNEY

## Guy's and St Thomas'

### Recruitment

- Referral primarily through Physiotherapy, followed by self referral, then by CNS referral.
- Other referrals from Dieticians, Radiographers, Consultants, Occupational Therapists, Complimentary therapists, Speech Language therapists and rarely GPs
- Referrals received via hospital online referral system, email, phone or face to face contact in line with appointment already allocated within Guy's cancer centre.
- Patient contacted between one and a maximum of three weeks from referral.
- The majority of self- referrals are generated through our presentations at routine Health and Wellbeing Events or additionally through promotion at other support groups and cancer events
- Promotion via leaflets
- Our greatest service users are Breast, Prostate and lung cancers.
- Majority of service users are over 40
- Around 16% have advanced/metastatic/ palliative disease.
- Service users usually in or post-treatment (uncommonly pre-treat)
- Relatively balanced gender ratio

### Initial behaviour change consultation

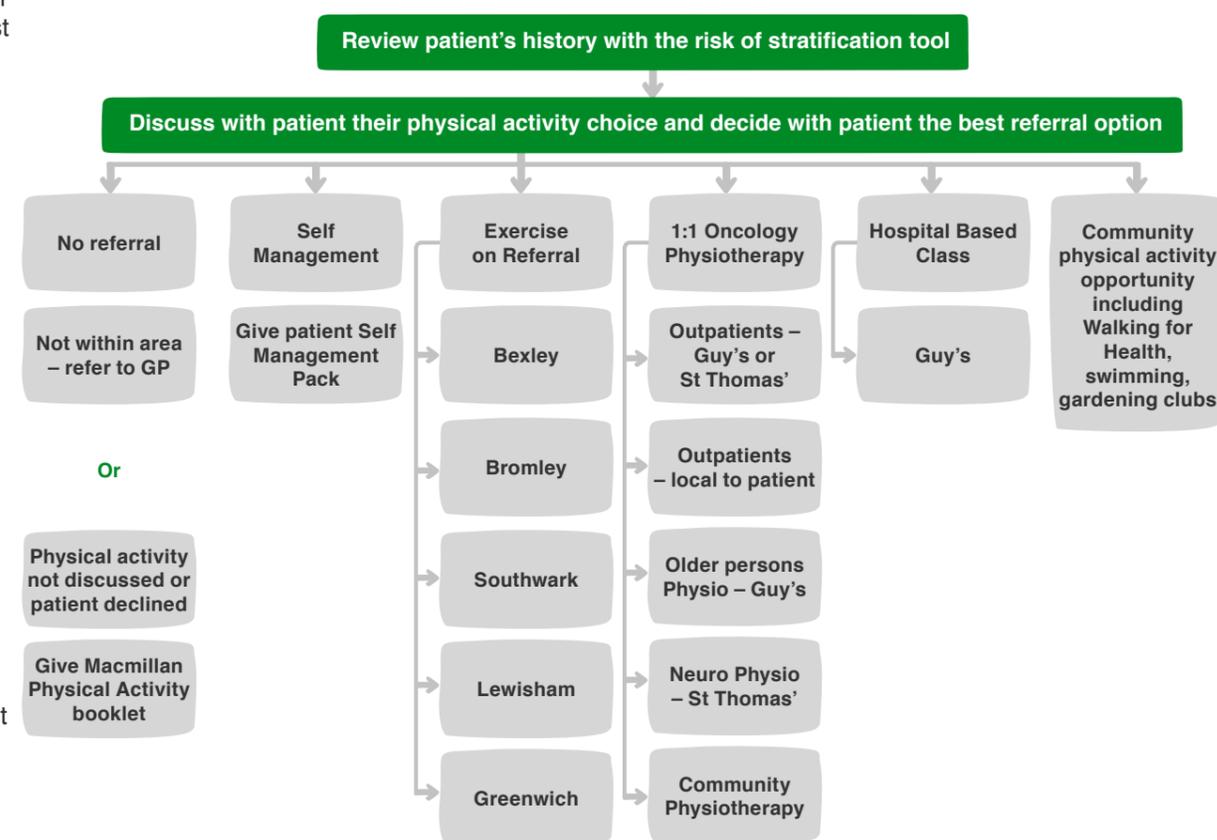
- Service receives referral and contacts patient
- Initial behaviour change can be face to face or via the phone (patient preference).
- Face to face consultations usually take place in Guy's cancer centre and can be co-ordinated with other appointments.
- Baseline questionnaire completed on paper (either at consultation or sent via the post)
- Delivered by Physiotherapist or qualified level 4 accredited cancer rehabilitation instructor.
- One to one consultation of 60 minutes. Opportunity to get to know the individual. Topics explored include:
  - General health and co-morbidities + current cancer status/ treatment
  - Past and present physical activity levels
  - Motivation, previous experiences and barriers
  - Level of support needed
  - Goal setting
  - Building activity into daily life
- Patient-centred, personal holistic approach.
- Advice and information offered if desired by individual.
- Individuals are guided through local activity options to decide what best suits them- can be physical activity within their own routine- doesn't have to be 'exercise'
- Support at all levels of ability and disease status and symptom burden.
- Plan made for both individual and practitioner. Depending on preference practitioner will either:
  - Book Guy's class assessment
  - Refer to another program or location
  - 1:1 intervention
  - Check progress in an agreed timeframe.
  - Letter is sent with agreed goal
- Individual will:
  - Plan a step toward their goal(s) in an agreed timeframe.
- Depending on symptoms reported a treatment plan will be implemented and onward referrals completed as appropriate.
- If the treatment plan incorporates an exercise program it is tailored to an individual's needs by a physiotherapist.
- 'Move More' pack given to each individual and used to plan where appropriate.

### Physical activity opportunities

- Delivery, referring and signposting service
- Delivery of classes (see below) and 1:1 intervention
- Can signpost to many activities and refer (where possible):
  - GSTT classes
  - Just Bowl
  - Activities/programmes within our six local boroughs including Exercise on Referral
  - Services vary between boroughs with regards to availability, duration and cost
  - Leisure centre providers and health providers
  - Walking for health
  - Local Hospice services
  - Other local opportunities.
  - Information and education around alternative forms of activity e.g. gardening, 'Move More' DVD.
  - Other services to address barriers
    - Psychological support, counselling, support groups, complimentary therapies, other health professionals
- Classes offered within Guy's cancer centre include circuit training and programs that incorporate principles of yoga and relaxation.
- Assessed by a physiotherapist to individualise exercise prescription while in the class.
- If the patient requires more support or supervision they can access 1:1 treatment sessions with a physiotherapist or level 4 cancer rehab instructor.
- The services are free and provided by specialist cancer therapist.
- Following the class the patients are signposted to further activity options

### Support and follow up

- Support over 12 months
- Participants can contact service via
  - Phone
  - Email
- Formal follow-up at 4, 7 and 12 months: coincides with questionnaire data collection and initial consultation structure.
- Clinic letters are sent following each formal follow-up with discussion points and goals documented
- Questionnaires are posted prior to consultation and returned in pre-stamped envelope.
- Capacity to provide more support with additional phone calls/face to face consults/reviewing of activity plans at other time points if required
- Signposting to other health services at any stage (if other concerns arise)



For all patients record the patient details on the information spreadsheet for participation in Active You project. If referring into self management, exercise on referral, physiotherapy or hospital based class, give patient the 'Active You' Project pack.

# END TO END CUSTOMER JOURNEY

## Lincolnshire

### Recruitment

- Referrals primarily from CNS's.
- Also physiotherapists, Macmillan. occupational therapist at Lincoln Hospital and rarely GPs
- Referrals received on paper or via email.
- Patient contacted as soon as possible after referral (within 72 hours).
- Self-referrals still uncommon but increasing.
- Talks frequently given to CCGs, local GPs, support groups, Vitality exercise classes etc.
- Good links with Macmillan Information and Support Centres which direct patients to programme.
- Posters and leaflets in village halls (where Vitality exercise classes take place), GPs and Macmillan Information and Support Centres.
- Promotional public appearances e.g. Lincoln 10K.
- Advert in local newspaper
- Facebook and Twitter pages updated weekly with events, motivational posts and success stories

- Majority of service users 60+ and post-treatment
- Breast and colorectal cancers most common (due to good CNS links)
- Most not active prior to diagnosis
- A few palliative patients – majority active prior to referral

### Initial behaviour change consultation

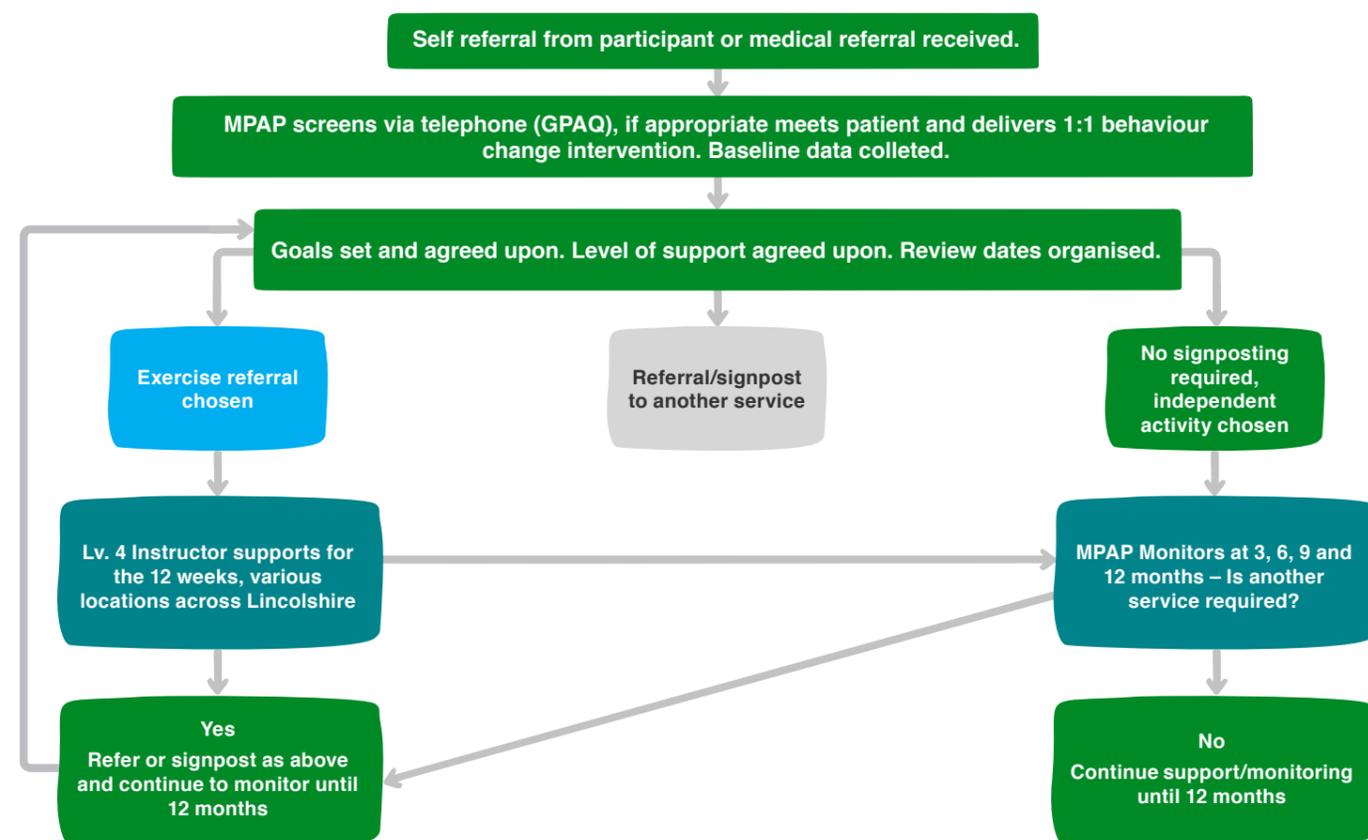
- Location usually at patient's home, but can be elsewhere e.g. café.
- Baseline questionnaire completed on iPad.
- Consultation topics include:
  - Current level of physical activity
  - What they enjoy doing and deciding an activity
  - Where they see themselves in three months time
- Three month goal (written in *Move More* guide)
- Emphasis always on physical activity rather than exercise
- Everyone receives *Move More* guide – used as 'homework'.
- Patient-centred, personal approach, considering all the other factors in the individual's life.
- Participant and project lead go on a short walk together to:
  - establish if three month goal is realistic
  - continue behaviour change intervention in neutral/private space
- Date set for starting first activity. Project lead can offer to join individual for initial session to make it less intimidating.

### Physical activity opportunities

- Signposting service, not delivery.
- Can signpost to any activity.
- Lincolnshire Sport Physical Activity finder used to find local opportunities.
- Walking most popular activity (rural location) – Lincoln 5k/10k common 9 month goals for participants.
- Sports least popular.
- Activities generally open to everyone (not cancer-specific).
- Information about other forms of activity e.g. gardening, *Move More* DVD.

### Support and follow up

- Formal reviews at 3,6,9 and 12 months (coincides with data collection at 3, six and 12 months).
- Similar structure to initial consultation:
  - Follow-up questionnaire completed on iPad
  - New three month goal set
  - Short walk
- Practitioner aims to visit participants at home once a month over 12 month period.
- Capacity to provide more support especially in first threemonths.
- Individuals receive personalised letter with first threemonth goal and what was discussed during initial consultation
- Participants can stay in touch with practitioner between visits via text, phone or email – can continue once 12 month intervention is finished.
- Facebook page with regular updates
- Website being built for individuals to use after 12 months – blog of achievements and success stories



# END TO END CUSTOMER JOURNEY

## Move More Northern Ireland

### Recruitment

#### Marketing, Promotion & Communications

- Project Launch Event
- Pull Up Banners in Leisure Facilities
- Macmillan Information Points in Leisure Facilities
- Posters & Flyers in Hospitals, Leisure Facilities, Community Centres, GP Practices
- Website, Facebook & Twitter
- Press Releases in Local & National Media
- Health & Wellbeing Events
- *Move More* Events

#### Referral Process

- Service user or healthcare professional completes *Move More* Postcard
- *Move More* Postcard is returned to *Move More* Coordinator who contacts service user within 48 hours to arrange Extended Brief Intervention
- Currently considering potential to develop *Move More* NI website to receive and allocate referrals

#### Referral Sources

- Clinical Nurse Specialists
- Self-Referral
- Macmillan Information & Support Manager
- Macmillan Health & Wellbeing Coordinator
- Other healthcare professionals including Physiotherapists, Occupational Therapists, Radiographers, Consultants & GPs
- Other cancer charities
- Community organisations

#### Referrals

- Over 600 referrals received in the first 12 months
- Age – 40 to 49 years (13%), 50 to 59 years (28%), 60 to 69 years (24%), 70 to 79 years (17%), other (18%)
- Gender – female (75%), male (25%)
- Stage of Cancer – Remission (46%), Stable (20%), Undergoing Diagnosis (12%), Advanced (7%), Localised (5%)

### Initial behaviour change consultation

- Baseline questionnaire completed in advance of the Initial Behaviour Change Consultation and returned to the *Move More* Coordinator
- Initial Behaviour Change Consultation delivered by the *Move More* Coordinator (trained in Level 4 Exercise & Cancer Rehabilitation, and Motivational Interviewing) as one-to-one, face-to-face intervention, lasting between 30 and 60 minutes
- *Move More* Guide used by the *Move More* Coordinator as part of the Initial Behaviour Change Consultation
- Topics discussed include:
  - Cancer type, stage of cancer, treatment
  - Current/previous physical activity levels
  - Barriers and motivators
  - Level, frequency and intensity of support required
  - Goals of the service user
  - Existing and accessible physical activity opportunities
  - Agreed physical activity opportunities to be undertaken including date, time and venue
- Initial Behaviour Change Consultation is delivered in a variety of venues, subject to the needs of the individual service user, including:
  - Leisure Facility
  - Coffee Shop
  - Community Venues
  - Service User's Home
- *Move More* Coordinator takes a patient centred approach throughout the consultation
- Where other needs are identified which cannot be addressed via *Move More*, and where possible, the *Move More* Coordinator also discusses other relevant services and referral opportunities (e.g. volunteering services, financial services, complementary therapies)
- *Move More* Coordinator provides service user with contact details

### Physical activity opportunities

- A diverse menu of physical activity opportunities is provided within the project including:
  - Cancer Specific Activity Classes
  - Classes within Leisure facilities (e.g. Dance, Zumba, Yoga, Pilates, Spinning)
  - Access to Health Walks & Walking Groups
  - Gym Based Activity Classes, including supported and non-supported sessions
  - Walking Football
  - Mindfulness & Relaxation
  - Water Based Activities (e.g. swimming, aqua aerobics, rowing)
  - Sports
- Subject to the needs of the individual service user, the individual is also supported to get active independently and/or at home (e.g. using the *Move More* DVD, walking more, gardening etc.)
- Where other needs are identified, the *Move More* Coordinator will provide the necessary support to help the individual to access a suitable activity
- A range of incentives are provided including:
  - Free taster sessions (ranging from 5 free sessions, to 12 weeks free)
  - Discounted membership & activity rates (following expiration of free sessions)
  - Free access for friend/family member/carer where relevant
- Healthcare professionals are invited to attend and/or participate in the programme to gain an understanding of the individual approach, and to encourage increased referrals
- *Move More* Events are organised on a regional basis, providing opportunities for people living with cancer from across NI to come together, and increasing awareness in relation to the benefits of an active lifestyle

### Support and follow up

- Ongoing Follow Up Support is provided subject to the needs of the individual
- Support is provided for at least 12 months, and potentially longer, subject to the needs of the individual service user
- The level, frequency and intensity of support required is discussed and agreed at the Initial Behaviour Change Consultation
- Support can be provided on a one-to-one basis or in group sessions, and either by telephone or face-to-face
- Where those needs change, the service user is encouraged to contact the *Move More* Coordinator to discuss a revised offer of Follow Up Support to address the changing needs
- The *Move More* Coordinator also follows up with the individual at 3, six and 12 months to collect data in relation to the impact of the programme. At these points, the Macmillan Physical Activity Questionnaire (Follow-Up) is used
- New developments are currently being considered including the development of:
  - A *Move More* NI Website
  - A *Move More* NI Newsletter
  - A formalised offer of Follow Up Support to ensure that a minimum offer of regular and appropriate support is provided

## 4. The *Move More* workforce

There are a number of roles required to deliver the full service offer. The resources you require will depend on the structure you choose and the geographic area you cover.

It is important to have clear structures and accountability for your service and to ensure the service team are adequately trained and staffed.

Below we have identified the key roles involved in the delivery of the *Move More* service. Some of these roles are directly employed by the service while others will be from other organisations but playing vital supporting roles.

In current practice, the roles of *Move More* co-ordinator, practitioner and administrator roles may be delivered by a single person, or the job roles may form part of a larger role. Combining roles has a direct impact on capacity, which will need to be taken into account when planning.

### 4.1 *Move More* co-ordinator (or service lead)

The *Move More* coordinator (MMC) is the lead strategic role for the service. This individual is responsible for the strategic direction of the service and smooth running of the day-to-day operations. Depending on the set-up of physical activity behaviour change services locally, and the delivery of the Recovery Package locally, the MMC will have different responsibilities.

The MMC, should be accountable for: the overarching monitoring and evaluation of the service; reporting back to funders on a regular basis; running the steering group; and providing leadership to the rest of the service team. It should be assessed locally as to whether this role is a full or part-time role, the structure depending on other support provided locally. It may be that someone can take on this responsibility as part of their existing job.

The MMC is also responsible for developing local partnerships with key stakeholders, primary and secondary care, and local physical activity and sports providers, and identifying new relationships to ensure a wider-reaching service through the execution of marketing techniques.

### 4.2 *Move More* practitioner

The practitioner is either a trained physical fitness instructor with a Level 4 Cancer and Exercise Rehabilitation qualification or a cancer specialist physiotherapist. Both are required to have strong motivational interviewing, empathy and listening skills and competencies; and cancer rehabilitation skills, including understanding the needs of people from diagnosis through to end of life, and taking into account different cancer journeys, consequences of treatment and co-morbidities.

The practitioner is responsible for raising awareness of the programme to healthcare and community referrers and potential service users. They provide one-to-one support to service users through conducting needs assessment and behaviour change sessions. They source, recruit and liaise with physical activity providers. In a number of services, the practitioner also delivers at least some physical activity, particularly in cancer-specific groups.

Where there is no dedicated administrator, they are also responsible for managing the referral process in its entirety (including arranging appointments and follow-up) and collecting data. Although this has a significant impact on capacity.

### 4.3 *Move More* support worker (or administrator)

The *Move More* support worker delivers the administrative and support functions of the service. This role may be absorbed into other roles in some services, depending on the capacity locally. But where this role is present, it plays a significant part in the efficiency of the service.

The support worker covers administrative tasks such as managing the referral process, booking first appointments, managing the Customer Relationship Management (CRM) system, managing data collection and reports and feedback to healthcare.

#### **4.4 Healthcare, allied healthcare, and information and support professionals**

These people refer patients as part of the Recovery Package core interventions and opportunistic consultations.

#### **4.5 Cancer and Exercise Rehabilitation professionals (Level 4)**

Where cancer-specific groups are in place, it is important that this is led by an appropriately trained professional; currently this is someone who holds the Level 4 Cancer and Exercise Rehabilitation qualification and has experience in working with vulnerable adults who have multiple long-term conditions.

#### **4.6 Sports coaches, instructors and physical activity leaders**

Coaches, volunteer leaders and instructors of local sporting and physical activity opportunities in the community play an integral supporting role in helping to support people living with and beyond cancer to increase, maintain, or in some cases reduce the level of decline in, physical activity levels and become more confident.

They have a major opportunity to influence the behaviour change journey at particular stages as well as ensuring the activities are welcoming, friendly, safe and well run. Excellent people skills are especially important for coaches and leaders working with people living with cancer in order to deliver activities in a way that is mindful of physical wellbeing, mental wellbeing and personal development goals.

There is a huge amount of community provision in the UK, which people living with cancer can access following signposting from the *Move More* practitioner. For example, it is estimated that there are 151,000<sup>105</sup> sports clubs in existence across the UK.

#### **4.7 Volunteers**

Volunteers can be a key resource for *Move More* services. There are advantages for *Move More* services utilising volunteers at each stage of the physical activity behaviour change care pathway: from signposting into services, taking part in health and wellbeing events, right through to attending sessions and supporting the ongoing support process.

Evidence strongly suggests that having a supporting individual (role model, peer supporter, someone from one's own community) who understands your journey, facilitates and joins in physical activities, can have the potential to increase self-efficacy levels and perceived social support. This in turn can motivate, empower and enable people living with and after cancer to choose to become and stay active at a level that is right for them.

Management time and effort, although burdensome at the start, provide many advantages in the long run with regard to the long-term sustainability of the intervention and offer effective solutions for barriers.

**‘I have met so many great people, improved my physical and mental fitness while helping others.’**

Scotland *Move More* volunteer

## 5. Workforce skills and competencies

It is important to assess on a local level the training needs of everyone who is involved in delivering your service. This includes physical activity providers, health and social care professionals, project coordinators and administrators, and volunteers. By assessing the workforce needs early on in the project, you will be able to factor training costs into your budget.

### 5.1 Healthcare, allied healthcare, and information and support professionals Understanding physical activity and cancer training

The National Institute for Health and Care Excellence (NICE) recommends that all health and social care professionals should be encouraged to deliver very brief advice to motivate people to make a lifestyle change. 'Very brief advice' means a short intervention of less than two minutes based on 'ask, advise, act'.

The recommended training is a 60-minute online course to understand the importance of physical activity for people living with cancer, find out what resources are available to support people to become more active, and to learn how to deliver effective advice on physical activity in less than two minutes. This is accredited by the Royal College of Nursing and the Royal College of GPs and has reciprocal accreditation across all Royal Colleges.

This training is available as an e-resource. More information can be found at [learnzone.org.uk/vba](https://www.learnzone.org.uk/vba). This short training course is targeted at any health and social care professionals, including those working in primary care.

### Understanding physical activity and cancer videos

Macmillan has produced training videos to support the training on understanding physical activity and cancer for healthcare professionals. These are now available on Vimeo:

- Understanding physical activity and cancer training: Introduction and the teachable moment  
[vimeo.com/202760582/ad47a3278a](https://vimeo.com/202760582/ad47a3278a)
- Understanding physical activity and cancer training – Introduction  
[vimeo.com/202761183/4b1d126a68](https://vimeo.com/202761183/4b1d126a68)
- Understanding physical activity and cancer training – the teachable moment  
[vimeo.com/202761346/46633d0e09](https://vimeo.com/202761346/46633d0e09)
- Understanding physical activity and cancer training – complete version  
[vimeo.com/202783942/a37c082b8c](https://vimeo.com/202783942/a37c082b8c)
- Understanding physical activity and cancer training – shortened version  
[vimeo.com/202785044/48d45884b3](https://vimeo.com/202785044/48d45884b3)

Healthcare professionals can be directed to the full 60-minute online training, which has been shown to increase practitioners' knowledge, develop their skills and lead to improved practice. The link to register is: [bit.ly/2yUfpbO](https://bit.ly/2yUfpbO)

Macmillan has also created a LearnZone of relevant training opportunities, this includes BMJ learning modules: [learnzone.org.uk/physicalactivity](https://www.learnzone.org.uk/physicalactivity)

### 5.2 Move More practitioner (MMP)

The role of the *Move More* Practitioner is to support individuals to become and stay physically active, at a level and in an activity that is right for them. This is through the delivery of a series of behaviour change interventions that integrate regular needs assessments over a period of at least 12 months.

To deliver this, *Move More* Practitioners are required to have:

- strong skills and competencies in behaviour change techniques such as motivational interviewing (MI)
- cancer rehabilitation skills, including understanding the needs of people from diagnosis through to end of life, and taking into account different cancer journeys, consequences of treatment and co-morbidities
- specific soft skills in consultation, empathy and listening, and experience of working with special populations or those with long-term conditions
- the ability to work with local physical activity and sport providers to ensure they are educated on the service and the requirements for people living with cancer
- the ability to take responsibility for the case management, delivery and coordination of behaviour change interventions
- a desire to acquire understanding of the local cancer care pathways within health and social care for both primary and secondary care and a good comprehension of the Recovery Package and how it is working in the local area. While it is not the role of the MMP to work strategically with the clinical pathways, it is important that they understand the services, roles and systems in and around cancer care.

### Recommended training

- Behaviour change skills, for example, motivational interviewing skills. You can find out about providers of behaviour change training at [motivationalinterviewing.org](http://motivationalinterviewing.org)
- Level 4 Cancer and Exercise Rehabilitation qualification. Additional training to equip them when working with complex and vulnerable service users, such as resilience training and peer supervision.
- Macmillan has created a Learnzone of relevant training opportunities including relevant BMJ modules at [learnzone.org.uk/physicalactivity](http://learnzone.org.uk/physicalactivity) The BMJ modules offer wider training options to assist MMPs with the terminology of healthcare professionals and information on diet.
- The Macmillan professional prospectus offers a wide variety of opportunities including presentation skills.

You should also consider additional training for those delivering your programme, for example, training that focuses on cancer awareness, listening and responding, and providing very brief advice. Some of this training is available from Macmillan, so please discuss your requirements with your lead Macmillan representative.



### Spotlight on behaviour change skills and competency training

Findings from the *Move More* service evaluation<sup>49</sup>, a rapid review of the evidence<sup>2</sup>, and work with behaviour change training experts has found that *Move More* practitioners require regular and ongoing training updates and supervision to ensure they have the required level of behaviour change skills and competencies, and are able to effectively implement motivational interviewing skills. This is critical for the long-term effectiveness of the programme. This needs to be built into the service budget and ongoing professional development of the MMP.

Motivational interviewing should form part of the professional's job description with ongoing training integrated into the workplace setting as part of professional development. In addition, a programme implementation needs to consider personal attitudes of practitioners, supervisors, managers, organisational cultures, and resources.<sup>106,107,108,109,100</sup>



### Spotlight on services

As part of their induction, Berkshire *Move More* practitioners spent a day with a nurse, an occupational health therapist and a physiotherapist to build trust and see what the multidisciplinary team meeting entails to understand the whole pathway.

Berkshire also offer psychological support workshops, resilience support and mindfulness for *Move More* practitioners.

An example job description and person specification for this role can be found on [page 111](#).



### Spotlight on the Level 4 Cancer and Exercise Rehabilitation qualification

In 2017 Macmillan carried out a training audit of qualification providers, this showed that the National Occupational Standards (NOS) tend to focus mainly on cancer post treatment, offering exercise prescription within a fitness setting and doesn't take into account co-morbidities.

The *Move More* service works with people at all stages and with all types of cancer from point of diagnosis, focusing on behaviour change support. This means that practitioners may need additional training or supervision. Please work with your qualification provider to ensure that this is in place.

CIMPISA are reviewing the qualification standards for exercise professionals in the UK working with people with long term conditions, an updated standard and qualification will be launched in 2018.

**‘My grandsons also motivate me with a quick kickabout, plus I recently discovered table tennis after a 40-year gap – but only because it was there and the family wanted to play.’**

Move More Participant

### 5.3 Cancer and Exercise Rehabilitation professionals (Level 4)

If your service is providing exercise classes specifically for people living with and beyond cancer, Macmillan advises the instructors leading these classes should take Level 4 Cancer and Exercise Rehabilitation training.

### 5.4 Physical activity providers

Macmillan has carried out insight research into sport and physical activity coaches and physical activity leaders. This shows they have the motivation to support people living with and beyond cancer, but often do not have the confidence, knowledge, skills and competencies to meet the individual's needs within their physical activity sessions. Some coaches and leaders were unsure of the adaptations to make, were worried about safety, and nervous about insurance and causing harm to the person affected by cancer.

We strongly recommend you consider additional training for those delivering physical activity elements of your programme or, if in a facility, the staff on reception. Include training that focuses on cancer awareness, listening and responding, and providing very brief advice. Some of this training is available from Macmillan, such as cancer awareness training, so please discuss your requirements with your lead Macmillan representative.

### 5.5 Volunteers

Macmillan has reviewed the evidence and identified and mapped volunteer roles against the physical activity behaviour change care pathway.

1. The **buddy** role helps to build the confidence and wellbeing of the person affected by cancer by accompanying them to undertake physical activities. Experience of cancer is relevant for the role and personal experience and traits are crucial. Having people from a similar background enhances effectiveness of the role.
2. **Committee member volunteers** play an important part in recruiting new service users and shaping services. They address shortfall in service provision and attend advisory group meetings. Volunteers, often previous service users, want to give back to the *Move More* service and the community, and enjoy their roles.
3. **Champions** fall in line with NICE guidance on community promotion. They are part of the communities in which they work and attend regular health fairs and informal opportunities. They raise awareness of the benefits of physical activity and signpost to *Move More* services.



#### Spotlight on services

Dorset has trained all local physical activity providers in cancer awareness, via Macmillan's online course. Available <http://learnzone.org.uk/courses/course.php?id=324>

### **Move More volunteer recruitment and support**

Volunteers should be carefully selected at the recruitment process through a matching and familiarisation phase.

There are many benefits to working with Macmillan volunteer advisors in relation to training and retention, as well as management.

Management of the volunteer roles works out as half a day per week for the *Move More* practitioner. This time is reduced if there is support available from Macmillan directly (via Direct Volunteer Services or the volunteer advisor).

### **Volunteer training**

Specific training is required for each role. Your Macmillan lead may be able to help with this.

Additional suggested training includes:

- Cancer awareness training – this is beneficial for all roles and this is available for free on the Macmillan Learnzone. Available <http://learnzone.org.uk/courses/course.php?id=324>
- Understanding physical activity and cancer WebEx training.



### **Spotlight on Eastleigh**

Eastleigh has introduced buddies to the service supporting new participants with their swimming. This has helped service users' confidence within the pool. The buddies are there to check on progress, and to ask how the sessions are going and if anything needs to be adjusted.



Edward, Lead volunteer

## 6. Awareness raising and referrals

### 6.1 Target groups

Physical activity can benefit people across all stages of the cancer care pathway and all cancer tumour groups. Therefore, it is important that your service is inclusive and isn't restricted to specific groups such as curable cancers post treatment or breast cancer.

In some areas, services may choose to put additional emphasis on a hard-to-reach target population to make it more inclusive, such as black and minority ethnic (BME) groups or those with advanced cancer. This will depend on the health needs of the population in a local area.

When developing a new service, it is useful to make an assessment of what is needed locally, to ensure that you have the best service model, with enough capacity to meet users' needs. This can be achieved by considering a number of key factors. These include the population size, geographical spread, cancer diagnosis rates, cancer prevalence and any health inequalities in the area.

If you're not reaching your targets yet, don't worry about who to focus on, just work on getting more referrals first. Once you are reaching your targets, look at which groups are common in your area and aren't getting referred onto the scheme, and look at our recommended methods for increasing referrals [page 76](#).

### 6.2 Integration with the Recovery Package

It is important that your service model is fully embedded within the cancer care pathway and Recovery Package for your area. Work with your key stakeholders and the Macmillan geographic service team lead to put this in place.

### 6.3 Gaining buy-in from healthcare professionals

The relationship with local healthcare professionals has proved essential to the success of the services in generating referrals locally. **47%** of referrals come from healthcare professionals, compared to **7%** from other professionals. All services have been encouraged to build these relationships through local networks, attending clinical nurse specialist (CNS) meetings. This requires an ongoing process to build the relationship with the potential referrers.

Regular face-to-face contact with healthcare professionals 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 must be carried out on an ongoing basis.

To get health and social care professionals to support your service, you will need to inform them about the considerable and convincing evidence-based benefits including:

- how a behaviour change approach can be adopted and the benefits of it
- how physical activity is something their patients can safely participate in
- the menu of activities your service offers and their suitability for their patients
- the referral process and how simple it is.

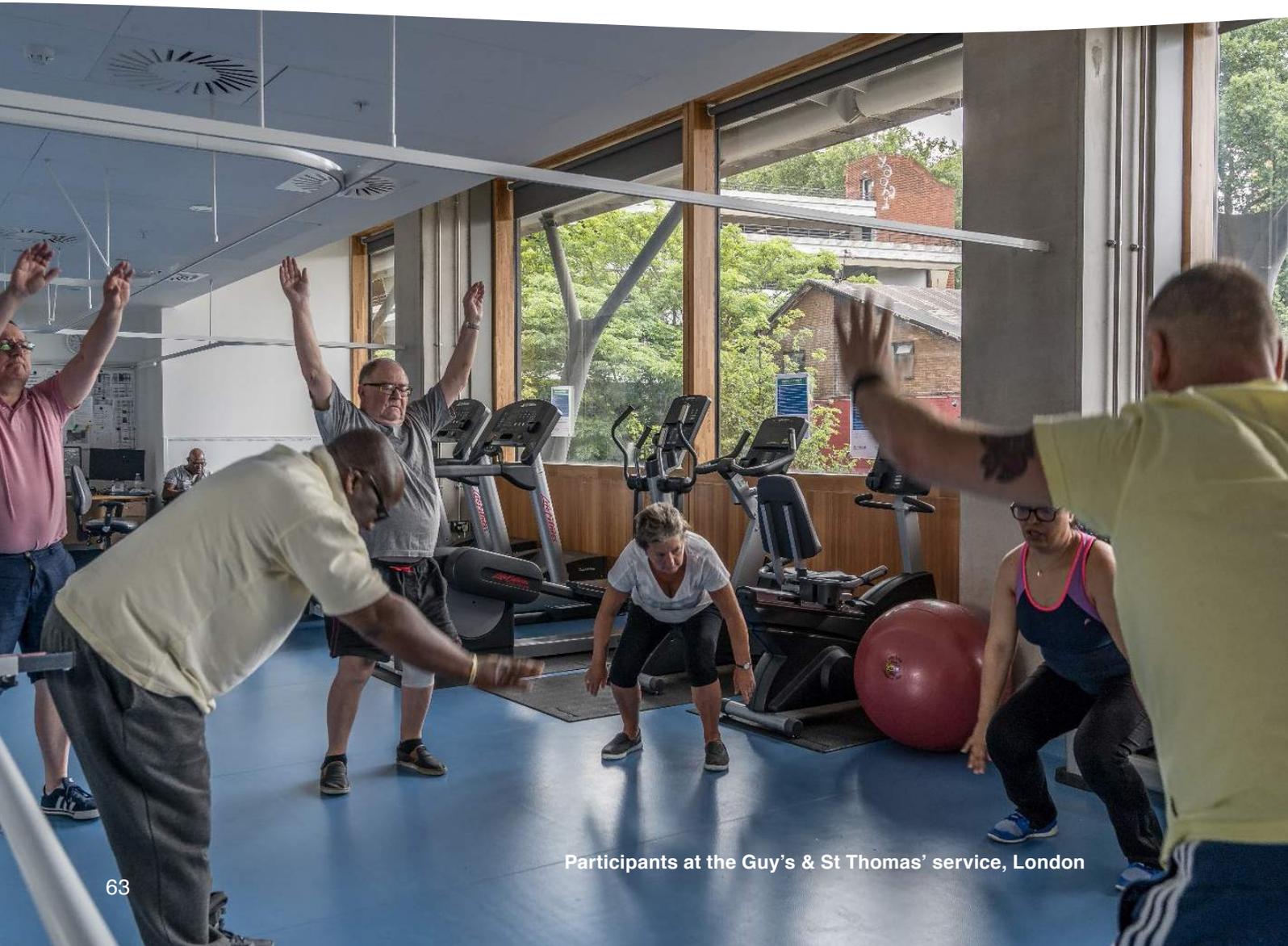
Macmillan's *Physical activity and cancer: a concise evidence review*<sup>111</sup> has been designed to support this.

It is important to establish these relationships early on, as referrals from healthcare professionals will not start coming through without engagement. The Macmillan training course *Understanding Physical Activity and Cancer* can support the knowledge and skills of professionals by raising their awareness of the benefits of physical activity in order to help them have an early conversation with people living with cancer.

It is important to build trust with health and social care professionals. Offering details on the training that service staff receive will help to improve confidence in the service and that their patients are going into a professional service, with highly qualified staff.

*Move More* practitioners have the skills and competencies to provide specialist physical activity support to people living with and beyond cancer. They are trained professionals able to suggest safe, effective, and individualised activities that are appropriate for people diagnosed with all types of cancer or who have different co-morbidities.

It is important to liaise with clinical nurse specialists and other health and social care professionals on a regular basis so they feel informed. This may involve attending team meetings, sending a newsletter once a month or visiting them regularly. Include within this an update on your service, the number of people attending it, individual stories and the types of activities on offer.



Participants at the Guy's & St Thomas' service, London



### Spotlight on physical activity clinical champions

In **Luton** the lead Macmillan CNS is a clinical champion for physical activity. The champion attends quarterly *Move More* Luton steering group meetings and ensures physical activity referrals feature in the monthly CNS team meetings and newsletter.

The champion also promotes a message to all healthcare professionals that physical activity is a free prescription and should be embraced.

As a result, on roll-out of the holistic needs assessment, all CNSs raise the importance of being active and signpost them to Active Luton. The Active Luton service is advertised in CNS clinics and treatment areas to remind CNSs to raise awareness, and it features in the information pack provided to patients.

Active Luton has been very successful and has provided support to many people living with and beyond cancer. A league table has been produced to show which CNSs (by type of tumour) are making the most referrals.

Other health and social care professionals in Luton who are involved in raising awareness include dietitians and a Macmillan psychologist.

A new system is now in place that involves Active Luton *Move More* practitioners providing a monthly update to CNSs about the patients they have referred to the service. This helps to encourage them to refer more patients into the programme.

The champion opens new opportunities for the *Move More* practitioners to attend CNS meetings and education days as well as hosting health and wellbeing events. The champion has accessed further funding for the service and also sits on key CCG meetings to open up future funding opportunities.

**Shropshire** have found that attaching the referral form to the leaflet and designing the form with input from the healthcare

professional has allowed for increased referrals from healthcare professionals. A smoother booking process is now established for Get Active Feel Good service users where their 1-to-1s are now booked within cancer services team.

Both **Shropshire** and **Dorset** have had success in linking with hospital apps to promote the service, build trust amongst healthcare professionals and increase referrals.

**Tottenham, Luton, Shropshire and Lincolnshire** have successful feedback processes in place for healthcare professionals to see how the service user they have referred in is getting on. Showing other nurses the success of the programme, the number of referrals coming in, and that it is progressing, leads to increased trust in the service.

**Dundee** keeps healthcare professionals regularly updated on the programme and receives positive feedback from referrers who appreciate weekly updates.

The **Walsall** *Move More* practitioner attends a number of meetings with health care professionals on a monthly basis to raise awareness of the programme including: a self-care management programme, dieticians meetings, a health and wellbeing forum, the Macmillan Recovery Package Conference, and support groups for BME, skin and sun awareness and brain tumours.

**Lincolnshire** have taken a different approach to attending CNS meetings by asking them what they need to do to get them to refer patients. They also show a service video and take a service user along to speak about the service.

**Sheffield** have attended meetings at the Northern General Hospital to inform staff of the service. This led to a discussion on how to prepare patients for surgery and they will now be piloting a prehabilitation service with the upper GI team using a holistic approach as part of the Active Everyday programme.

### Other Macmillan professionals

Developing relationships with Macmillan cancer information and support centres is also useful for generating two-way referrals and making links with key healthcare professionals. Developing positive relationships with staff working in Macmillan information centres is likely to be fruitful for services.

Centre staff have good links with key healthcare professionals and can thus broker introductions and provide information about the local cancer care landscape. As important sources of information for people living with cancer, the centres provide opportunities for self-referrals. Services can also signpost service users to complementary support and advice via the centres.

In many instances, information centres are based either within or very close to hospital grounds. *Move More* practitioners have found working closely with Macmillan information professionals helpful in opening up referral routes.

In Manchester, the information 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 in Antrim and Newtownabbey, the relationship between the project staff and the information centres has opened doors to improve referral opportunities. Information centre staff are often involved in the set-up of health and wellbeing events and can prove helpful in facilitating access to these for *Move More* services.

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.

Having a good relationship with the information centre offers additional benefits for service users. Services can signpost to a wide range of additional information and support via the centres including counselling, complementary therapy and support for returning to work.



### Spotlight on Berkshire

In order to offer optimal benefit to patients, the service offers *Move More* service users a specialist cancer service. This is provided by Macmillan professional psychologists and dieticians who have an understanding of a patient's cancer, treatment and side-effects.

Free sessions are also available from a Relate counsellor to support patients and their families on an individual or couple basis across Berkshire. There is also access to Macmillan Citizens Advice Bureau staff for help with financial advice, benefits and Macmillan grants.

The service has looked at many opportunities to facilitate social support, such as support groups, volunteer buddies, a singing group and gardening. The service also delivers the self-management course *Help Overcoming Problems Effectively (HOPE)* and works towards SMARTER goals for service users.

Some services have worked alongside their **Macmillan pharmacist** as part of the Boots national partnership and have arranged a meeting to start promoting the programme in store.

The Boots pharmacists via the Luton service ordered the *Move More* guide and the exercise DVDs for them to give out to patients. Luton held a successful wellness event at the Boots information stand. Services can access their local store via the Boots store locator on the website and through discussion with their Macmillan geographical lead. Staffordshire have had success increasing referrals through a pop-up in their store, and Dorset have held *Feel Good evenings* at the store and offered pharmacist health checks. The service also offers incentives for service users, including makeovers.

#### **Automatic referral process**

This has been trialled in a small way in Shropshire, where referral or signposting directly into a service for specific tumour groups has taken place. In this instance, the lung cancer patients receive an automatic referral into the service at the point of diagnosis as part of their prehabilitation programme for those identified as requiring surgery. They are prescribed a supervised, gym-based programme to follow up to their surgery date, with a focus on being as physically fit as possible prior to surgery to aid better surgery outcomes and post-surgery recovery. Once the service user has been signed off post-surgery they are picked back up by the *Move More* service to enable them to maintain the physical activity habit in a way that is right for them and supported for a further 12 months. This is delivered in a multi-disciplinary way and in collaboration with consultants, CNSs and physiotherapists.

#### **6.4 Direct mail letter from hospitals**

Macmillan worked in partnership with Make Sport Fun to test the concept of direct mail from hospitals to invite individuals who have had a cancer diagnosis onto our services. Macmillan worked in partnership with three hospital trusts in Luton, Dorset and Swansea to test the feasibility and acceptability of a letter sent to patient lists by the hospital advocating physical activity as part of treatment. On average, each trust had between a 15–20% response rate to the letters. This meant that in some cases, the letters were doubling monthly referral numbers. The approach also engaged with a wider variety of tumour groups and demographics than standard recruitment methods. The approach also increased CNSs awareness and referrals.

Approaches in each of the test sites were different. Some went for specific time periods, for example, all people diagnosed in the last month, while others targeted specific tumour groups. Dorset sent the letter to breast, prostate and colorectal patients where physical activity evidence and benefits were greatest, and achieved a response rate of over 20%. We have suggested that this source of recruitment is likely to be the single biggest source of referrals if implemented properly.

We have put this process into a guide, which can be found in the Appendix on [page 109](#). This includes a template letter that can be edited for local use and a guide of how to do it. The guide also includes tips on alleviating potential barriers, for example, by approaching information governance via the CNS rather than directly.

The idea behind the letter is that people who have had a diagnosis of cancer are very engaged in any communication they receive from their hospital or healthcare professional. Research looking at motivations driving people to increase activity levels shows that healthcare professionals can cut through other barriers and strike a note with the patient, encouraging them to act. Hearing it from them means the person living with

cancer views it as part of their health plan rather than an optional extra. Macmillan cannot access health records or patient information: sensitive data owned by the hospital trust. Therefore, any letter to the cancer population has to come from the hospital and the key to the success of this is ensuring that the hospital trust is on board.

**Key findings:**

15—20% increase in self referrals from recipients of the letter (effectively doubling monthly referrals to the local *Move More* services).

- It engages a wider variety of tumour groups and demographics.
- It generates interest from new CNS.
- It forms positive links to the Recovery Package.
- If one hospital that your service covers has 2,000 cases per year, potential for up to an additional 300 referrals per year.
- The letter is effective in getting new CNSs on board and engaging with new tumour groups as well as reaching wider BME groups.

The hardest part of the process is to get the initial sign-off and set up a system to compile the list of patients. Once you've set this up once, you can send quarterly mailings without too much extra effort.

The letter will need to gain sign-off from your steering group, specifically the lead CNS.

Your lead CNS will have access to the database of patients. During some of the pilots, CNSs preferred to start small and send to a certain tumour group, while others sent to people diagnosed in the past six months or five years. The most successful pilot was linked to the Recovery Package: where the letter was linked to an invite to health and wellbeing events; or through sending an automatic letter when a patient had ticked physical activity on the holistic needs assessment. Services will need to ensure the database is kept up to date before sending out the letter and that an accurate tracking process is in place for monitoring and evaluation.

Database systems in hospitals are often not satisfactory so allocate extra time when working with hospital databases. Start small: one CNS, one hospital, one nurse at a time; or with one tumour group, such as breast, prostate or colorectal.

Dorset now have a successful quarterly mass mailout to increase referrals with a regular 17% response rate.

**‘Physical activity helped beyond measure – improving muscle weakness which enabled me to do more and more regular activities, like zumba and long walks.’**

Mike

## 6.5 Marketing

It is ideal that people hear about the benefits of physical activity from a healthcare professional. However, it is important that the messages to those healthcare professionals are correct and consistent, and that they are confirmed by other messages the person diagnosed with cancer, or their family, see around them. By reinforcing these messages, not only are healthcare professionals reminded to raise the subject of physical activity, but people living with cancer and their friends and family aren't reliant on them to hear that physical activity can be beneficial.

Services use a variety of marketing methods including websites, magazines, social media including Twitter, Facebook YouTube and Instagram, newsletters, flyers and banners.

One of the key observations from the evidence is that people need to be less inactive rather than 'sporty'. Using terms such as 'exercise' leads to connotations of gyms, classes and a serious commitment that could be off-putting. Instead, it's important to use terminology such as:

- getting active
- moving more
- physical activity (occasionally this is found to have negative connotations, but not as strongly as 'exercise' or 'fitness')<sup>112</sup>.

Another important aspect is that the message to individuals is very different to healthcare professionals. Professionals respond best to facts about clinical outcomes, recurrence and survival rates. For a person who has been diagnosed, research suggests they want to know: how it will make a difference to their life on a daily basis; that it's achievable; that it could help with their side effects; or that it will give them the chance to be themselves again rather than just a 'person with cancer'. They can control something and get a sense of achievement through accomplishment. This uplifting language can apply at any stage of the cancer journey, as it's not focused on outcomes and survival. However, it's important that you don't overpromise and or talk about 'getting fit'.

In terms of increasing referrals, it's important that:

- there is a clear call to action – tell people what you want them to do and how to get in touch. A generic message about the benefits of physical activity won't encourage them to sign up or contact you.
- the poster or leaflet isn't too busy or people will ignore it (avoid a montage of images).
- you only include photography on a leaflet or where there's room to show diversity (of both participants and activity), as people engage with images of people who look like them. If there's only room for one image, it's as likely to put people off as engage them. A graphic could be a good alternative.

The following headlines have worked well for people living with cancer:

- *Tailored support to help you get more active*
- *12 free physical activity/<type of activity> classes for people with cancer*
- *Get active at a level that suits you*
- *Living with cancer? We'll help you get active*

The following headlines have worked well for healthcare professionals:

- *Helping people with cancer get active in [place]*
- *Helping people feel the benefits of physical activity*
- *Tailored exercise plans for people with cancer*
- *'Physical activity is safe and beneficial for cancer patients'* Professor Rob Thomas, Consultant Oncologist

The Richmond group of charities also did research on messaging to see what works well. People with long-term conditions and attitudes towards physical activity was published in 2016. [[https://richmondgroupofcharities.org.uk/sites/default/files/richmond\\_group\\_debrief\\_final.pdf](https://richmondgroupofcharities.org.uk/sites/default/files/richmond_group_debrief_final.pdf)]

Rating messages out of 10, *'It's never too late'* and *'Every movement matters'* do best, while *'Get fit'* does worst.

When asked what the most effective message was:

- 20% of people said 'Every movement matters'
- 15% said 'It's never too late'
- 15% said 'Every step counts'.

When asked to select the least effective message:

- 34% of people said 'Get fit, make friends'
- 15% chose 'Physical activity is a natural painkiller'
- 14% chose 'Be a natural painkiller'.

Macmillan's Guide Promoting your Service contains lots of helpful advice<sup>13</sup>.

**‘Keeping active helps to prevent, get you through, and recover from cancer. Walking in a group reduces stress as it is a social activity. It is like a support group! The boost it gives carers when they see a patient wanting to remain active is also of great benefit.’**

Ian

**Hertfordshire** used imagery and messaging from the Macmillan toolkit to feature in Welwyn Hatfield Borough Council's *LIFE Magazine*. This resulted in a huge boost of over 20 referrals, making it the best marketing effort they have tried. The advert also appeared in Herts Valleys CCG's newsletter.

**Free activity sessions for anyone affected by cancer**

If you've been affected by cancer, or know someone that has, there's free sport and exercise sessions taking place in Welwyn Hatfield to help you or them get active.

Move More Herts is a physical activity programme, funded by Macmillan Cancer Support. Working in partnership with Finesse Leisure in Welwyn Hatfield, 12 fully funded activity sessions are available to adults with a current or past history of cancer, including:

- Health walks
- Supervised gym and exercise classes
- Swimming
- Racquet sports
- Outdoor activities.

For more information please visit: [oneymca.org/movemoreherts](http://oneymca.org/movemoreherts), call 01727 731540, or email: [sam.movemore@oneymca.org](mailto:sam.movemore@oneymca.org)

**TAILORED ACTIVITY FOR PEOPLE AFFECTED BY CANCER**

THE MACMILLAN CANCER SUPPORT

The **Staffordshire** service has a stand in the chemotherapy unit to let people know about the service. It also has pop-ups in Boots stores, which has led to increased referrals. Similarly, the *Move More* Scotland services placed a pop-up banner for the service in the radiotherapy and chemotherapy departments, which led to increased awareness of the service and referrals.

The **Brighton** service has received increased press coverage following a photo call. The service has featured in *The Argus*, the *Brighton Herald*, on *BBC 5 live*, *BBC Sussex* and *BBC South East Today*. The service also featured in an online and radio promotion campaign with *Juice 107.2*. This was a 30-second advert for the service and a bespoke page on the website linked to the project video. This was featured for eight weeks and received 203 unique clicks.

[www.juicebrighton.com/business/directory/bus/52](http://www.juicebrighton.com/business/directory/bus/52)

[www.theargus.co.uk/news/14991968](http://www.theargus.co.uk/news/14991968).  
**Fighting fit runners who are beating cancer set to tackle a 10k run**

The **Wandsworth** *Move More* service took part in a health pop-up shop event within the shopping centre resulting in five referrals.

The **Bury St Edmunds** service featured in a two-page spread within the local newspaper. This featured a service user who was a famous rock guitarist within the area which led to increased referrals into the service.

**Manchester** changed healthcare professionals' perception of their service by removing the word sport from the postcards promoting the softer outcomes. They ran a workshop for physiotherapists to share the learning from the Level 4 course and inform them about the service, and also provided marketing material to prove it is a safe behaviour change service.

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 more straightforward. Similarly, simple self-referral mechanisms are working well in other services. For example, **Ards and North Down** (where 47% of referrals are self-referrals) uses postcards effectively.

**Antrim and Newtownabbey** advertise their Nordic walking classes as *Simply Strolling*.

The language used in promotional material in **Manchester** was changed to highlight the wider and 'softer' benefits of physical activity.

## 6.6 Digital marketing

On any website, ensure you use terms people can relate with, but don't strip out all references to exercise. If you do this and someone searches 'cancer and exercise', Google will not think your site is a good match. Ensure your main page has reference to key search terms to help increase traffic.

The most cost-effective way to reach people online in terms of both cost and time is to utilise local links on the website and social media, and encourage users to share. We have produced tips for social media and newsletters. A larger investment in both cost and time is needed for more sophisticated targeting.

## 6.7 Marketing within the hospital/clinic

Examples of effective ways of raising awareness within the clinic or hospital environment include:

- promotion on noticeboard displays within the hospital
- promotion on waiting room screens in surgeries and clinics and hospital radio
- inclusion within the 'What's on this week' timetable at the cancer centre
- activity sessions for patients in waiting rooms, for example, a group walk where there are parks nearby the centre with patients receiving a pager to notify them when it is time for their appointment
- the service contact details on the back of the *Move More* pack being included at the hospital information centre.

## 6.8 Attendance at health and wellbeing events

Health and wellbeing events are part of the Recovery Package, and are usually run by local NHS Trusts. They are designed to provide information to people affected by cancer about the support available during and after cancer treatment. They typically include information on a range of topics including: an explanation of treatment processes, financial support, diet and

lifestyle and other key healthcare messages. Events vary considerably in length, format and frequency across the country.

*Move More* practitioners should present at health and wellbeing events to promote the service to people affected by cancer and healthcare practitioners. Consider offering short bursts of taster activity and getting current or former service users to attend as ambassadors for the service.

Health and wellbeing events are designed to help people living with cancer and their families to access the support 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 local services available. They may be tumour specific or generic (covering all tumour sites). They may also be delivered as an appointment.

### Key points:

- Health and wellbeing events are a successful way of recruiting people living with cancer onto the service and engaging with healthcare practitioners.
- Events are particularly effective where the practitioner gives a presentation and/or short taster session.
- 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 people affected by cancer and professionals.
- The events give professionals the opportunity to see the service staff in action and to assess how they relate to patients.
- 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.

### 6.9 Cancer support groups

Accessing and presenting to support groups continues to be a successful method for engaging with individuals from different backgrounds and tumour groups. However, services often only focus on this kind of engagement during the set-up phase of the service, whereas a continual commitment to this type of engagement work is required. Services also often found success in support groups not related to cancer, as well as through community groups and faith groups.

Support groups 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 resources available in the service to carry out this type of promotion.

There are often a number of cancer support groups running in a local area. To promote physical activity services to them, you may want to contact the CNS at a local hospital who is responsible for a group, or speak to the group directly. You can then discuss when is a good time to attend the group and the best way to inform the group's members of your service.

From each group, it is likely only a few people will sign up to the programme; others may then sign up after hearing feedback about your service from other group members.

You need to provide people with the opportunity to ask questions about the project and receive reassurance that it is suitable for them. Therefore, please make sure you add phone and email contact details on all promotional materials and encourage people to ask any questions they may have.

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In **Hertfordshire**, the *Move More* service linked with various cancer support groups supporting specific tumour groups such as prostate, breast and lung cancer. They attend their meetings on a monthly basis to deliver an informal practical session and signpost individuals to other physical activity opportunities in their area. The service team also attend hospice-based sessions in partnership with allied health professionals and attend HOPE courses or sessions focussing on nutrition for head and neck cancers. This has helped to facilitate transition of care into a community setting, while helping move people through services and away from health and social care reliance.

*Move More Hertfordshire* regularly visited local cancer groups where they delivered talks on the benefits of physical activity with a cancer diagnosis, while stressing it is safe to be physically active during this time. Sometimes a gentle and optional physical activity session was delivered, depending upon the audience. They gave the participants an option to ask about the *Move More* service and how to become part of the programme.

**Dorset Living Well Active** offered brief advice sessions to local people via free, friendly and informative evenings. These involved healthcare professionals delivering motivational talks that feature the stories of people who have overcome problems through physical activity and are now enjoying good health, fitness and happiness. The talks also explained what the Dorset Living Well Active service offered to help people get going, keep going and get results. In addition, people who signed up to the project received a Macmillan *Move More* guide, filled with advice, tips and a goal-setting diary to help them on their way.

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### 6.10 Other community awareness raising

Many services have generated referrals from a **range of organisations** across the public, private and charitable sectors.

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In **Fife** and **Aberdeen**, the service has established a strong working relationship with CLAN Cancer Support and Maggie's Aberdeen managing breathlessness group (both charities). These have allowed the service to engage with participants and volunteers, which has led to an increase in referrals. *Move More* Aberdeen has been awarded the Aberdeen Council of Voluntary Organisations (ACVO) Award for 'Connecting and Collaborating' in recognition of the impact that partnership-working has made across cancer services in Aberdeen City.

Similarly, **Manchester** linked with Maggie's in Stockport where they offer emotional and psychological support workshops, living well courses and physical activity sessions, and they regularly refer in to the *Move More* service.

**Luton** have established referral routes with Virgin Care, a private healthcare provider of services to the NHS. Word of mouth is also viewed as an important route for generating self-referrals.

**Brighton** and **Fife** *Move More* service established a strong working relationship with Breast Cancer Care's Moving Forward course and the **Nottingham** *Move More* practitioner is a regular presenter on this course.

The **Cardiff** service has linked with the Marie Curie hospice and Dorset linked with Shine Cancer Support to increase self-referrals.

**Universities** have proven to be an effective link for services to encourage referrals. A student at a local university created a promotional video for the **West Lancashire** service which increased self-referrals. This service user found attending cancer specific circuits beneficial and stopped using walking aids as a result.

**Eastleigh** engaged with a university to join the *Move More* steering group, which led to the service being involved in a local research project at the University Hospital Southampton. A senior lecturer from Southampton Solent University became involved in linking the service with a prehabilitation programme.

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#### Spotlight on the Manchester Giants

The Manchester Giants delivered a half-time display promoting the Macmillan Active Manchester *Move More* service during one of the local league matches. The service also featured in the matchday programme with details of how to refer in, and on the basketball club's social media.

The following are examples of community services that *Move More* services have engaged with and which you may wish to consider:

- Local pharmacies, for example, Boots.
- Local hairdressers have promoted their service via business cards and offer further incentives for their service users.
- Schools have provided additional opportunities for services to widen their community reach through *Move More* practitioners promoting services at parents' evenings and delivering talks at the schools.
- Libraries have been an effective way in for referrals and promoting the service.
- Universities have positively engaged in the services including the University of the Third Age (U3A).
- Outreach activities have taken place in church halls for specific BME communities, and translation services have been available for services to translate their promotional materials and websites in order to reach a wider audience.
- Many services have been successful in gaining new referrals by taking the sports sessions into the community, for example, within faith groups, community centres, housing associations and local events, linking with existing organisations where possible. There is strength in numbers and working in partnership has been critical to the success of the *Move More* services to date. For instance, many services have created mutual signposting systems with local community partners to maximise the benefits to participants and increase recruitment to their activities.

### 6.11 Launch event

It is often useful to hold a formal public launch for your service. It is a good way to market your service to the public and local professionals. It can also provide a good opportunity to secure coverage in the local press and social media, so invite local media in advance.

To encourage people to attend your launch and engage them, you may want to offer taster sessions for activities and have information stands manned by representatives from Macmillan and local physical activity providers.

It is also good practice to invite along local partners, key stakeholders and local councillors to the event. Work with your regional service development teams for support in attracting local press and marketplace stalls.

Where services have promoted their service through celebration events and launches, they reported a resulting spike in enquiries. An important part of increasing referrals is networking and ensuring *Move More* Practitioners are comfortable in doing this and have the confidence to present at key events. Some project leads do not have the skills to do this.

Tottenham effectively used football club ambassadors to attending celebration events. These events celebrate service landmarks and increase self-referrals through images shared via social media.

The *Move More Scotland* launches are extremely effective in attracting media attention and increasing self-referrals into the services. The events are attended by Macmillan professionals, healthcare professionals, volunteers, service users, local media and many others. Speakers at the event include the local NHS health improvement lead, the Macmillan partnership

manager, the CEO, service users and volunteers. Newspaper articles in *The Telegraph* and a piece on the *ITV* news have helped to promote the service following the event. This has been supported by interviews and video clips posted on both *Live Borders* and *Macmillan* social media.

The *Sheffield* launch included a visual cartoon of the service and pledges for healthcare practitioners and partners to sign up. A follow up thank you was sent out post event reminding partners of their pledges. The service now sits within the *Sheffield* cancer survivorship group.

### Sheffield visual cartoon of the service



**Top tip:** Take pop-up sports equipment along to wellbeing events and launches to promote the session. The National Governing Bodies of Sport (NGBs) will have portable equipment they may be able to bring along to your events.

The Dorset Living Well Active *Move More* service invited NGBs to their launch event. The NGBs brought along their pop-up equipment for service users to try out while they were walking around the stands. This included target zones and rebound boards.

Issue	Referral tactics – top tips from <i>Move More</i> test sites
Increasing referrals from secondary care healthcare and allied healthcare professionals	Update each CNS and other professionals at least once a month on how the specific patients they referred are doing in the programme (activity levels and improvements)
	Attend monthly CNS and other professional group team meetings and present to the group about the evidence, what the service does and how to refer
	Create a league table showing who is making the most referrals
	Invite CNSs to behaviour change and physical activity sessions
	Set up a six-weekly email newsletter using Mailchimp
	Work with your Macmillan service development lead to contact CNSs and other health professionals via the Macmillan database
	Work with your Macmillan service development for an introduction to the Macmillan healthcare and allied health professionals within their area
Primary care referrals	Work with your NHS trust communications department and advertise in staff newsletters and on intranets
	When increasing referrals from specific segments, for example, during treatment, specific types of cancer, ages, look at which cancer nurses will be reaching these patients and target these CNSs with specific messages about how our programme is appropriate for that group
	Get a breakdown of GP referrals, by age and the conditions they have, and compare this with the people you are trying to reach
Primary care referrals	Track GP referrals
	Work with GPs and commissioners to make changes to the GP referrals as necessary
	Try to influence GPs and practice nurses via roadshow, health checks, CCG magazines and the health and wellbeing board agenda
Self-referral	Send direct mail via hospitals
	Start to distribute postcards to participants at each point of contact and encourage them to refer a friend
	Encourage first time participants to bring a friend or family member – especially if they've had cancer
	Have pop up banners, posters and leaflets in the hospital
	Work with your Macmillan regional communications team
	Have a website, Twitter and Facebook accounts and update regularly, linking with local community groups
	Organise walking football tournaments at half-time during a football match and make sure there's a clear call to action to text a telephone number
	Set up a form for sign-up at cancer support groups
	Present at cancer support groups at least every six months and encourage people to sign up
	Self-referral forms in supermarkets and GP surgeries
Make a list of community events to attend or advertise at them	
Design and print business cards with the name of the scheme, website address and a one-line description on the front, and space for someone to fill in their name, phone number or text message number on the back	
Include a self-referral form on your website	
Check whether there are any other appropriate local websites to get links from	

## 7. Referral process

Referral includes self-referral, formal healthcare professional referrals and signposting from community services.

The evaluation highlighted that a simple referral mechanism, preferably electronic, was key to effective recruitment into services. It can also be noted, through the evaluation and our wider insight, that self-referral is key to the success of any service. Individuals who are more motivated are likely to refer through this route, meaning they are also more likely to change their behaviour.

Across Macmillan's UK-wide test sites, self-referrals are the highest source of referrals (30%) followed by CNS (29%), GP (6%), physiotherapist (4%), information centre (3%), other charities (2%), other Macmillan services (2%), and practice nurse (1%).

### 7.1 Text numbers

Text numbers or five-digit short codes offer quick and easy communication with a service. These have tested well within pilot sites. Short codes can be more memorable and can be used effectively in promotional materials. If you wish to set up a short code, speak to your organisation's IT team.

### 7.2 Electronic referrals

It is important to make your referral processes as streamlined and simple as possible to encourage professionals to refer into your service. Existing services have found that the most effective route is via electronic pathways, making it simpler for healthcare professionals to refer people living with cancer.

Where services are able to be set up with an NHS.net email address, professionals can quickly and securely send across referrals to the service. NHS email addresses can be obtained through a lead CNS for referral purposes and the organisation does not have to be situated within health and social care.

### 7.3 Referral forms

It is important to keep referral forms as simple as possible. For self-referral, these can be kept very simple as information can be collected at the booking call. When referrals come from healthcare professionals, it is useful to have some essential information from them as this saves time and is less of a burden for the service user once they have entered the service. An example referral form can be found on [page 111](#).

To sign up to Move More Worcestershire or for more information, please complete the slip below and return to:  
SPHW c/o Sarah Blackburn, Hines Building, University of Worcester,  
Fitzgerald WR223, Harwick Grove, Worcester, WR2 6A7

Name \_\_\_\_\_  
Phone \_\_\_\_\_  
Email \_\_\_\_\_  
Best time to contact \_\_\_\_\_

Our Move More programme is available to people from Worcestershire who are living with and beyond cancer in the county.  
The Move More programme is available on referral from your CNS or other Health professional. Alternatively, you can self-refer by completing the slip above and returning it to us.  
If you've received a referral to the Move More programme, this is because your nurse or healthcare professional has seen that increasing physical activity can be of benefit to your health and your quality of life.  
What's more, getting active is also a great chance to meet others with similar experiences.  
To find out more about the programme, please contact the Move More Coordinator on 01925 825 498 or email [movemoreworcestershire@worc.ac.uk](mailto:movemoreworcestershire@worc.ac.uk)

For information and advice about getting active, call 0800 800 00 00 or visit [macmillan.org.uk/physicalactivity](http://macmillan.org.uk/physicalactivity)

Move More Worcestershire. Be a more active you.

Partner with Macmillan  
sports for people  
with cancer

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## 8. The *Move More* guide

The Macmillan *Move More* guide is a print-based resource pack complemented by online tools, which aims to support people living with cancer to become active at a level right for them.



This can be used as a standalone supported self-management resource that healthcare professionals can signpost their patients to, or it can be used by *Move More* services as a support tool to guide behaviour change conversations and support long-term change.

The guide includes a step-by-step booklet with a diary and tips on setting goals, as well as practical information about getting active. The guide also comes with a copy of the booklet *Physical activity and cancer*, five flyers about popular activities and an activity chart (with magnet) for service users to put on their fridge and remind them of what they've achieved each day. There's also a *Move More* DVD, which shows gentle activities they can do at home. The guide includes ongoing digital support over a minimum of 12 months. More information about this can be found at [macmillan.org.uk/beactive](http://macmillan.org.uk/beactive) (Order code: MAC13314)

**Move More DVD:** In this DVD, cancer and fitness expert Dr Anna Campbell MBE guides service users through three exercise plans to complete at home. This can be ordered separately: order code MAC14016.

**Activity chart:** This is designed to help service users record daily achievements over 12 weeks – from spending less time sitting, to walking to the park. Within the *Move More* guide, there's a magnet so they can stick the chart on their fridge and remind them of progress. The chart can be downloaded separately in PDF format so you can print off another 12 weeks if it's useful.

**Activity flyers:** A5 flyers give an overview of five popular types of activity – in daily life, walking, swimming, gardening and getting back into sport.

**Physical activity and cancer booklet:** This booklet is written for people living with or after cancer, who want to know more about the benefits of being physically active. This can be ordered separately: order code MAC12515.

**Online tools:** The *Move More* guide links to digital resources that will help your service users become and stay active before, during and after cancer treatment. For more information go to [macmillan.org.uk/beactive](http://macmillan.org.uk/beactive)

Find out about activities in your area, such as walking, gardening and sports, and how to get involved.

Ask our experts about being active. Your service users can talk to professionals and get practical advice on how to become more active.

Order a pedometer: service users can keep track of their steps with a Macmillan pedometer. Or find out how to download a step counter to their phone. There's also an app to help you reduce sitting time.

Hear personal stories and talk about being active: Watch the playlist featuring Ted, Joy and James talking about how physical activity benefited them, and how it can help. Service users can share their experiences online at our Online Community.

## 9. The *Move More* back office processes

### 9.1 Service interaction

For those service users who are referred by a professional, the *Move More* support worker will be required to send a receipt of proof of referral to the professional referrer. For those who self refer, details should be collected directly. The completed questionnaire will then need to be uploaded. This creates a case record with initial case notes input to the case management system.

A customer relationship management (CRM) system should generate a prompt for the relevant appointments. Following that, the case record will need to be updated and next contact agreed and recorded with a contact prompt sent. Ongoing progress will need to be recorded on the system and a 6–12 month case review appointment made. It must be noted that all information is kept private, safe and secure within a robust CRM or paper-based system.

Feedback to the referring agent will take place at the case closure stage as well as key follow up points.

### 9.2 Support resources

The service will need to ensure support tools are in place including: access to IT and phone system; meeting space; venue access for appointments; case management system account; electronic referral forms and questionnaires; case closure documents; and feedback documents.



## 10. The physical activity behaviour change care pathway

### 10.1 Initial engagement

During this stage, following self or professional referral, the service responds to the contact, sharing information on the service along with a baseline questionnaire for completion. The service invites the individual to an introductory call which is arranged at a time suitable to the individual. This stage in the pathway can be processed by the *Move More* support worker. A receipt or proof of referral should at this stage be sent to the referring agent (if a professional referral). The questionnaire should be returned via email or post to the service.

### 10.2 Introductory call

Once scheduled, the individual takes part in a call with the *Move More* practitioner (MMP) or support worker. This stage of the pathway is known in the literature as ‘brief advice’ and lasts between 5–10 minutes. It provides an opportunity to assess an individual’s readiness to change their behaviour and their physical activity levels (people should be asked to consider levels before and after diagnosis and treatment). The MMP or support worker goes through the detail of the service, informing the service user of the options available to them, the individual is given details on the *Move More* guide as a support tool. If self-referred, the MMP will use this opportunity to collect information on the individual’s cancer history and record it on a case management system.

The service user may choose to exit the service at this point, either to become active on their own, or because the service is not currently of interest to them. In which case, the individual should be given a choice of being contacted in three months’ time to discuss progress or re-engagement in the service.

If the service user wishes to progress through to the next stage, the MMP will schedule the first appointment at a time and location suitable for the individual. The

service will send a prompt to the individual prior to the appointment time (we recommend 48 hours) by either text or email.

If the support worker is leading the introductory call, it is important they are trained in motivational interviewing as well as cancer awareness training.

### 10.3 Behaviour change intervention: first appointment

This person-centred approach is designed to support people through the process of increasing their physical activity levels through a process of long-term behaviour change support. This can be delivered through a variety of different methods, including face-to-face, group-based and telephone interventions. It is believed that delivering this support face to face in a private one-to-one appointment is the most effective.

The first appointment is usually 30–60 minutes long, but can be upwards of an hour long depending on the complexity of each individual case. In the initial appointment, the purpose is to work through the individual’s history (to check if anything is missing from the introductory call), to carry out an assessment of the individual’s needs, and to deliver a person-centred intervention. The literature refers to this stage as the extended-brief intervention.

A **needs assessment** enables the *Move More* practitioner to understand the individual’s safety considerations based on: their stage and type of cancer; the treatment they are having or have undergone; the consequences of their treatment; any co-morbidities they may have; their current levels of fitness; and previous levels of physical activity. The practitioner establishes any contraindications to physical activity that the individual may have, enabling them to give advice on any physical activity to avoid.

The **behaviour change intervention**

establishes the individual's readiness to change in order to help build confidence and overcome barriers to being physically active. For those who are then ready and would like to become more active, the practitioner helps them to choose a physical activity that is right for them (taking into account safety considerations, enjoyment, location and timing), set goals and put in place plans to overcome setbacks.

Support at this stage is vital: some individuals may find it useful to find a 'buddy' to go to the first session with, or they may need some encouragement in the form of a prompt prior to the allocated time.

The *Move More* practitioner should use a person-centred guiding style using motivational interviewing techniques.

The practitioner should establish the level and type of ongoing motivational support the individual requires and agree a **follow-up plan**. This will vary depending on the needs of the individual. A Customer Relationship Management (CRM) system should be used to ensure this takes place and that prompts to the service user are proactive and person-centred.

Not all service users will need regular follow-ups for 12 months. However, it is important that it is available for those who do, to ensure that the least active and least motivated are proactively supported to make a change.

Services should ensure practitioners devote the whole intervention to discussing behaviour change. Any requirements for data collection should be completed before or after the intervention.



**Spotlight on Lincolnshire**

The *Move More* programme in Lincolnshire covers a very large geographic area and employs two *Move More* practitioners to deliver all behaviour change interventions and follow-up interventions.

The *Move More* practitioners are mobile and often hold interventions in people's homes, libraries, community centres, garden centres or coffee shops. They do not have a central centre for people to come to them.

Once the service user has identified their preferred method of communication, they may Skype, phone, text or email on a regular basis to check on progress, goal attainment or engagement with activity. The practitioners employ a robust tracking and relationship management system.

Based on the large geographic area and rural location, Lincolnshire have adopted a signposting model, linking to existing local physical activity opportunities. As part of this signposting, the *Move More* practitioners review the quality of the activities being used by the participant, and offer to attend the first visit with them. They also utilise other engagement tools such as the home-based DVD or buddy roles through friends and family.

**From Macmillan's evaluation findings this delivery model is cost effective and achieves statistically significant outcomes in relation to physical activity, fatigue and quality of life.**

David, diagnosed with throat cancer in 2008



#### 10.4 Detail of the needs assessment

A needs assessment of each individual service user should be conducted (by the *Move More* practitioner), this would also typically include a safety consideration or risk assessment process. This needs to take into account: whether someone was active prior to diagnosis; their stage and type of cancer; the treatment they have had or are undergoing; their current fitness levels; their consequences of treatment; and any co-morbidities.

It is important the person undertaking this assessment is either a specialist cancer physiotherapist or a professional qualified in Level 4 Cancer and Exercise Rehabilitation. An overview of safety considerations is available within the patient information booklet within the *Move More* pack.

It is important to note that the pre-activity readiness questionnaire (PAR-Q) is not appropriate here as cancer is currently not covered as a condition and is considered a

contraindication to exercise. This can result in creating exclusion criteria and an additional barrier to participation. Loughborough University are working on a more refined version of the Par-Q+, which may provide a viable solution in the future. It must be noted that the *Move More* programme is a behaviour change service, with signposting to physical activity sessions, rather than a traditional exercise-on-referral and exercise-prescription service set within a gym environment.

The *Move More* services based within clinical and healthcare settings tend to use a more stringent process. An example of the process created and used by Guys' and St Thomas' and the Sheffield services can be seen overleaf.

## Sheffield Active Everyday *Move More* service

### Active Everyday – 1st Appointment Session Guideline

#### Aims:

- Introduce service user to the service
- Understand expectations and outline the programmes aims

#### Resources:



*Move More* guide



Completed pre-activity questionnaire

#### Equipment:



Laptop or tablet to introduce person to *Move More* website



Pens



Paper

#### Introduction



10 mins

1. Sit down, make comfortable and introduce self and the session
2. Build rapport and set agenda for the session
3. Ask how they heard of the service

#### Physical Activity and lifestyle discussion



15 mins

- Utilise *Move More* Pack for support
4. Ask participant to discuss their cancer journey
    - a. Year of diagnosis
    - b. Treatment received
  5. Current wellbeing
  6. Discuss what they hope to get from the service
  7. Discuss what are their reasons for becoming more active
  8. Discuss what activities the person enjoys
  9. Discuss what could be a barrier to becoming and staying active
    - a. Explore these barriers
    - b. Create plan to overcome these barriers

#### Goal setting



10 mins

- Utilise *Move More* Pack for support
10. Discuss short term goals (one month)
  11. Discuss medium term goals (six months)
  12. Discuss long term goals (12 months +)

#### Physical Activity plan



10 mins

13. Design physical activity plan utilising *Move More* activity diary
  - a. Base on FITT principles
  - b. Refer to relevant services e.g. cancer specialist instructor, health walks

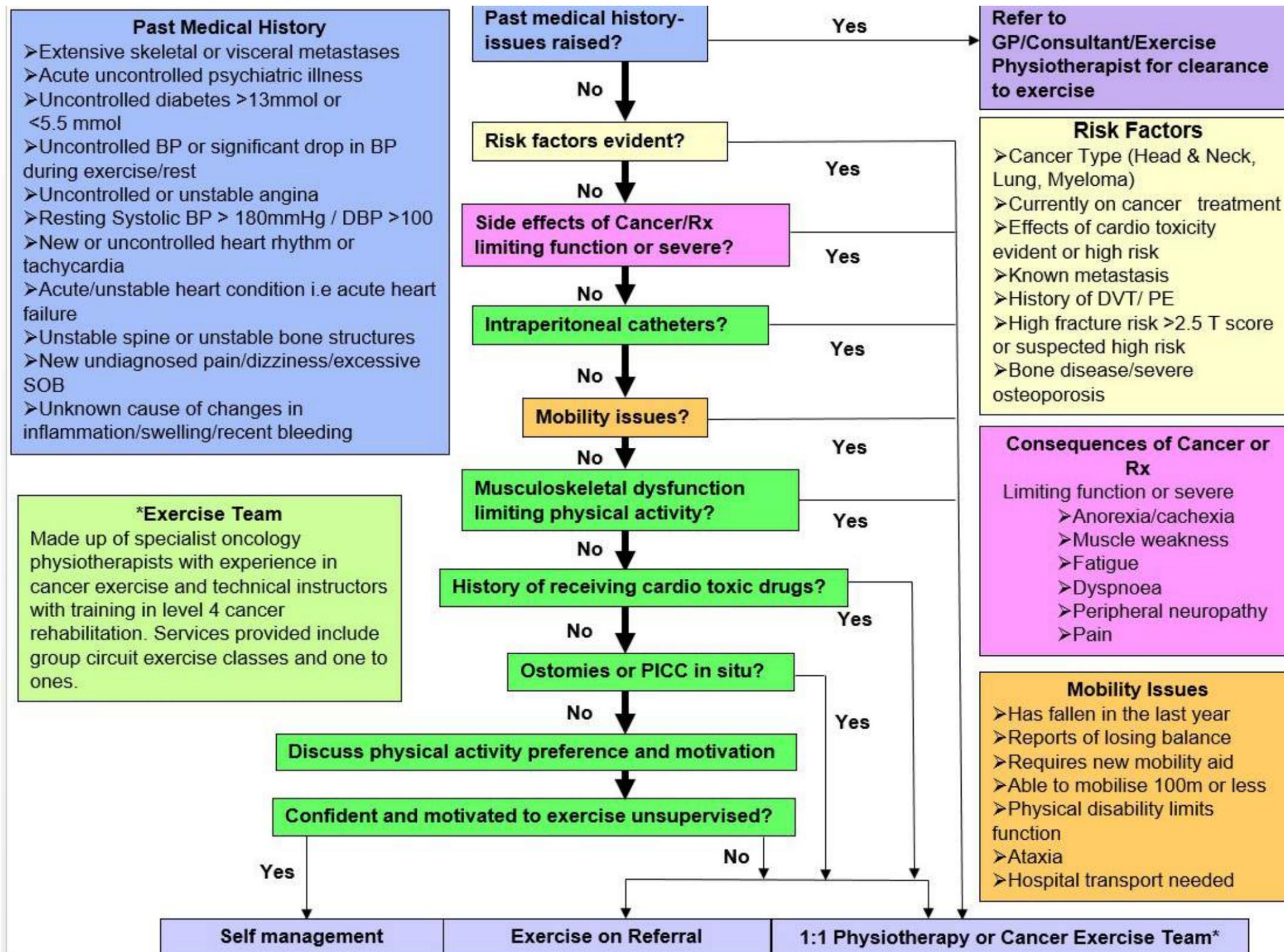
#### Next steps



15 mins

14. Navigation of *Move More* Be Active website and online community
15. Discuss next steps
16. Book follow-up session and agree format

Cancer activity tool – Physical activity for people with cancer



## 11. Physical activity opportunities

### 11.1 Introduction

It is important that people living with and beyond cancer can access an activity of their choice that they enjoy and participate in, at an intensity that's right for them.

Services should offer individuals access to a menu of activities to choose from.

It is also important not to assume that cancer specific group-based activities are the preference for all service users. 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. The type of activities on offer should be varied, and at a range of venues and times suitable to individuals who may also be working.

It is recommended that the following activities (many of which will already be available locally) be included within the activities on offer:

- health walk groups
- community activities, such as those offered in community venues or local parks and open spaces

- sport, such as entry level sporting opportunities offered through National Governing Bodies of Sport (NGBs) or local sports clubs

- exercise on referral where available, including exercise that is condition specific (for example, for cancer, fall prevention, or cardiac rehabilitation)

- everyday activity – encouraging people to build activity into their daily lives

- self-directed activity such as the Macmillan exercise DVD.

Services should review the profile of service users and consider how the activities available may need to be adjusted in order to ensure they meet the diverse interests of the participants. This can be done by ensuring there are activities likely to appeal to men and that they cover a wide geographical area, for example, the 'Men in Sheds' project. Services should identify local activity providers first before deciding if there is a need for directly delivered activity to fill gaps.

It is important to note that, when identified as a need in a local area, some cancer-specific activities may be added to the menu of activities on offer.



Sue, diagnosed with head and neck cancer in 2016



Ruth, diagnosed with Ewing sarcoma in 2015

### 11.2 How to identify the right physical activity opportunities

Macmillan's approach is based on supporting individuals to become and stay active in an activity and at an intensity that is right for them. This means ensuring there is sufficient access to a range of trusted activities locally and not just cancer specific exercise sessions.

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 activity alone, rather than as part of a class, or appreciate the 'normality' of taking part in physical activities open to all. Others prefer to engage with people who are also living with and beyond cancer. It is important not to make assumptions about what activities service users will want to access.

From data insight<sup>h</sup> walking is the most popular activity followed by swimming, gym, cycling, golf, badminton, yoga, keep fit, bowls and aerobics.

Travel can be a barrier to participation, so it is important that not only are there a wide variety of activities but that these are available in a variety of locations and settings accessible by public transport.

It is also vital that this mixed activity offer is available at a variety of times to cater for those who are working or have caring responsibilities.

**'Physical activity can make you feel less tired and more able to cope with the impact of cancer treatments.'**

Dr Ollie Minton PhD FRCP, Consultant and honorary senior lecturer in palliative medicine

<sup>h</sup> Macmillan analysed data from Cancer Research UK, Sport England, Macmillan Cancer Support and the Census to identify preferred activities.

### 11.3 Recommended physical activities

#### Health walks

Walking is a safe and free activity that is easily accessible as no special equipment is required. It has the lowest contraindications to exercise and has been shown to alleviate consequences of cancer treatment by reducing fatigue and the decline in physical function. Group walking can reduce the feeling of social isolation by providing the opportunity to meet new friends, share laughs and explore the local area in an achievable, non-stressful way.

There are walking programmes across the UK: Walking for Health in England, Walking for Health in Northern Ireland, Paths for All in Scotland and Let's Walk Cymru in Wales.

#### Sporting opportunities

'Get back into' and walking versions of sports (such as walking football) are popular activities. They are usually designed by National Governing Bodies of Sport (NGBs) and are often in partnership with Age UK. Most sports now have an offer that is aimed at adults who need an introductory moderate-intensity offer that allows them to step up or step down in their chosen sport in a social setting.

Examples include: Walking Football, Footgolf, No Strings Badminton, Run Together, Walking Cricket, Slipper Soccer, Sitting Netball, Breeze Cycling and Just Bowl.

For more information, go to the relevant NGB website. If you are in England, you can contact your local County Sports Partnership (CSP).

#### Exercise on referral

Where available, exercise on referral may be an excellent signposting option for relevant service users. This includes condition specific exercise, for example, cancer, falls prevention, cardiac rehabilitation.

It is important that individuals feel supported where they may have multiple health conditions. Local exercise-on-referral programmes may be able to help with this.

Typically, individuals are supported with a personalised physical activity programme for 12 weeks.

Signposting to an exercise-on-referral service may be a great starting point for some, provided that the individual has ongoing behaviour change support from the *Move More* service during and after the 12-week programme, and a review of their needs and next steps takes place.

#### Circuits

Circuits appear popular and valued by service users, allowing them access to tailored exercise appropriate to them that they can replicate at home. Cancer specific sessions allow service users to exercise in a safe and private environment and provide important opportunities to get mutual support and encouragement from others with similar experiences.

#### Everyday activity

This is one of the easiest ways people can become more active. Building activity into their daily lives, whether as part of a commute to work, trips to the shops or walking the dog, all adds up to increasing activity. Individuals find that by building it into their already busy schedules, it helps them to prioritise, which can feel easier than a dedicated time to exercise.

#### Self-directed activity

Self-directed activity such as the **Macmillan home exercise DVD** can also be a great way to get people started. As part of the *Move More* pack, individuals have access to the DVD, which they can use at leisure in their own space and time.

#### Seasonal activities

Services have also reported that some activities are seasonal. It's important to note that outdoor activities are more popular in the warmer months. This is to ensure individuals have an opportunity to discuss their activity choices with a practitioner who supports the process of swapping between activities or seeking new ones.

#### **11.4 Engaging with local physical activity providers**

It is important to engage with local physical activity providers in your area to increase awareness of your service. Work with them so they feel confident about offering their activities to people living with or beyond cancer. These partnerships should be developed based on local need. Working with local providers is the most sustainable options for these services.

Our evaluation feedback from service users demonstrated that they would like to be referred on to sport and physical activity providers who are appropriately trained with the right skills and are confident in delivering their sessions to people affected by cancer.

**‘At the beginning I thought there was no way it would be possible for me to attend a Move More Glasgow walk due to my condition, but I can’t believe the difference it has made to my health and wellbeing. I can now walk at a good pace and distance comfortably and now the Move More walk leaders are telling me to slow down! I feel so much better in myself and I can now paint doors around the house.’**

Move More Participant



**Top tips:**

- Develop quality assurance for signposting into community provision by attending the first session with the service user or having a service level agreement in place with the organisation.
- Ensure there are accurate activity timetables from sports coaches and physical activity leaders on their website to signpost service users to.
- Coaches and physical activity leaders should access Macmillan resources including LearnZone workshops of basic cancer awareness and fatigue management, and the *Move More* guide. Coaches should show *Move More* practitioners a certificate of LearnZone course completion before signposting in.
- Physical activity and leisure providers must express empathy to cancer patients, have the appropriate level of knowledge, skills and competencies around cancer and physical activity, and be competent in conducting conversations that are underpinned by behaviour change techniques.
- Where group sessions are in place, offer a social opportunity post session. Retention rates are dramatically improved if there is a place nearby where people can socialise after taking part in an activity, for example, a café where they can have a cup of tea and a chat. It's important to consider this when establishing where your service's physical activities will take place. Many of the *Move More* services combine sporting opportunities with social activities by having sessions and events conclude with a tea and a chat. The service users valued this element as highlighted in the national evaluation report.
- Utilise Macmillan volunteers to provide additional support to coaches and physical activity leaders.
- Encourage key family, friends and carers to become active together in order to support the individual.
- Provide activities that target specific groups, for example, men's groups or women's groups.
- Don't just work with the existing provision, but also work to bring provision to where people already engage in social activity. This can be done by linking with a broad range of community partners, for example, faith groups and support groups. Taking activities to existing community groups where people feel safe and comfortable can support them to take up activity. You are designing the offer to suit their needs.
- Fundraising with your service is an effective way of increasing referrals and increasing awareness of the service locally.
- Incentives such as offering free introductory sessions can increase uptake and can help participants try activities that they perhaps wouldn't have otherwise.



**Spotlight on top tips in practice**

**Sheffield** has signed a service level agreement with their delivery partners that they are referring into for quality assurance.

**Dorset** has trained health walk and Nordic walk leaders, and running and cycling coaches in basic cancer awareness training using the Macmillan online LearnZone to increase their understanding of people living with and beyond cancer.

**Velindre** has developed a feedback form for service users to complete after they have attended the physical activity session. The form includes a section on activities they will continue to do and suggestions for improving the service.

**Berkshire** has recruited volunteer buddies who accompany service users in daily life activities.

Berkshire has offered community sports taster sessions via the **Macmillan Sporty Coffee morning** fundraiser.

**Shropshire** has been working with their CSP, mapping local physical activity opportunities, including sports. They have conducted a survey of people going through their programme to find out what sports would be most popular in order to run an educational evening for sports coaches. The service now **actively signposts** to Parkrun, fishing and golf and has linked with Macmillan fundraising for the Coracle World Championship.

**Wandsworth** offers **discount membership** through its leisure partnership with Places for People.

**Brighton** linked with the local Age UK who offer **free door-to-door** transport for service users.

**Walsall** offer *Move More* service users **reduced gym membership**, including waiving the joining fee and offering **half price sessions**.

Get Berkshire Active CSP has an activity finder of all appropriate activities to which *Move More* service users can be signposted.

Joyce, diagnosed with Head and Neck cancer in 2009, with her Walking for Health group



### 11.5 Tips for partnering with health walks

- Build a relationship with your local scheme: set up an initial face-to-face meeting, and try to maintain regular contact.
- When setting up the link, emphasise the mutual benefits such as more participants for health walks and specialist support for walkers affected by cancer through your service.
- Many health walks schemes in a region meet as a network. Consider attending the meetings to get to know the schemes in your local area and promote your service.
- Make use of the registration form for the health walk scheme when signposting individuals to your local scheme. For many people, the form increases their confidence in the walking scheme.
- Let your health walk scheme know that free cancer awareness training is available on LearnZone for their volunteers.
- Share details, such as leaflets of your service, and ensure you stock the local walking scheme's information and keep the details up to date.
- Health walk coordinators may want to support walk leaders to become ambassadors for your service. You can help promote health walks through your networks too.
- Make use of the Macmillan brand as people tend to respond positively to this. Health walk coordinators are busy people, but many will find the time to meet because of Macmillan.
- Invite your local scheme to service events, for example, launches, knowledge exchanges and celebration events.
- Share walking case studies and good news stories.
- Ensure websites are kept up to date with accurate timings and locations of the walks.



### Spotlight on services

**Guys' and St Thomas'** included a handout in letters to patients which directed people to local health walks.

**Hertfordshire** and **Lincolnshire** linked with walking festivals to promote the activity and their service users are now getting trained to deliver health walks.

**Wandsworth** and **Luton** set up new health walks from the hospital and hospice which has attracted more service users.

The Get Active, Feel Good service in **Shropshire** linked with two of their local health walk groups and signposted patients who are interested in getting active through walking.

### 11.6 Top tips for partnering with sporting opportunities

- Identify and make links with local sporting partners.
  - Our insight from services suggests that the 'get back into' sports are popular activities to build relationships with and promote locally. These partners range from National Governing Bodies of Sport (NGBs), for example, British Cycling, County Sports Partnerships (CSPs in England, sports clubs, universities, support groups, faith groups, community centres, football associations, local authorities, leisure providers, other charities, challenge events, fundraising, volunteer organisations, libraries, and NHS and private organisations.
  - Work with these partners to ensure their offer meets the needs of your service users.
  - Many NGBs have proven able and willing to adapt and merge products to better meet the needs of inactive people when working in partnership with the services. Some *Move More* services have fed back to services how to shape their products to meet the needs of people affected by cancer. For example, in Blackburn they have created a video to demonstrate their work engaging with NGBs. Watch it here: [youtube.com/watch?v=RX1A9mVoi8Q](https://www.youtube.com/watch?v=RX1A9mVoi8Q)
  - Link with national campaigns including:
    - *Badminton for Macmillan Week* and *Bowling for Macmillan Week*. Contact your regional fundraising officer for further information.
    - *This Girl Can* where services will have access to a toolkit including insight, imagery and slogans to promote their services.
    - Mind's *Get Set to Go* national programme, which encourages service users to take up sport to help with mental health issues.
  - Engage with your local professional football clubs.
  - Both Football League and Premier League clubs host community schemes that deliver a range of activities. Having a football club on your side can be a great asset, as they may offer branding, experienced coaches and reduced facility hire. *Move More* services have successfully engaged with their local clubs and have featured in match programmes, promoted the sessions at half-time displays and engaged with the Fit Fans initiative.
  - Reframe the term 'sport' in promotional messages. For many inactive people and healthcare professionals, the term 'sport' is viewed negatively even if it is beneficial and they would enjoy it.
  - Utilise local champions and sport ambassadors to spread the work, making sport the norm. For example, a local football player with a connection to cancer.
  - Sports taster sessions are a useful recruitment tool. Some services offered sport as monthly 'mix it up' session and trialled a variety of sport in the widest possible sense, for example Footgolf, walking netball, walking football, dragon boat racing, adapted ballet, archery and aqua aerobics.
  - Combine sport with social events, such as coffee mornings to engage inactive people and increase confidence prior to moving them into activity opportunities.
  - Link with Macmillan challenge events and offer the 50% off *Move More* code.
- A toolkit has been developed with key lessons learnt and information on the sports products available for our target audience. A link to this can be found in the tools and resources page.



### Spotlight on services integrating sporting opportunities

**Dorset** Living Well Active has developed working relationships at a local level with **Walking for Health, dragon boating, Nordic Walking UK, British Cycling, England Athletics, and EMD UK**. It has also connected with another local project to offer an extensive range of free and subsidised outdoor recreation activities to people affected by cancer.

The Pink Champagne Breast Cancer **Dragon Boat** team in Dorset was set up by a group of breast cancer survivors in 2008, as part of the menu of opportunities of the Dorset Living Well Active service and in collaboration with the breast cancer team at the Royal Bournemouth Hospital and an expert team of exercise therapists at the Littledown Centre. Together another 150 breast cancer survivor dragon boat teams worldwide, team members are contributing to a number of education and research programmes to inspire and encourage other men and women to achieve the physical, psychological and social benefits of physical activity through the sport of dragon boat racing.

Through the **Velindre** Cancer Centre project in Wales, a partnership with Pedal Power has been developed where Macmillan *Move More* physical activity events are held and promoted by the organisation. The project has also developed a relationship with Sustrans around **cycling**.

In **Bridport**, the service has arranged a free Saturday morning six-week block (with coaching) in collaboration with **Table Tennis England's** local table tennis development officer and Dorset Table Tennis Centre (DTTC). New Living Well 'activators' are being trained up to promote the service.

**Guys' and St Thomas'** *Move More* service have linked with **The Bowls Alliance** as part of the Macmillan national partnership and campaign to deliver Just Bowl training to the physiotherapists in the cancer department. The team have accessed portable bowls equipment and will be offering taster

sessions alongside the circuit class, and at health and wellbeing events. The team have also commenced stretch and relax yoga at the cancer centre and staff have attended a yoga training course.

**Southport and Formby** have launched new **No Strings Badminton** sessions and also trained up service users as Nordic walking instructors to give back to the programme.

The **East Lancashire Blackburn with Darwen** service has launched **Dance for your Cuppa** sports taster sessions and female-only activity sessions.

A **Hertfordshire** service user has looked at ways to engage more males into the service and has set up a **cycling activity support group called Prostate Pedlars**. This service user has attended motivational interview training and has set up a website and printed business cards to promote this activity option.

**Move More Blackburn with Darwen** formed a partnership with the Lancashire ASA aquatic officer and the Lancashire Sport Partnership to run a six-week pilot in Blackburn with Darwen and Ribble Valley (areas in which the two breast cancer support groups were based). Sessions included an adaptable floor to provide appropriate depth for shallow aqua based activities (1m–1.5m), and a small private pool. Also provided was a lockable, private changing area including toilets and showers, a seated social area for participants to gather and chat after sessions, and friendly and helpful staff on reception to greet new participants and direct them to changing facilities. It was also ensured that the pool was ready and set up for sessions on time, the same female lifeguard was present for each session (the ladies were comfortable with this and got to know this helpful member of staff) and equipment was readily available for each aqua session.

Successful links have been made with the Accrington lung cancer support group, where the service delivered an information session, a tai chi taster session and adapted ballet.

The service is in talks with Blackburn Rovers FC about linking with the walking football group in order to encourage male cancer referrals. Recently, the service has promoted the importance of bone health and resistance training to existing *Move More* exercise classes and breast cancer support groups, with each person having a resistance band and booklet to take home.



#### Spotlight on partnerships with professional sports clubs

The **Manchester Giants** have delivered a half-time display promoting the Macmillan Active Manchester *Move More* service during one of the local league matches. The service also featured in the matchday programme, with details of how to refer in, and on the basketball club's social media. The club are now planning a Basketball Legends event to promote the service.

**Tottenham Hotspurs Foundation.** As a result of the Foundation reaching its 10-year anniversary, a bowls service user was filmed to showcase his experience on the programme and the benefits of being part of *Move More*. The film was shown on BBC News and Sky Sports, and the participant attended the three-year celebration event alongside Tottenham footballers, which received press coverage and generated further referrals. You can view this at [app.frame.io/f/BdweKKHQ](http://app.frame.io/f/BdweKKHQ)

Successful walking football programmes have been set up in partnership with **football clubs** in **Sheffield** and **Dorset**. Dorset have focused on 'healthy essentials for life after cancer treatment' for testicular cancer service users in partnership with Bournemouth AFC. The project has received further funding from a local scaffolding company. Sheffield have focused on fans with testicular cancer at Sheffield United. They have helped to shape the programme curriculum and have featured in the matchday programme.



#### Spotlight on sports ambassadors

**Active Luton** recruited a local **boxing champion**, Billy Schwer, who helped spread the word about the service and attend local events. Billy, himself a vocal advocate for reversing poor health through good nutrition and regular activity, said: 'I feel proud to be able to support such a fantastic programme. I believe that a combination of physical, mental and nutritional health will aid prevention and recovery of any disease. This programme gives the tools to help people fight against cancer. You only have to look at the participants today to see the benefits that they are getting from the scheme.'

**'Staying active through treatment is so empowering. It's control in a time of confusion, can help give you headspace, and make you feel capable. It's about being fit for living.'**

Siobhan



### Spotlight on sports taster sessions

Luton's new monthly 'mix it up' sessions are taking place, which have included taster sessions in indoor bowls, walking cricket, walking netball, walking football and table tennis. Following the tasters, the sessions have become sustainable with links to other long-term condition service users taking part.

### Dorset Living Well Active

The *Move More* service in Dorset teamed up with another charity to hold a climbing taster activity session at Snowdon in Wales. There were training sessions on offer in the build-up to the event at the local climbing centre. Over 30 service users took part in the event.

'For me to walk up a hill was a feat, but a mountain, after cancer, was definitely an eye-opener. I felt proud of myself and I knew so many people would be too. Maybe it was physical tiredness that brought all the emotion out, and the fact it brought back memories of my own battle of cancer, the reason I was doing it. What a fantastic weekend. Bring on the next one.'

'Participating in the group is also a personal statement of accepting publicly the diagnosis of cancer, and "normalising" it and reducing the stigma. We have a routine of stopping for coffee in the bar of the tennis club after each Friday session. We have not only been able to share our past and present experience with others, but have also been able to support one another with misdiagnosis, treatment successes, recurrence, and other experiences of treatment. The instructor – her enthusiasm, fun personality, liveliness and positive outlook make it a joy to participate. While I love the music and dance, the atmosphere she creates is in itself very uplifting, and leaves us all in an energised and buoyant frame of mind on a Friday afternoon. Who would have guessed Macmillan could provide such an opportunity given the point at which individuals start on this journey!'

Manchester Giant service participant.



### Spotlight on services linking with challenge events and fundraising

In some areas, service users required more of a challenge. Therefore links to Macmillan challenge events locally and nationally were established with a 50%-off code for participants who had engaged with *Move More*.

A *Velindre Move More* service user developed their own challenge completing 25 park runs in 25 weeks.

The *Lincolnshire Challenge* Macmillan campaign encourages local sports clubs and activities to raise awareness of the service. Through this campaign, 20 groups were reached with over 500 people taking part. The Lincolnshire 5k walk raised £2,000 for Macmillan family members who attended and the Lincolnshire mayor spread the word about the service which led to increased referrals.

The *Luton* service has actively signposted to Parkrun UK and has created *Move More* t-shirts with a text code to promote the service. Following the *Move More* sessions, service users have entered the 5k race in the Milton Keynes Festival of Running, raising money for the charity. They have also engaged with the NHS Choices 'Couch to 5k' programme, as well as the Luton Parkrun.

*Move More Aberdeen* have engaged with challenge events to offer further opportunities for their service users, for example, the Macmillan Longest Day Golf.

*Luton* Macmillan's sporty coffee morning raised £493, including proceeds from a cycling challenge. Walsall's sporty coffee morning raised £175, while Stafford and Cannock raised £385, and Bridport £784.

## 12. Ongoing behaviour change support

It is essential to provide regular ongoing behaviour change support to people to help them stay active. This support should be available to the individual for at least 12 months, although not all will need this length of support. This support needs to be flexible in style and format, and based on the individual's needs so that it is person-centric.

During the first and subsequent interventions, the *Move More* practitioner (MMP) should agree when follow-up support will be delivered and how, such as over the phone, face-to-face or by email. The level and type of support required will depend on the individual and their needs at that time.

The service user will 'attend' the follow-up support session, detailing their progress since the last conversation. The MMP will deliver behaviour change support consistent with the first appointment. They will take the opportunity to review the service user's health status and any broader life changes, their progress against goals, and participation in physical activity. If required the MMP will assist the service user in finding a different or additional suitable activity, discussing progression of their activity levels.

Case notes should be updated on the case management system and any additional follow up support sessions would be scheduled by the service. If the individual wishes to exit the service at this point, this option should be supported. They should be given information on the options for reconnecting with the service if needed in the future.

For all scheduled appointments, prompts should be given by the service to individuals a minimum of 48 hours prior to the scheduled appointment. This not only will give the individual a reminder, but can also decrease wasted appointment time through non-attendance. Text and email support can

be built into the delivery protocol for tips, motivational messages and reminders.

The production of a regular e-newsletter or print newsletter, blogs, and posts on social media can be a significant factor towards support and guidance. This needs to be regular and consistent in terms of content. Good news stories such as service user stories, details on different activities or local talks would all be useful content.

**Group behaviour change sessions** are another delivery option. Group-based behaviour change support has a growing evidence base. It also helps with the sustainability of your service, as less capacity from the MMP is required. These sessions can form the basis of a local programme, with a variety of different topics being covered in each session. Specific training is required to deliver this. However, it is important to also offer some one-to-one time if required.

**Informal support mechanisms can support** formal follow-up. Some ways to provide ongoing support are:

**Informal drop-in sessions** at a café in the local leisure centre, or community venue so people can easily stop by and say hello and discuss any issues or set-backs they may be experiencing.

**Providing an 'open door' policy**, where the individual has access to the MMP's contact details and can access them when they need help. In order to support this process, it is important the service has a policy on the regularity of response to such queries, for example, no more than 72 hours, and that the individuals are made aware of this. This can also be supported by a text or email system for contact and support.



Macmillan @ Glasgow Libraries



### Spotlight on services

**Wandsworth** utilise local library facilities as a non-threatening environment to deliver the initial appointment and follow-up sessions.

Active **Luton** uses a number of methods to provide ongoing support to their service users. Examples include a weekly drop-in session at the local leisure centre, activity support groups and monthly 'mix it up' sports taster sessions. People who have previously benefited from the service buddy up with new participants to offer support.

Active **Manchester** provides ongoing support through a variety of media. This includes a website, social media such as Facebook, and a blog written by the project's ambassador. Marketing materials have also been developed that feature the contact details of project coordinators, which helps participants to access additional support when they need it. The service has also linked to other Macmillan programmes such as support groups, Helping Overcome Problems Effectively (HOPE) courses and gardening groups.

Text message support is working well for the Walking for Health group based out of the Macmillan cancer information and support centre at Wythenshawe hospital. A group has been set up on WhatsApp Messenger that involves members of the group uploading motivational quotes and poems and sharing advice and tips with each other.

### Social events

Services have arranged social events for their service users to aid with the follow-up process, including bowling events, meals and coffee mornings. Services have formed patient information groups and service user forums to help shape the service and follow-up process.

## 13. Case review and exit

It is essential that individuals receive regular reviews throughout the service support period to ensure they are receiving the correct level of support, guidance and information for their needs. Service users are invited to attend these case reviews at six and 12 months after joining the service. These appointments could be delivered face to face or over the phone, depending on the individual's preferences.

The purpose of the case review is to make an assessment of the individual's progress. It would take a motivational-interviewing, person-centred style to assess the individual against longer-terms goals and agree any additional support if needed. If the individual at this time decides to exit the service (at either six or 12 months), they should be given information on the options for reconnecting with the service if needed. The *Move More* practitioner (MMP) should at this point update the case record management system, feed back to the referring agent, and if at 12 months, they should contact the individual's GP (if agreed).

### 13.1 Case management system

A customer relationship management system (CRM) will help to organise and manage service users, and act as a prompt for scheduled appointments and interventions. As ever, an effective system will only be as good as the information input into it and how it is maintained to show accurate information.

An example of a very simple system would be on an Excel spreadsheet to flag appointments. There are many sophisticated CRM IT packages many of which are commonly used by leisure organisations and the NHS.

Case notes from each intervention (whether that be over the phone, a text sent or a face-to-face appointment) could be recorded on the system, so an evidence trail can be created for each service user. This is particularly important should a *Move More* Practitioner leave the service to ensure continuity for their replacement and the service users.

## 14. Ongoing management

### 14.1 Quality assurance

Quality assurance needs to happen throughout the intervention, with a plan from the start.

Macmillan has a national quality standard in development that can be used for this process. Discuss this with your Macmillan geographic lead.

### 14.2 Data collection

In order to review quality of delivery, assess it against local key performance indicators, develop a business case for funders, and review individual progression using a standardised data set wherever possible (as recommended by NICE ). This is usually best collected at baseline, then at three, six and 12 months.

To support this, Macmillan, along with experts in the field of physical activity, cancer and behaviour change, developed the Cancer and Physical Activity Standard Evaluation Framework (CaPASEF) in January 2013. This framework was developed with the evaluation of local services in mind. This was based on the learning from Public Health England's physical activity standard evaluation framework<sup>1</sup> and uses validated measures. Local services are encouraged to use this framework to evaluate the outcomes and impact of their services.

These measures include prior levels of physical activity, current levels of physical activity, self-efficacy, fatigue, wellbeing, and demographic data. In addition to measuring change, these can also be used to assess need and tailor interventions for the individual.

All measures within this survey are validated for self-completion. Some measures require a license, which is covered when working in partnership with Macmillan.

The data set has been developed into a Macmillan branded questionnaire, and is available both in paper and electronic format (currently through the Views system).

Macmillan's preferred method of data collection requests that it is kept separate from the behaviour change and support interventions.

A video has been developed to explain the questionnaire to service users who are part of a site run in partnership with Macmillan. Available here: [youtube.com/watch?v=bVlymnejl60&sns=fb](https://www.youtube.com/watch?v=bVlymnejl60&sns=fb)

It is important to discuss with potential funders and local stakeholders whether there are any specific additional measures they want to be included.

Macmillan's evaluation demonstrates that data collection can be onerous and that it is important to set this up as a separate system from the behaviour change support. To prevent confusion between the collection of data with the delivery of behaviour change support, additional capacity may be needed. Anyone involved in data collection will need training.

All services funded by Macmillan are required to collect this information from their service users, so it is important that capacity for this is built into the funding agreement.

<sup>1</sup> [www.gov.uk/government/publications/health-matters-getting-every-adult-active-every-day/health-matters-getting-every-adult-active-every-day](http://www.gov.uk/government/publications/health-matters-getting-every-adult-active-every-day/health-matters-getting-every-adult-active-every-day)



### Spotlight on collecting follow-up data

The Velindre service developed a tracking spreadsheet for collecting follow-up data. This system alerts project coordinators when follow-up calls and appointments are due for each individual participant, and states what support needs are to be provided. Categories that feature on the spreadsheet include reason for drop-off and information provided in the three, six and 12-month follow-up questionnaires

### Collecting data

If you are using an electronic system, it is important this looks the same as the paper version of the questionnaire, as different 'looks' can affect the way service users complete the information. It is particularly important the questions remain in the same order.

Macmillan's recommended data collection protocol is outlined below:

1. Service user receives questionnaire and is asked to complete prior to initial behaviour change intervention (either by post, email or in person prior to their initial session).
2. Service user returns questionnaire and attends initial behaviour change intervention. At this point the individual leading the session can discuss any missing data or go through any of the questions a service user has on particular sections of the questionnaire. The answers can be used to understand prior and current levels of physical activity, and to assess need, self-efficacy, fatigue, and wellbeing.
3. If this initial behaviour change intervention is over the phone, the individual leading the intervention must ensure the service user has received the questionnaire in advance.

4. Where responses to some of the questions may help discussion, such as assessing need, it is important that time spent on data collection should not replace a behaviour change intervention with the individual.
5. The measures used are all validated for self-completion. Where participants need support in completing the questionnaire, try to avoid introducing any bias into the process. This might be through helping someone with their answer, or 'rounding up' responses, for example, time spent being active.
6. If the service user has complex literacy needs, it is recommended that someone supports them to complete the questionnaire. Again, to avoid introducing bias into the process, each question should be read out clearly and as stated with the answer coming from the user.
7. These steps should also be used when collecting follow-up data at three, six and 12 months.

### Timing for collecting data

Completing the questionnaire takes approximately 30 minutes. It is useful to inform the service user of this when first inviting them to the service.

### Recording data

It's important to establish a local data collection method for a service so you can record information key monitoring data on each of your participants. Local organisations use different solutions such as simple Excel spreadsheets, which may be preferable for an area to use.

If you are working with Macmillan, you may be asked to use a specific data collection package. Currently, Macmillan is using the Views system, from an organisation called Substance. Views is a flexible user-friendly online monitoring, evaluation and impact reporting platform, which we have developed for services to collect and store the information required by the Cancer and Physical Activity Standard Evaluation Framework. By using Views, services can also benefit by:

- recording information about the people living with and beyond cancer that you work with
- recording information about the services you deliver

- evaluating the impact of your services
- interrogating statistics to understand the outputs and outcomes your services have achieved.

Views has been designed to make the process of data collection and feedback to

Macmillan a simpler process. Views data is hosted by a UK-based virtual hosting company. The company's data centres are accredited to ISO27001 standards and Information Governance Level 2.

You can access the training at [www.substance.net/video-hub](http://www.substance.net/video-hub)

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### **Coding**

Services should provide a unique ID number for each service user, which remains the same for the duration of their attendance at the service. The Views system provides a unique ID automatically. This is important to ensure that data can remain anonymous, but also supports the monitoring of individuals for tracking progress from baseline through each follow-up.

### **Data protection**

In order to comply with Data Protection legislation, it is important that projects are careful when inputting, sending and storing personal data. It is important to ensure all files and folders containing service user data are password protected. This data should only be accessed by those who need the information in order to run the service. Please ensure you are storing the completed paper questionnaires in a locked drawer. All parties will ensure that data will be kept for no longer than necessary, in line with Data Protection requirements.

Though Macmillan would urge that all services comply with this guidance, the service is ultimately responsible for ensuring

compliance with Data Protection legislation when handling personal data.

If services are working with Macmillan, Project leads should take direct responsibility for ensuring all the data requested is fully anonymised and that this does not include any data which can identify the service user. This should be encrypted and/or password protected before sending it back to Macmillan. The password should be communicated to Macmillan over the phone or in a separate email.

### **Ethical considerations**

Key ethical considerations when collecting data from service users are voluntary participation and informed consent. This means that service users should be informed that it is up to them whether they provide data to the service and, where working in partnership, Macmillan also. They should also be informed that a decision not to provide data doesn't exclude them from taking part in the programme. They can decline to answer any question at any time. It also means they should be told how their data is going to be collected, stored and used by projects before they agree to give

their data. Service users also have the right to request access to their data and to stop providing data at any time.

### **Providing support to service users**

Macmillan has found that service users may ask why certain questions are being asked. It is useful to provide an explanation to the individual as to how this information is being used to support the service more widely and how information is used to support them.

### **14.3 Process evaluation**

While the monitoring data you collect using the standardised questionnaire will give you data on the outcomes you are achieving for people affected by cancer, it is also valuable to conduct a process evaluation. This means investigating how you have implemented your service, the systems you have put in place, the relationships you have built, and working out whether they are the most effective or appropriate ways of working to achieve your goals.

Thinking about your key successes and lessons learned will help you deliver more effectively in the future. If you choose to do this, it will be important to engage the key people involved in the delivery and oversight of the project to make sure all viewpoints and parts of the process are included. You may also want to consult people affected by cancer who are taking part in the programme to see what they thought worked and what didn't.

Qualitative work can help you develop case studies of participants' experiences to share with potential funders and other stakeholders. Other external agencies such as local authorities and clinical commissioning groups may also be worth including to understand broader perceptions of your project and put it into context.



### **Spotlight on capturing participant progress**

There are other novel ways of collecting data on outcomes which capture details about the individuals taking part, their goals and achievements. The Lincolnshire service is using video blogging where participants record their own progress through a webcam. These videos provide an impactful piece of evidence of who a service is reaching and how the service is making a difference to their lives.

From the outset of a service, it's important to factor in time and resources to support an effective evaluation, whether you are conducting it yourselves or contracting this out to a local university, research company or independent researcher. It is possible to carry out a robust local evaluation using resources within your own team, if you have the resources available to devote to this, although an independent evaluation is more credible with external agencies.

Whichever route you choose to go down, you will need to plan for evaluation as close as possible to the start of your project and allow for enough time to meet outcomes before the end of the evaluation. Possible suppliers could include local universities, small research agencies and independent (freelance) researchers.



### Top 10 tips for starting your local evaluation

1. Consider whether you want to do the evaluation in-house (self-evaluation) or whether you'd rather have an independent observer do this for you. Possible ways of getting an independent evaluation for a limited budget could include contacting your local university's public health or sport science department, and offering the project to a fellow or student as a dissertation.
2. If you are happy to do your own evaluation, consider getting some training. Macmillan have an online course on the basics of evaluation on their LearnZone site <http://learnzone.org.uk/courses/course.php?id=229>. It's important to be realistic in terms of how much time you can spend on the evaluation and what you can realistically hope to measure.
3. Consider using a logic model to map out how and why your project will make a difference, what activities need to happen to achieve this, and what the short and long-term outcomes you want to see for people with cancer will be. It can help you be clear about what you need to set about evaluating.
4. Come up with a set of indicators – things that can be measured to show that you are doing what you said you would do and whether or not your project is achieving its aims. You may want to establish your measures in conjunction with stakeholders such as your local Clinical Commissioning Group (CCG) so that you can provide the evidence they want to see before they consider funding or supporting your project in the future.
5. Decide what methods you want to use in your evaluation. Remember that qualitative data can be as useful as quantitative data; where a survey can tell you how many people changed their physical activity levels, an in-depth interview can tell you about why that has happened for an individual. If it's more about idea generation, convene a focus group.
6. You can use the monitoring data that you submit to Macmillan to measure changes in activity levels and quality-of-life scores by comparing scores over a period of time for each individual participant. But be careful who you share this data with and how securely you store it. If there is personal data in the file, for example, names, postcode or date of birth, it comes under the Data Protection Act 1998.
7. If you have contracted out the evaluation, then the supplier will have their own data protection and ethical protocols that they will follow. Non-academic consultancies will most likely follow either the Market Research Society (MRS) Code of Conduct,<sup>114</sup> the Social Research Association (SRA) ethical guidelines,<sup>115</sup> or they may well have their own internal processes. Academic institutions will have their own ethical processes that they will have to adhere to. These are likely to involve, depending on the nature of the research or evaluation, putting research tools through ethical approval, which can be a lengthier process. It is important in all cases to be clear about which data protection and ethical process suppliers are following and ask them to provide you with their policies and guidelines. These may include guidelines of how to transfer personal data between themselves and you.
8. If you are undertaking a self-evaluation, then you will need to research and plan how you intend to carry out an ethically sound piece of work that protects people involved in the evaluation, potential participants and stakeholders, and data that you collect and store in general. For information on data protection and ethics, you should refer to your organisational policies, the MRC and SRA guidance referred to above, or the Information Commissioner's Office<sup>116</sup> (ICO).

## 15. Service sustainability

Commissioning can be described as 'planning with money'. The four nations have devolved how this planning and spending is organised and therefore it is carried out differently in each of the nations.

If you need support in gaining sustainable funding, Macmillan geographic service development teams may be able to help.

As a result of key stakeholders working together at a local level, supported by their local Macmillan service development team, many services now have sustainable funding. In England, for example, this has included a range of funding models including: CCGs funding as part of a long-term condition approach using an integrated health and wellbeing service model; Cancer Alliance funding as an integrated part of the Recovery Package transformation fund bid; and hospital trusts directly funding within the tariff.





### Top tips for engaging with the local decision maker

1. Invite your local decision-maker representatives to your steering group.
2. Ask to present your service to local decision makers. When presenting, bring a healthcare professional and service user with you to advocate on your behalf. Explain to the local decision maker the benefits of your service, including how it can help to improve both clinical and quality-of-life outcomes, meet national policy and local targets, and may save them money. This should be done even when the service is not yet ready to ask for funding, so the local decision makers are aware of it. Your Macmillan service development team will be able to help you with this.
3. Different decision makers have slightly different approaches. Talk with local commissioning or planning managers about what you are aiming to achieve early, to establish when a business case or other documentation is required.
4. Ensure your service is fully embedded within the Recovery Package.
5. Know your costs. Funders are very interested in cost per head or any figure around cost savings. You can use the example costs from the evaluation to support this.
6. Align your service with local decision-maker priorities.
7. Carry out a local evaluation of your service and ensure it meets local decision-maker needs.
8. Create a postcode map of where your service users come from, know who your service users are – their demographics, their level of health inequalities, their type and stage of cancer, and their co-morbidities.
9. Ensure you are clear what you are asking the local decision makers to commit to and for how long. Also ask which Key Performance Indicators (KPIs) are appropriate.
10. There are people within the commissioner organisation as well as other organisations who can assist you in putting together your business case. These people may have access to wider information about commissioning intentions, the local commissioning context, patient and cost data, existing evidence reviews and other projects in which the proposed project, pilot or service change can link into. Building as wide a network of support for your idea as possible can help enhance the likelihood of success.

In England Responsibility for commissioning cancer services is shared across multiple commissioners; CCGs are not solely responsible and accountable for all of the stages of the cancer pathway. All commissioners must therefore collaborate closely to plan across the cancer pathway in order to deliver improved cancer outcomes and experiences.

### **Common challenges in engaging with decision makers**

To aid in your thinking, Macmillan have captured some common challenges that are raised:

- ‘This is not part of our funding or commissioning remit’. The funder or commissioner may not have the commissioning authority and budget for your proposed change. You should establish who the commissioner is early on.
- ‘How does this align with our current priorities?’ Unless it is extremely clear how a business case meets a funder’s or commissioner’s priorities. it is very likely to be rejected.
- ‘This is already paid for within contract’. If your proposed change is operational, funders or commissioners may expect providers to pick up any additional costs. You may need to consider raising the business case with the provider rather than the commissioner.
- ‘What is the business case asking of us?’ Quite often, decisions are not made because the funder or commissioner is unclear about what role they are being asked to play, and what financial commitment they are being asked to make. Using the executive summary to clearly state what commitment is being sought at the beginning helps clarify this.
- ‘This is the first we have heard of the idea – where has it come from?’ If a funder’s or commissioner’s first experience of a proposed change is through a received business case, then quite often it is rejected as they don’t feel they understand enough to make a decision. It is vital that you can gain internal sponsorship for the business case and there is someone from the commissioning organisation that can advocate for the process undertaken to get to the point of producing the business case.

**‘Cancer patients who have increased their physical activity often report feeling more motivated and less tired.’**

Kate Rawlings, Macmillan Berkshire Cancer Rehabilitation Lead

## Case studies

### **Brighton and Hove**

Brighton and Hove CCG commissioned a local charity providing football in the community, Albion in the Community, to pilot a new scheme to support people living with and beyond cancer to access physical activity. In the first five months of the scheme, 118 people had been referred, with 47% of referrals being self-referrals and 45% from a clinical nurse specialist (CNS) or consultant.

The service team have been building a case and delivering presentations to spread activity and support through the city and across Sussex. The service was invited to tender for a three-year project with Brighton and Hove. It has been awarded a three-year contract by Brighton and Hove NHS CCG to continue to coordinate the Brighter Outlook scheme as part of their Recovery Package across Brighton and Hove. This contract commences September 2017.

‘We’ve just been awarded a three-year contract to deliver physical activity as part of the Recovery Package by Brighton and Hove CCG. We had been fortunate to have won some pilot funding from them previously, and from our findings, they decided to scope out a tender. It did take some time to get to the tender stage (18 months) and the bidding process was very intense. KPIs centre around high referral numbers and completion, onward referral and support to, for example, lose weight or stop smoking, and a choice of free-to-access groups that suit the needs of the service users. We also have to deliver training to healthcare professionals on the benefits, and attend protected learning for GPs, practice nurse training, CNS and oncology meetings – to share Macmillan training and some of our findings. Our CCG wants to see the need is there and that we are supporting secondary cancer prevention and linking in well with existing services.’

**Siobhan Meaker, *Move More* Practitioner**

### **Shropshire**

The service was given a strict 15 minutes to present Get Active Feel Good service verbally to their local CCG. This was made possible through a CCG representative for cancer attending the service steering group. The service utilised the Macmillan CCG presentation template as a base and included key quotes from stakeholders and service users. The objectives of the 15-minute presentation were for the potential service funders or local decision makers to be made aware of the programme and how it can contribute to their shared objectives, and to encourage an action to follow up with Get Active Feel Good or include in further discussion. The presentation was very well received, and the group and the chairperson proposed a working group be formed to get into a more detailed conversation about Get Active Feel Good. The CCG were very interested in the evidence and the service was asked to demonstrate the cost savings.

‘Engaging with CCGs in differing financial situations was started through a brief presentation at a joint CCG and Cancer Alliance meeting, after which both CCGs have met with us to discuss future provision. There’s a long way to go and the timescales for CCG decision making has had to be factored into the process.’

**Gareth Mapp, *Move More* coordinator**

### **Luton**

Active Luton has worked with Luton and Dunstable Hospital, the cancer, long-term condition and palliative care leads within Luton CCG, Public Health in the local authority, and the Better Together board. As a result, the *Move More* programme has been included within an integrated wellbeing (healthy lifestyles and Improving Access to Psychological Therapies IAPT) service that Luton CCG and Public Health England are jointly commissioning to start April 2018. Within the specification it states that Active Luton must deliver this programme alongside programmes for other long-term conditions and exercise referral. The model will still have an element of condition-specific activity and specialisms, but it will be opened up to include other long-term conditions, including chronic obstructive pulmonary disease (COPD), cardiovascular illness, neurological conditions and mental health disorders.



# APPENDICES

## Useful tools and resources

### Governance and quality assurance

- [A checklist for services page 110](#)
- [Steering group terms of reference template](#)
- [Referral form example](#)
- [Cancer and Physical Activity Standard Evaluation Framework](#): a validated framework for monitoring and evaluating physical activity services for people living with and beyond cancer

### Workforce

- [Move More practitioner example job description and person specification, see page 111](#)
- [Move More coordinator example job description and person specification see page 111](#)
- [Volunteer role descriptions, see page 111](#)  
[Committee member](#)  
[Buddy](#)  
[Champion](#)
- [Cancer awareness training](#)
- [Understanding physical activity and cancer training](#)

### Physical activities

- [Sport, physical activity and cancer: a toolkit](#) guidance for services setting up or signposting to local physical activity and sporting opportunities as part of the physical activity and behaviour change care pathway.

### Marketing and increasing referrals

- [Marketing top tips](#): best practice for services developing e-newsletters, social media and websites
- [Factsheet on direct mail letter from hospital and GP](#): a step-by-step process on how to work with primary and secondary care to increase uptake of physical activity services. [Letter from hospitals template](#).
- [Feeding back to healthcare professionals](#): examples of feeding back to healthcare professionals on service users progress see [page 120](#)

### Budget

[Costings template](#): a costings template for *Move More* services

### Evidence and insight

- [Physical Activity and Cancer: a concise evidence review](#)
- [Physical Activity and Cancer: the underrated wonder drug](#)
- [What motivates people with cancer to get active](#)
- [Evaluation of Macmillan's Physical Activity Behaviour Change Care Pathway](#)

### Checklists for services

A checklist for the key actions suggested in setting up a *Move More* service as an integrated part of the Recovery Package in cancer care.

1. Work with your identified Macmillan representative to identify the local need for the service and the alignment to the local priorities.
2. Conduct stakeholder analysis to identify key members for steering groups.
3. Arrange an initial scoping or planning meeting with key stakeholders.
4. Develop roles and responsibilities of the steering group, including governance and accountability structures for the project.
5. Investigate the options for sustainability of the service – by who and when will the funding be picked up?
6. Identify and recruit clinical champions for physical activity and cancer for each locality. Begin advocacy work with local health and social care professionals.
7. Identify the best delivery model for your area. Understand and fully align the service with the Macmillan physical activity behaviour change care pathway.
8. Identify the local delivery mechanism for each stage of the pathway, including the need for recruitment of additional workforce where required.
  - a. Integration into Recovery Package.
  - b. Promotion in healthcare and community setting.
  - c. Behaviour change intervention (first appointment).
  - d. Physical activities.
  - e. Ongoing behaviour change support mechanisms including volunteers.
  - f. Data collection.
9. Scope the local opportunities for physical activity and develop relationships with the key providers, identifying any perceived or actual gaps in provision.
10. Assess the local learning and development needs for key staff:
  - a. Those delivering the Recovery Package.
  - b. Those delivering the behaviour change and needs assessment.
  - c. Those delivering physical activity opportunities.
  - d. Volunteers.
  - e. Those delivering data collection and evaluation.
11. Work with Macmillan to register as a Macmillan professional and access training bursaries.
12. Identify mechanisms for access and referral to service; develop simple pathways.
13. Agree a local evaluation brief.
14. Download the Cancer and Physical Activity Standard Evaluation Framework and the physical activity questionnaire pack.
15. Identify key service targets and outcomes, and develop a service plan.
16. Consider the mechanism for collecting and recording data and evaluation.
17. Develop a marketing and communications plan for the service, including branding and the use of existing Macmillan resources.
18. Organise a formal launch event for when the service is up and running.

**Referral form**

**Job descriptions – workforce**

***Move More* Practitioner  
job description**

***Move More* Coordinator  
job description**

**Job descriptions – volunteers**

**Volunteer Committee  
Member role  
description**

**Volunteer buddy role  
description**

**Volunteer physical  
activity champion**

### Terms of Reference

#### **Move More 'Location' Steering Group**

##### Purpose of the Steering Group

The Steering Group exists to oversee, monitor and provide directional guidance on the delivery by 'service provider' and associated partners of the *Move More* Service across 'location/geography'.

##### **Frequency of meetings**

The Steering Group will meet approximately once a quarter for the course of the service.

##### **Membership of Steering Group**

The Steering Group is a multi-professional working group, which will bring together key stakeholders including representatives of the following organisations (identified individuals listed under the organisation):

- 'names of organisations'
- 'names of organisations'
- 'names of organisations'

The group will be chaired by 'name'.

##### **Aims of the Steering Group**

1. To provide strategic and operational expertise in developing and implementing the service model for the 'location' *Move More* Service.
2. Members to act as ambassadors/ champions for the programme.
3. To be a source of guidance, information and support.
4. Oversee and provide directional guidance to the *Move More* coordinator, practitioner and any support staff.
5. Monitor the progress of the service against its goals and review regularly.
6. Build a business case for long-term service delivery and engage with potential funders.

7. Bridge the gap between the programme and wider sector bodies, including providing information on any related projects or organisations which may be of interest, and disseminating programme information to relevant parties.

##### **Governance and accountability**

The Steering Committee agenda will be circulated by the chair, with attached meeting papers at least five working days prior to the next scheduled meeting.

Full copies of the Minutes, including attachments, shall be provided to all Steering Committee members no later than seven working days following each meeting.

Members of the Steering Committee should nominate a proxy to attend a meeting if the member is unable to attend, and inform the chair of this in appropriate time.

This group will report to 'funders' quarterly and at each Steering Group meeting.

##### **Quorum**

The meetings will only occur if at least one third of the appointed members are present.

### **Cancer and Physical Activity Standard Evaluation Framework**

Cancer and Physical Activity Standard Evaluation Framework: a validated framework for monitoring and evaluating physical activity services for people living with and beyond cancer.

##### Baseline questionnaire

##### Follow-up questionnaire

### Service costings template

The template below outlines areas where a service is likely to experience cost and can help a service to business plan. [A spreadsheet exists](#) to support this.

Item	Detail	Definition
<b>Overview</b>		
Total project set-up costs		Detail here the overall costs for the set-up phase of the service. They are items that will only be bought or paid for once. Some examples are below in breakdown section.
Total project running costs		Detail here the overall running costs year by year for the service. They should not include the set-up costs. They should include all costs incurred by the project.
Funding breakdown	Partner funding one	Detail all other funding received from grant or funding applications and service commissioners or providers, for example, Public Health, charity, sponsorship. Include who, how much and what it was for (if a specific part of service).
	Partner funding two	
In-kind donations	Detail	Any item that has been given 'in kind', for example, room hire, use of facilities, free session passes, hosting office space.
<b>Set up</b>		
Breakdown of costs (set up)	Training	Detail all training delivered in order to get the service started, for example, Level 4 training for staff, behaviour change training. There may also be an ongoing cost for this, but the bulk is likely to be up front.
	Equipment	Any equipment that has been purchased for use on the project.
	Resources (sustainable)	Include here details for resources that have been purchased as 'one offs' for example pull up banners.
	Launch event	Include the costs associated with a launch event for the project
	Evaluation (first 2–3 years)	Include costs associated with an evaluation of the service in its first 23 years.
	IT system	Include details of any costs associated with IT systems, whether set-up or purchase of IT equipment, production of new websites or digital resources, such as apps.
<b>Delivery</b>		
Breakdown of costs (delivery)	Office and management	Include all associated management costs of the service: management of service-specific posts, office space/hosting location, refreshments, meeting room hire, administration costs.
	Salaries	Include breakdown of all staff associated with project; include detail of the role, banding/grading, hours worked, and cost, for example 'admin, band 3, 0.4 FTE, £7,000'.
	Resources and marketing	Ongoing marketing/communications costs, resources, printing, design that is required each year.
	Training	Any ongoing training required, for example, CPD, additional staff.
	Events	Include support to local events, either hosting or attending, for example, health professional learning events.

Item	Detail	Definition
	Clinical champions	Detail any instances where backfill is paid to one or more clinical champion, including how much will be allocated to this on a yearly basis (if required).
	Physical activity vouchers and incentives	Any costs to the service in providing physical activity taster vouchers to individuals attending the service.
	Physical activity sessions	Include any costs incurred by the organisation of new physical activity sessions (where identified by local need) being introduced, including ongoing costs if required.
	Signposting to other services	Any costs to service when signposting to other physical activity providers. Please do not include training here, include that within the training section.
	Facility and room hire (Behaviour Change Interventions)	Include any facility or room hire required when delivering the behaviour change intervention.
	Cost of behaviour change	For each of the stages of the behaviour change model, include any specific costs associated with each stage. For example, brief advice being delivered by a CNS, support and follow-up being provided by another support service. Please note any crossover of posts included in the 'Salaries' section above.
<b>Volunteering</b>		
	Volunteering hours per year	Detail the total volunteering hours per year (estimated or actual where available).
<b>Participant costs</b>		
Average cost to participant	Behaviour change interventions	Detail any costs associated with the behaviour change stages, for example, refreshments, attendance at local group.
	Physical activity sessions	Any costs associated with attendance at the physical activity opportunities (please provide an average).

### Marketing top tips

#### E-newsletter guidance

E-newsletters can be a great way of keeping people engaged and up to date with your latest news. For people living with cancer, you want to ensure they stay active rather than just signing up for a class. This can help them to do that. For healthcare professionals, you want to keep the idea of referrals to your service fresh in their minds.

We have put together some top tips for how to increase subscribers and the type of stories you might want to include. This guidance will vary slightly depending on whether the e-newsletter is for healthcare professionals or people living with cancer. Some elements will not vary by audience, so here are some general top tips for all of your e-newsletters:

#### Setting up your e-newsletter

Use an email marketing system for your e-newsletter rather than sending it from Outlook. This will make sure you have a good design, that your email looks right in different systems, for example, Gmail and Yahoo Mail, and that it's easier to manage your subscribers. Mailchimp has a free option for up to 2,000 subscribers. Visit [mailchimp.com](https://mailchimp.com)

#### Sending your e-newsletter

Send your e-newsletter out to subscribers about once a month. This gives you a chance to keep people engaged without annoying them by emailing too often.

#### Content for your e-newsletter

Include between three and five main stories in each e-newsletter. If you have more stories than that, include the least important ones as one-line links at the bottom.

Always try to include a photo with each of your main stories. Photos help people to engage with your content. If you are working with Macmillan, you will be able to use professional photos of people living with cancer getting active. Contact your Macmillan communications lead.

To use hyperlinks in your e-newsletter, select the text you'd like to be a link and then click the button that looks like a chain.

Make sure your newsletter has links to your Twitter and Facebook page and contact details, such as a telephone number, website or email address for those that forward your e-newsletter onwards.

If you're struggling to find content, you might find it better to send your e-newsletter less frequently. This will make sure your content is always relevant.

If you are working with Macmillan, it's a good idea to run the draft e-newsletter past your Macmillan regional communications lead. They can provide advice.

#### Monitoring your e-newsletter

Mailchimp and other email marketing systems allow you to see how many people open your emails and how many people click on your links – to give a 'click-through rate' for each link. You should aim to have an open rate of around 30% or higher. If it's below 30%, it's a good idea to review what could work better. For example, you might need to send it less often, include different content or delete subscribers who haven't opened any of your emails. If you're not sure what to change, ask your regional communications lead for support with this. You should also review which content is getting the highest click-through rates, so you can include more of that kind of content in the future.



### Top tips for e-newsletters that vary by audience

#### E-newsletters for people living with cancer: how to get subscribers

Include a tick box for participants to say they'd like to subscribe to your e-newsletter as part of your registration process (both online and any paper-based registration forms). Don't add people who haven't opted in, as this breaches data protection laws. Ensure you have an unsubscribe link in every email.

You should also include an e-newsletter sign-up form on your website. E-newsletter providers such as Mailchimp provide the code for these forms, so whoever manages your website content should be able to easily add it to your webpage.

Try and explain clearly what will be in the e-newsletter, so people understand what they're signing up for.

Stories you might want to include in your e-newsletter to people living with cancer include:

- an upcoming event, for example, taster sessions or talks for people living with cancer
- an update about a new activity session
- an interview or a case study with someone who has participated in your scheme
- an interview with a volunteer involved in your scheme
- how to become a health walk leader
- a survey – Survey Monkey is free for up to 10 questions, which is great for getting feedback.

#### E-newsletters for healthcare professionals: how to get subscribers

When you're meeting healthcare professionals, always take a sign-up sheet asking them for their name, email address, job title and whether they'd like to receive your e-newsletter. Hand this around just before the end of your presentation to encourage people to sign up.

On the sheet, explain clearly what will be in the newsletter, so people understand what they're signing up for. For example:

Sign up for monthly email newsletter. It includes updates on how the service is doing, case studies of people who've become active and how it's benefited them, and tips from other healthcare professionals.

This newsletter should be very short. Healthcare professionals will normally only read something that, if printed, would fit on one side of A4. It will act as a reminder that you're there rather than providing a lot of information.

Stories you might want to include in your e-newsletter to healthcare professionals include:

- interviews with volunteers involved in your scheme
- interviews with participants from your scheme
- interviews with CNSs who refer onto your scheme
- a nurse's pedometer challenge
- news from a conference
- an award your project has won
- an update about new activity sessions
- World Cancer Day and other relevant events
- taster session promotion
- Macmillan mobile information unit visits
- new partnerships, for example, Living Well Active with Amateur Swimming Association.



### Top tips on social media

Social media allows you to communicate quickly and effectively with your local area. If done correctly, supporters will echo your messages and help you be more successful in your goals. It can be a useful tool to offer ongoing support and encouragement, which is essential to establish behaviour change. Remember to allow time for answering any replies that might come about from your posts, for example, questions. As your time is limited, we'd recommend that you focus on Twitter and Facebook, for which we have developed icons for you to use.

### Twitter

If you don't already have an account, you can easily set one up by visiting: [twitter.com](https://twitter.com)

Use @xxxx to send a tweet directly to another user or group. For example, @macmillancancer will send a tweet to all followers of Macmillan Cancer Support. If you don't start with '@', your tweet will be seen by all your followers. Therefore, it's often better to start with another character so that more people can view what you're saying. Including @xxx within the tweet, will ensure that everyone following that address sees the tweet. Each tweet can be up to 140 characters and images or links each take 23 of those 140 characters.

### Hashtags

A hashtag (#) is a way of making a word, phrase or name easily searchable. Those 'trending topics' you see on the side of Twitter are the most popular hashtags being discussed, for example, #CoffeeMorning

Hashtags can be used for local areas too, so something like 'Our Macmillan information bus is coming to #Grimsby' can be a great way to update people in a given area. If you're running a big event or campaign, you can create your own hashtag.

Here are some tips to get you started:

Post once or twice a week on both your Twitter and Facebook accounts depending on the setting.

Think about your audience and objectives – don't post for the sake of it.

Plan ahead and think about the general messages you want to convey each week.

Focus on content that you think others will want to share. This could include:

- case studies
- photos
- a call to action (what you want others to do, such as visit a website and register)
- events
- tweeting a link to an e-newsletter.

Ask your followers what other kind of content they'd like to see.

If you attend conferences, tweet while you're there and use the conference hashtag – this is a good way to get new followers.

To save time, schedule Tweets and Facebook posts once a week using a programme like TweetDeck or Hootsuite.

Post content at times of day that will reach most people using your service.

Add photos to your Tweets and Facebook posts. Anything with a photo tends to get about three times as much engagement. These should be landscape (not portrait) so they are compatible with all formats; if viewed on mobiles, portrait photos will be significantly cropped, which could drastically change what is seen.

Ask participants to share information about your service with their friends on Facebook.

Ask participants to add their own content to your Facebook page to help to drive user-generated content.

Ask current participants to comment on your posts and status updates.

Tag people in photos on Facebook (if they're happy for you to do so).

Make a list of local organisations who have big followings, then follow them. Examples include local papers, radio stations, hospitals, CCGs, doctors, local celebrities, charities, Macmillan, local BBC, Women's Institute, the local council and sports teams.

Conduct a search with key words, for example 'Macmillan Luton' and 'cancer Luton', to see which other organisations are working in this field in your local area.

Ask those organisations or people with big followings to retweet and share your posts. On Twitter, you can do this by tweeting them.

Examples of other projects' social media accounts:

### Twitter

[twitter.com/active\\_everyday](https://twitter.com/active_everyday)  
[twitter.com/gafglincs](https://twitter.com/gafglincs)  
[twitter.com/movemoreabdn](https://twitter.com/movemoreabdn)

### Facebook

[www.facebook.com/pages/Macmillan-Active-Manchester/553964061393215](https://www.facebook.com/pages/Macmillan-Active-Manchester/553964061393215)

### Website guidance

Here are some top tips to help you develop a website that not only looks good, but functions effectively and is easy to use. If you are developing a new website, you should look at the Disability Discrimination Act (DDA), which aims to ensure websites are accessible to blind and disabled users.

#### Text

Explain your offer so that people know what they will get if they sign up – for example, you might offer a 'first session free' voucher. Include a clear list of activities that are available through your service, so that people can see if there's an activity that's right for them.

Include a clear list of activities that are available through your service, so that people can see if there's an activity that's right for them.

#### Search engine optimisation

The idea of SEO (search engine optimisation) is to make sure that when someone searches something relevant, your site will be high on the list of search results. This depends on how frequently that term is used within the text of your site, but also on how well your site is built and whether other sites link to yours. Therefore, you should include phrases that people search for online, such as cancer or the name of your service, within the text on your page. Then your website will appear higher up in the search engine rankings. It's also important to include a link to your site on other relevant sites, where possible, as this will drive traffic and increase your rankings within searches.

#### Call to action

A call to action is what you're asking people to do, for example, 'sign up now' or 'register now'. You should have a single focus, but include the two call-to-actions at least twice on the page – once towards the top of the page and once at the bottom. This should stand out from the rest of the text. Using a bright secondary colour on a link to an online self-referral form, for example, will ensure it stands out.

The self-referral form should only ask for minimal details: name, phone number, address and email address. By keeping the fields to a minimum, you increase the conversion rate (the percentage of people who complete the form) and you can collect the rest of the information later on.

Also include your service's phone number and email address, so if someone wants to ask any questions before they register, they can get in touch.

#### Photography

If you only have one page, stick to silhouettes of shoes or trainers. If you have a longer page with more information, include multiple photos of people from different ages, genders and ethnicities doing different types of activities.

Other content to include:

- Links to stories from participants – videos or written ones.
- Quotes from health and social care professionals.
- Links to your Twitter, Facebook and e-newsletter sign up pages. This gives people a way to follow you without signing up now.
- Links to relevant websites, such as Macmillan's physical activity pages.

#### Promotion

Ask other local websites to link to your service's new site. This will help in two ways. Firstly, it will drive traffic directly. And secondly, getting links from other websites will make your site appear higher in Google's rankings – so you'll get more traffic from online searches.

**Feeding back to healthcare professionals**

**Example**

# FEEDBACK TO HEALTHCARE PROFESSIONALS

<b>Name</b>	<b>Start date</b>	<b>Progress made to date</b>
Mrs B	1.12.14	Is attending the gym regularly and is planning on doing the race for life in July.
Mrs C	17.12.14	Is attending the gym once a week and is building up her fitness.
	30.1.15	Has had to stop due to an eye operation but is keen to start again once she has recovered.
	Feb	Is attending our cardiac rehab sessions once a week.
		Left message.
	April	Swimming three times a week and attending a studio session. Had a break for Ramadan.

## Glossary

### **Cancer survivorship**

Having no signs of cancer after finishing treatment.

### **Clinical nurse specialists**

Registered nurses who are clinical experts in nursing practice within a specialty area.

### **Co-morbidities**

Diseases or disorders co-occurring with cancer (eg diabetes or heart disease).

### **County Sport Partnerships:**

CSPs are regionally-based, strategic sports and physical activity organizations, in England. Typically these do not directly deliver physical activity opportunities, instead working to support partners in the type and quality of service provision across the geography.

### **Cardiorespiratory fitness**

The ability of the heart and lungs to supply oxygen to skeletal muscles during sustained physical activity. Also known as cardiovascular fitness, aerobic capacity, or exercise tolerance.

### **Exercise**

A form of physical activity that represents planned, repetitive training performed with a specific purpose such as maintaining or improving physical fitness or health.

### **EQ5D**

A standardized questionnaire used to measure health outcomes.

### **FACIT (Functional Assessment of Chronic Illness Therapy)**

A set of standardised questionnaires used to measure aspects of quality of life such as Physical Well-Being, Social/Family Well-Being, Emotional Well-Being, and Functional Well-Being.

### **Holistic needs assessment**

An assessment of a patient's needs, including issues such as: physical concerns; practical concerns; family/relationship concerns; emotional concerns; and lifestyle or information needs.

### **Move more coordinator**

The individual is responsible for the strategic direction of the service and smooth running of the day-to-day operations of the *Move More Service*.

### **Motivational interviewing**

A counselling method based on facilitating and engaging intrinsic motivation within the client in order to change behaviour

### **Palliative care**

Care for the terminally ill and their families,

### **Physical activity**

Any volitional movement of skeletal muscle that results in energy expenditure. Physical activity is therefore a broad term that encompasses general activities of daily living and active transport, as well as planned participation in exercise or sport.

### **PLWC**

Person living with and beyond cancer, someone who has had at some stage in their life a diagnosis of cancer.

### **PABC**

A person affected by cancer, someone who's friend or family member has had cancer and this has had a significant impact on their life.

### **QALY**

Quality Adjusted Life Year; a generic measure of disease burden, used in economic evaluation, including both the quality and the quantity of life lived.

### **Recovery package**

A package of interventions (holistic needs assessment and care plan; treatment summary; cancer care review, and health and wellbeing event) recommended by the NHS for all cancer patients.

### **SPAQ**

Scottish Physical Activity Questionnaire.

### **Teachable moment**

A time when an individual is more inclined to change their behaviour.

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- 114. Market Research Society (MRS)  
*Code of Conduct*
- 115. Social Research Association (SRA)  
*Ethical guidelines*
- 116. Information Commissioners Office  
(ICO)

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