

HOW TO RUN A PHYSICAL ACTIVITY PROJECT

WE ARE
MACMILLAN.
CANCER SUPPORT



Your step by step guide to developing a physical activity behaviour change service for people living with and beyond cancer



How physical activity can help people living with and beyond cancer	4
Reaching our physical activity ambition	6
Macmillan and physical activity	8
Macmillan's behaviour change care pathway in detail	14
Monitoring and evaluation	24
Before you start	28
Delivering and monitoring projects	34
Keeping in touch	38
References	39



If you're planning on starting a physical activity service for people living with and beyond cancer or you need more support then please contact the Physical Activity team.

[Physicalactivity@macmillan.org.uk](mailto:physicalactivity@macmillan.org.uk)

All our resources are available on the Physical Activity teamspace, please contact **physicalactivity@macmillan.org.uk** to get access.

How physical activity can help people living with and beyond cancer

Thanks to improvements in the detection and treatment of cancer and the support provided by organisations such as Macmillan Cancer Support, almost 4 in 10 people¹ diagnosed with cancer will not die from the illness.

While it's clearly good news that more people are surviving cancer, many patients experience significant physical, emotional and social problems during their treatment and after it has finished.

49% of people with cancer say they experience depression as a result of their diagnosis.²

At least 1 in 4 people living with cancer (around 500,000 people in the UK) face poor health or disability after cancer treatment.³

65% of cancer survivors report that they have to deal with fatigue during and after treatment.⁴

These problems hugely impact the quality of life of people with cancer and

their families, resulting in them needing high levels of support. To help people manage and overcome these problems and reduce the demand on healthcare services, Macmillan has worked with the Department of Health and NHS England to develop the Recovery Package.

The Recovery Package involves a series of key interventions taking place during an individual's cancer journey to identify their concerns and support needs at that time. People are then provided with the appropriate level of support to help them self-manage problems they're facing and have as normal a lifestyle as possible.

One of the three key elements of this self-management support is helping people to get physically active as part of a healthy lifestyle. This is because as well as reducing the prevalence of cancer,⁵ we are seeing more and more evidence that physical activity can improve clinical outcomes and quality of life during and after cancer treatment.⁵

In addition, we are also beginning to understand what effective physical activity interventions⁶ for people living

with and beyond cancer should involve: there is evidence that people living with and beyond cancer want to become more active, if they're given the opportunity to take part in an activity they enjoy and provided with the tailored support they need.⁷ We know that becoming active during and after most cancer treatments is safe⁸ and that the age appropriate guidelines for physical activity and health apply to people affected by cancer.⁹

A healthy lifestyle including physical activity can have the following effects:

- Help to prevent and manage some of the consequences of cancer treatment, including fatigue, depression, bone thinning, muscle wasting, blood clots, erectile dysfunction and heart damage.
- Help to prevent over 20 long-term conditions, including breast and colon cancer, type 2 diabetes and cardiovascular disease. It can also be used as an additional treatment for conditions such as hypertension, depression and chronic obstructive pulmonary disease (COPD).¹⁰
- It can help reduce social isolation and help people return to work, if they want to. 43% of people who give up work or change job as a result of their cancer felt they were not physically able to return to their previous job; but many of them felt they could have returned to work given the right support.¹²
- May help reduce the relative risk of recurrence for some cancers and disease progression for others.¹² This is very important, as one in five women living with and beyond breast cancer will have a recurrence.¹²
- Be effective in improving other conditions, such as cardiovascular disease. The importance of this is highlighted by the fact that 50% of people living with and beyond cancer also have at least one co-morbidity.⁶ The number of people with three or more long-term conditions is predicted to rise from 1.9 million to 2.9 million¹³ by 2018.



Reaching our physical activity ambition

Our ambition is to ensure that everyone living with and beyond cancer is aware of the benefits of physical activity and is enabled to choose to become and stay active at a level that's right for them.

To achieve this, we must change behaviour on an individual and national level. We will do this by increasing the awareness of the benefits of physical activity among people living with and beyond cancer and those with greatest influence on them, such as carers and healthcare professionals.

We're also working in partnership with service development teams to test the scalability of a proven model of intervention based on NICE public health guidance. The approach focuses on enabling and supporting people to make sustained behaviour change. We are testing this through local strategic partnerships between clinical care, public health, local government and local providers of physical activity.

This guide focuses on the development of this intervention at local level. It will support the planning and implementation of services from proposal through to embedded sustainable services. It has been developed for local project leads and potential commissioners of physical activity behaviour change services for people living with or beyond cancer.

It outlines the physical activity behaviour change care pathway approach adopted by Macmillan, including examples of how to set up the care pathway and how the pathway has worked in other sites.

The local health and physical activity landscape should be taken into consideration before embarking on the development process; this guide should be used to inform practice.



Macmillan and physical activity



Physical Activity team

We have a dedicated physical activity team based at our UK office in London. It is responsible for our physical activity strategy and supports the development of physical activity services throughout the UK. There are also a number of roles based within the regions to support physical activity service development. This includes providing tools and resources to support services from the implementation stage to helping them secure long-term funding.

Service development teams

Our regional service development teams have a wealth of experience of developing health and social care services throughout the UK. They are the main link for services, and can help you in many ways, including identifying gaps in service provision; offering advice on the development of new posts, based on their previous experiences; and developing innovative solutions to meet the needs of people affected by cancer.

You can find the contact details of your region's Macmillan service development team at [macmillan.org.uk/service-development-contacts](https://www.macmillan.org.uk/service-development-contacts)

Macmillan Physical Activity Behaviour Change Care Pathway

We have been working in a number of areas across the UK to develop and test an evidence based approach to physical activity behaviour change. This approach was initially based on NHS England's physical activity care pathway Let's Get Moving.¹⁴

Now, this model has been put into the context of the cancer care pathway and adapted and developed by using evidence from our initial test sites and the latest guidance on behaviour change.

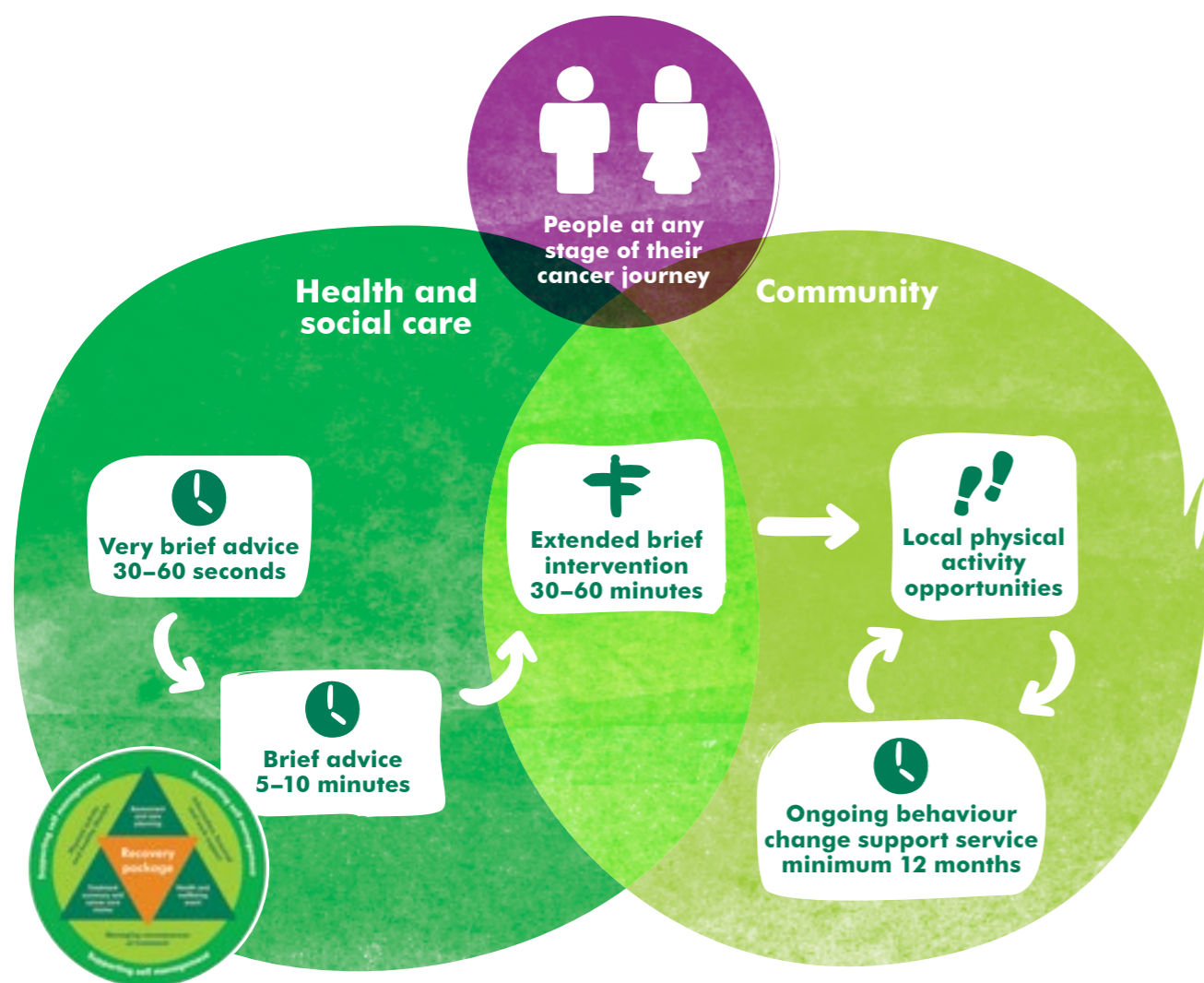
This approach is underpinned by effective partnership working and a clear governance structure. This is led by a project lead and Macmillan development manager, and supported by a local steering group to make sure all the right partners are on board.

The steering group should also hold monitoring, evaluation and quality assurance responsibilities. They should oversee the service and report back to the Macmillan Physical Activity team. Local project evaluations should be implemented using the Macmillan Cancer and Physical Activity Standard Evaluation Framework (CaPASEF).

We know:

- to successfully embed physical activity into cancer care, the Macmillan Physical Activity Behaviour Change Care Pathway needs to be implemented in its entirety
- when recruiting in secondary care, a clinical champion adds strength to the programme by gaining support and referrals from other clinicians
- a full behaviour change intervention is essential; without it an individual is unlikely to increase their physical activity levels in the long term
- appropriate marketing is critical to the uptake of physical activity services
- to gain local support that can secure long-term sustainability, projects need to be monitored and evaluated at a local level using the Macmillan Cancer and Physical Activity Standard Evaluation Framework.

Macmillan Physical Activity Behaviour Change Care Pathway



© Macmillan Cancer Support 2013.
 Permission granted for use as seen, this notice
 must remain intact in all cases. All rights reserved.

Very brief advice: use any appropriate opportunity to introduce the individual to physical activity. This could take just 30 seconds and be delivered by a number of people who have contact with the individual. This should take an 'Ask, Advise, Act' approach.

Brief advice: a 5–10 minutes intervention to explain the importance of physical activity and what support is on offer. If the person is interested in getting active, they can be referred for a longer behaviour change intervention. Alternatively, they can be provided with information on local services. This could be offered in secondary care, primary care, cancer support groups, as part of a health and wellbeing clinic or in an information centre.

Extended brief intervention: a 30–60 minutes person-centred behaviour change intervention. The practitioner assesses the individual's needs, discusses the individual's motivations and barriers to taking part in physical activity, supports them to set achievable goals, and then supports them to decide how they will get active through an activity they enjoy (eg joining a walking group or sports club, exercising at home using Macmillan's exercise to music DVD, or exercise on referral).

Get and stay active, accessing local physical activities: it is important to offer a menu of activities across the local area. If necessary, additional activities may have to be provided to help people become and stay active.

Long-term behaviour change support and follow-up: over a minimum period of 12 months, provide tailored support and encouragement at regular intervals that's appropriate for an individual. At each follow-up appointment re-evaluate goals and review progress.



Checklist for services

1. Contact Macmillan
 - a. Identify your local Macmillan development manager who will work with you to identify the local need for the service and the alignment to the local priorities.
 - b. Contact the Physical Activity team in Macmillan UK office
 - c. Book to attend the next knowledge exchange workshop
2. Conduct stakeholder analysis to identify key members for steering groups
3. Arrange an initial scoping/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/recruit clinical champions for physical activity and cancer for each locality, begin advocacy work with local health and social care professionals
7. 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. Very brief advice
 - b. Brief advice
 - c. Extended brief intervention
 - d. Support and follow up
9. Scope the local opportunities for physical activity, develop relationships with the key providers, identifying any perceived/actual gaps in provision
10. Assess the local learning and development needs for key staff
 - a. Those delivering the very brief advice/brief advice
 - b. Those delivering the extended brief intervention
 - c. Those delivering physical activity opportunities locally
 - d. Those delivering support and follow up to individuals
11. Work with your Macmillan development manager to register as a Macmillan professional and access training bursaries
12. Identify mechanisms for access/referral to service, develop simple pathways
13. Agree a local evaluation brief
14. Download the *Cancer and physical activity standard evaluation framework* and *Physical activity questionnaire pack*
15. Identify key service targets and outcomes and develop a service plan
16. Consider mechanism for collecting and recording data and evaluation
17. Develop a marketing and communications plan for the service, including branding and use of existing Macmillan resources
18. Organise a formal launch event for when the service is up and running.



Macmillan Physical Activity Behaviour Change Care Pathway – in detail

Very brief advice

The first step in the physical activity behaviour change pathway is very brief advice (also known as raising awareness). This stage is the introduction to the benefits of physical activity. It often only takes 30 seconds and adopts a 'making every contact count' approach. This involves everyone who has an opportunity to raise the issue of physical activity doing so in a patient centred way.

Very brief advice can be delivered by health or allied healthcare professionals, or during a health and wellbeing event. The professional asks if the individual is aware of the benefits

of physical activity and if they can share this information; advises that physical activity can benefit people living with and beyond cancer in many ways and that by accessing support they are more likely to improve their physical activity at a level that is right for them; signposts to more help and support.

Evidence demonstrates that it's appropriate to promote physical activity at all stages of cancer care from diagnosis onwards. This highlights the importance of involving a range of health and social care professionals in this early part of the pathway and throughout it.



A spotlight on... physical activity clinical champions

The lead Macmillan nurse and Macmillan urology cancer clinical nurse specialist (CNS) are the physical activity champions for the Luton physical activity service. They attend quarterly Move More Luton steering group meetings and make sure that physical activity referrals feature in the monthly CNS meetings and newsletter. They also promote a message to all healthcare professionals that physical activity is a free prescription and should be embraced.

Good relationships have been built with CNSs because of the holistic needs assessment (HNA) crossover. During an HNA with a patient a CNS will raise the importance of being active and signpost them to Active Luton. The referral is then faxed promptly through.

The Active Luton service is also 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 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 healthcare 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 Level 4 practitioners providing a monthly update to CNSs about the patients they have referred in to the service. This helps to encourage them to refer more patients into the programme.

Brief advice

Brief advice may happen as an extension of the first stage, as the same person often delivers very brief advice and brief advice. It lasts between 5–10 minutes and 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/treatment). At the point at which physical activity is raised (very brief advice), an individual may often be referred/signposted to a longer intervention where brief advice is also covered.

A spotlight on... group support

Dorset Living Well Active offers brief advice sessions to local people via free, friendly and informative evenings. These involve 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 explain what the Dorset Living Well Active service offers to help people get going, keep going and get results. Plus, people who sign up to the project receive a Macmillan Move More pack, which is filled with advice, tips and a goal setting diary to help them on their way.

Extended brief intervention (behaviour change support)

The extended brief intervention builds on the previous stages by sharing what other patients have achieved through physical activity and highlighting the information, opportunities and support that are available locally. It can last between 30–60 minutes and uses behaviour change techniques such as motivational interviewing, in a guiding style. We have conducted research to find out what messages appeal to people about getting active. It revealed that most people want personalised and tailored support, which this intervention can provide.



Adopting a person centred approach, the person delivering the intervention can use the Move More pack to guide an individual through the behaviour change process. Possible futures should be explored, such as what life would be like if the individual changed their

behaviour, how confident they feel about changing and what importance they attach to change. This intervention should be used as an opportunity to set personal goals and plan support, including what needs to happen if setbacks occur.

A spotlight on... offering extended brief interventions

Get Active Feel Good Shropshire follows the Macmillan patient led behaviour change model. The Move More pack supports the practitioner in having difficult conversations and finding out what's right for the individual.

require very little support, if the support given initially was enough for them at that stage. The commitment may be all that they can manage, or they may have been signposted to a local service where further support was given.

Not all patients require additional continued support, so an agreed method of follow-up is sought. Some individuals

Patients value the Move More pack to guide the conversation, set their goals and complete the diary.

At this point the individual should be supported to identify an activity they enjoy and which they can do at an intensity that is right for them. Together, the professional can help the individual make a plan of what they could try and how to overcome any barriers they may face.

may be required, such as motivational interviewing skills.

It is important to note that the individual delivering the intervention does not need to be a health professional, but that the person's skills should be considered, as additional behaviour change skills



A spotlight on... providing telephone support

Following an identification of need for advice and support to help someone affected by cancer to become more physically active, a referral is sent to Move More Aberdeen (either by a health professional or self-referral). Once the referral is received a telephone consultation is carried out by one of the team, (both of whom have received NHS Scotland 'Level 2 Health Behaviour Change' training). This includes questions about the person's cancer diagnosis, treatment and side-effects, a discussion about the person's previous levels of physical activity and what they are managing to do now. It also looks at the person's desires and motivations to get more active, including their physical activity preferences and goals. Barriers are identified and potential solutions discussed. All of this information is used to develop a jointly agreed activity plan developed in collaboration between the Move More Aberdeen staff and the participant.

To help you or other professionals carry out successful extended brief interventions, you may find it beneficial to order the following Macmillan resources from be.macmillan.org.uk:

- *What to do after cancer treatment ends: Ten top tips booklet (MAC13615)*
- *Move More pack (MAC13314)*
- *Get Active Feel Good DVD (MAC14016)*, which includes exercises specifically for cancer survivors.

Accessing local physical activities

It's important that people living with and beyond cancer can choose an activity they want to do and participate in it at an intensity that's right for them. Because of this, projects should offer individuals a menu of activities to choose from.

From research we've carried out, we know that people prefer a mix of activities on this menu: some that are available to the general population in the local community and other activities that are just for people who have been diagnosed with cancer or another long-term condition.

It is also important to engage with local physical activity providers in your area to increase awareness of your physical activity service and work with them so they feel confident about offering their activities to people living with or beyond cancer.

This work may involve identifying the training needs of local providers and helping them access relevant courses, for example, a cancer awareness programme which increases their understanding of people living with and beyond cancer and makes them feel more confident about working with them.

It may also be useful to deliver more specific cancer rehabilitation training (level 4 accredited) to provide local physical activity providers with the knowledge and skills to provide classes

and support specifically for people living with and beyond cancer.

Hints and tips...

As well as providing Level 4 cancer rehabilitation training for leisure centre based instructors, it can be useful to provide cancer awareness training to associate activity providers and leaders, such as walking and cycling group leaders. This training can help them become more understanding, mindful and considerate of members of their group who are living with and beyond cancer, and feel confident about directing them to other sources of support.

One way of providing this training is by asking associated activity providers and leaders to complete Macmillan's e-learning course for Volunteers – *Understanding cancer and survivorship*. This could then be followed up with a group meeting of local activity providers to explore what they learnt from the course in relation to their activity, in order to learn about the wide range of support Macmillan can provide to people who participate in their activity and answer any questions they may have.

The type of activities that should be offered to people living with and beyond cancer should be varied. Many of which will already be available locally.

It is important to note that where identified as a need in a local area, some cancer-specific activities may be added to the menu on offer. It is recommended that the following should be included within the offer of activities:

- Walking
- 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 or local sports clubs
- Exercise on referral where available, including condition specific (eg cancer, falls prevention, cardiac rehabilitation)
- Everyday activity – encouraging people to build activity into their daily lives
- Self-directed activity such as the Macmillan home exercise DVD

A spotlight on... establishing a local offer of physical activity

Dorset Living Well Active has developed working relationships at a local level with Walking for Health, Nordic Walking UK, British Cycling, England Athletics, and EMD (Exercise, Music and Dance). 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. In addition, Dorset

Living Well Active is working with Active Dorset County Sports Partnership (AD) to increase the number of community sports it offers on its menu of activities. AD aims to add four new sports to the menu every three months and work, when possible, with the appropriate national governing bodies. All the new sports are promoted on Dorset Living Well Active's website.

A spotlight on... walking

The Get Active, Feel Good service in Shropshire linked with two of their local health walk groups. The relationship has grown from a simple email exchange between the service and the schemes, exploring the opportunity to offer walks as part of the project's patient led behaviour change programme. Linking with Walking for

Health (the health walks programme in England) has provided a great signposting option to patients coming through the project who are interested in getting active through walking. The walks range from under 30 minutes up to 90 minutes and the service supports patients to set goals to work up to longer walks.

Ongoing behaviour change support

It's essential to provide regular ongoing support to people to help them stay active for a minimum of 12 months. This support should be provided in the same way the extended brief intervention (behaviour change support) is delivered.

During the extended brief intervention, it is useful to agree when follow-up support will be delivered and how, such as over the phone, face-to-face or by email. Follow-up support is only likely to take 5–10 minutes rather than the 30–60 minutes for an extended brief intervention. The level and type

of support required will depend on the individual and their needs at that time.

Importantly, ongoing support will provide an opportunity to plan for setbacks and increase the confidence of a person living with and beyond cancer to come back for support, if they need it.

Some ways to provide ongoing support are:

- group drop-in sessions
- drop-in sessions at a café in a leisure centre, so people can easily stop by and say hello
- providing a project coordinator's contact details so people can contact them if they need help
- producing an e-newsletter or print newsletter that is sent to participants on a regular basis
- providing updates and support via text messages or email.

A spotlight on... providing ongoing support

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.

A spotlight on... text message support

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 *What's App* group has been set up that involves members of the group uploading

motivational quotes and poems and sharing advice and tips with each other. A short questionnaire on the walks provided has also been sent out via text, and information on training for walk leaders and upcoming events is shared in the same way.

It's important to record certain baseline information collected on the individual again at three, six and 12 months, to support the local evaluation of a service. These data collection points can be used as part of support offered to the individual, but it is important not to use the time solely on measurements.

It's also essential to have a system in place that can track an individual's progress, flagging when follow-up data is required.

A spotlight on... collecting follow-up data

The Berkshire physical activity project developed a tracking spreadsheet for collecting follow-up data. This system alerts project coordinators and leaders when follow-up calls and appointments are due for each individual participant

and states what support needs to be provided. Categories that feature on the spreadsheet include exit dates, number of sessions attended and information provided in three, six and 12-month follow-up questionnaires.



Monitoring and evaluation

There is increasing interest in promoting physical activity to people living with and beyond cancer. This builds on evidence that physical activity can help to improve physical function and maintain independence and wellbeing.

However, we must improve the evidence base for the effectiveness of such interventions. It is important that we learn from the experiences of projects and interventions that are taking place in health and community settings. These services need to be carefully evaluated to make sure they are reaching their objectives, and to increase our understanding of what works.

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 also important to discuss with potential funders and local stakeholders whether there are any specific measures they want to be included in an evaluation, or if they need to see certain outcomes from a service. More information on how to develop local evaluations is available in our library of fact sheets.

Many past evaluations have used a variety of outcome measures and recorded data at different stages of a service. This has made it difficult to draw overall conclusions and compare

different approaches to providing physical activity opportunities.

This is why we have worked with a wide range of stakeholders, including cancer experts, academics, project managers and cancer survivors, to develop a standard evaluation framework to help local services evaluate their offering. We now require all physical activity services to use the Macmillan Cancer and Physical Activity Standard Evaluation Framework (CaPASEF) to collect the minimum data it outlines.

Macmillan Cancer and Physical Activity Standard Evaluation Framework

This framework standardises the evaluations of physical activity services by establishing a core set of outcome measures across all the Macmillan funded services. These should be measured at the outset of an individual's participation in the project and then at 3, 6 and 12 months after this.

We selected questions and scales that are well validated (approved by research experts) for self-completion

and easy to use in a practical setting. Full details of the selection criteria for the outcome measures and the process used to develop the CaPASEF are available from Macmillan's Evidence team: evaluation@macmillan.org.uk Following your use of the CaPASEF, headline data should be reported locally and to Macmillan's Physical Activity team on a quarterly basis. You can contact the team for the reporting schedule.

How using the CaPASEF benefits your project

- Allows you to closely monitor outcomes and make timely improvements to your services.
- Helps you to influence the future commissioning and funding

of your service by having data that demonstrates where you are successfully achieving key outcomes.

How using the CaPaSEF supports Macmillan and the wider cancer and physical activity agenda

- Helps to support the development of the evidence base for interventions.
- The regular reporting of headline data to Macmillan helps us to analyse the effectiveness of different approaches across the UK.
- Helps Macmillan to understand the needs of individual projects and the level of support they require.

Top tip

Sometimes people mention that the questionnaires are quite long. However, as they have been developed and validated for self-completion, you might find it helpful to send a questionnaire to an individual before your meeting or ask them to fill it in while they're in the waiting room.

Data collection

It's important to establish a local data collection method for a service so you can record information on each of your participants and key monitoring data (as outlined in the previous section).

Local organisations use different solutions such as simple Excel spreadsheets, which may be preferable for an area to use. As part of our physical activity service

support package, we have developed a central solution (Substance Views) that can be accessed by Macmillan-funded projects where needed.

Substance Views

Macmillan-funded projects can access Substance Views, an online monitoring, evaluation and impact reporting platform. It features four core modules your organisation can use to:

- record information about the people living with and beyond cancer you work with
- record information about the services you deliver
- evaluate the impact of your services
- interrogate statistics to understand the outputs and outcomes your services have achieved.

Substance Views has been designed to make the process of data collection and feedback to Macmillan a simpler process.

Substance 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.

Other ideas for demonstrating and measuring impact

There are also other ways of measuring impact in a more qualitative way. An example of this is outlined in the box entitled 'A spotlight on... capturing participant progress' on page 29, which uses technology. However you could also conduct interviews before, during, and after the intervention with participants about what they hope to achieve and whether they have achieved their goals. Qualitative work can help you develop case studies of participants' experiences to share with potential funders and other stakeholders in the form of poster displays or written format.

Process evaluation

While the monitoring data you collect based on the CaPASEF will give you data on the *outcomes* you are achieving for people affected by cancer, it is also worth conducting process evaluation. This means investigating how you have implemented your service, the systems you have put in place and 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.

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. 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.

Self evaluation or independent evaluation?

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. There are many resources which can help small services conduct self evaluations, some of which we have listed in the fact sheet on our



Teamspace. You may however choose to contract out your evaluation for a range of reasons (see our fact sheet for more detail on the pros and cons of the two approaches). 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.

Before you start

Developing a service steering/advisory group

It's important to engage with key stakeholders during the development stage of a service. This will help to make sure the service meets key local priorities and increase its chances of becoming sustainable. Partners should include:

- potential funders and commissioners, for example, public health organisations, clinical commissioning groups, local commissioning bodies and local health boards
- referrers, for example, clinical nurse specialists, oncologists, local cancer charities and cancer support groups
- people, organisations and services that can promote your service, for example, Macmillan cancer

information and support centres, and council and leisure organisation websites

- activity providers, for example, council sports development teams and leisure providers
- local evaluation organisations, for example, local universities.

Ask to present your service at a potential partner's team or board meeting, enabling you to capture partners collectively. This increases the likelihood of senior level buy in. We have developed presentations for you to use locally, which you can access from our Teamspace. It is also good practice to develop basic information sheets that can be left with potential partners following a meeting.

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 project.

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. A quarterly meeting provides an opportunity to review progress and decide if any improvements need to be made. It's 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 of the terms of reference for a steering group and a detailed suggested membership can

be found on our Teamspace, as well as information on the key stakeholders to engage with.

A 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.

A 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)
- Members of the Macmillan Physical Activity team
- Macmillan information centre managers
- Clinical champions from Wythenshawe and Stockport NHS Trust
- Project ambassador
- Macmillan development manager
- Walking for Health lead
- Sport England regional lead
- Representatives from Manchester Physical Activity Referral Service (PARS)
- Manchester University evaluators
- GreaterSport Manchester County Sports Partnership.

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

Programme governance

It's important to have clear accountability for the service. This includes a service team having responsibility for:

- working with key stakeholders, primary and secondary care, physical activity providers
- working with health care professionals and other professionals to raise awareness of a service and generate referrals
- identifying existing local activities that are suitable for people living with and beyond cancer
- developing additional activities or improving the skills of existing providers so their activities are suitable for people living with or beyond cancer
- delivering or coordinating behaviour change interventions, long-term support and follow-up for individuals
- monitoring and evaluating a physical activity service.
- The size of the geographical area a service covers, for example, county versus town, will impact on what is required from a service team. Some areas employ one person to coordinate a scheme and deliver behaviour change interventions, while in other areas a number of people have different roles as part of a service team.

Physical activity services need an operational lead who is responsible for the day-to-day running of a service, especially if there is no local physical activity behaviour change

care pathway. This person should be responsible for coordinating the distribution and collating of monitoring and evaluation forms, developing local partnerships and, if necessary, organising new physical activities.

Local structures are likely to determine which organisation an operational lead is employed by, with different organisations providing different benefits:

- Leisure trust or provider – supports positive links to local activities.
- Council – provides good links with public health professionals and local leisure providers.
- University – offers helpful links for making sure the project is properly evaluated.
- Hospital – easier to build positive relationships with clinical nurse specialists and other healthcare professionals.

Targeting your participants

Evidence suggests 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.

In some areas, services may choose to target a specific population to make it more inclusive. 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 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.

Applying local physical activity data to the cancer population, we have developed a spreadsheet for calculating the number of people diagnosed with cancer in a service area who want to get active. This is a useful tool when planning your project and can help when targeting specific groups. It's available from the Teamspace.

Promotional materials

Messaging

When asked why they've chosen to get active, people living with and beyond cancer give a range of answers. One of the most common and most powerful is "it helps to manage my cancer." However, our research has shown that when this is used as a message in promotion it receives a negative response. People have told us that they feel like they are being bullied into getting active. For example, when we said that getting active could help reduce the chances of some types of cancer coming back, people said they felt we were saying that if they didn't get active it was their fault if the cancer did come back.

People are also dealing with lots of barriers to becoming active such as aches, pains, fatigue, motivation and concerns about safety. Because of

this, you need to make sure that the messaging for your project is focused on how you can help people to get active and the support available to them. Your messages need to be:

- supportive
- personalised
- empowering (position activity as their choice)
- informative.

The most effective message we have ever tested is to tell people that we can offer a personalised activity routine for cancer patients.

Leaflets

A key promotional material to create for your service is a simple leaflet that gives a quick overview of your programme and the ways people can register their interest in it. Please contact your regional Macmillan communications lead to help you do this. Other services have also found it useful to produce posters and pop-up banners for their service, which are displayed at their local Macmillan cancer information and support centre and in local hospitals.

Launching your project

You may wish to hold a formal public launch for your service. Other physical activity projects have found this a good way to market their 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 at it, 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 with attracting local press and marketplace stalls.

Training needs

It's 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 these needs early on in the project, you will be able to factor in training costs into your budget.

In particular, we have identified some key training that should be made available to individuals who deliver extended brief interventions (behaviour change support):

- behaviour change skills training, for example, motivational interviewing skills
- Level 4 Cancer and Exercise rehabilitation qualification.

You can find out about providers of behaviour change training at motivationalinterviewing.org If your service is providing exercise classes specifically for people living with and beyond cancer, the instructors leading these classes need to take Level 4 Cancer and Exercise Rehabilitation training. The organisations that currently provide this training are:

- Cancer Rehabilitation – www.canrehab.co.uk
- Wright Foundation – www.wrightfoundation.com

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 development manager and Macmillan learning and development leads or email physicalactivity@macmillan.org.uk

Delivering and maintaining projects

Working with health and social care professionals

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:

- the benefits of physical activity for people living with or beyond cancer
- 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.

We have developed a number of tools and resources to support this process. This includes an easy-to-read, 20-page report on the importance of physical activity for cancer survivors. Titled *The importance of physical activity for people living with and beyond cancer - a concise evidence review*, it contains all the information needed to explain why physical activity is good for cancer survivors. You can order copies of the report from be.macmillan.org.uk and

the reference number is MAC13820.

If Level 4 Cancer and Exercise Rehabilitation training is delivered locally, you will be able to demonstrate to health and social care professionals that qualified staff are available to provide specialist physical activity support to people living with and beyond cancer. These trained professionals will also be 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's important to liaise with clinical nurse specialists and other healthcare 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. Consider updating them on your service, the number of people attending it, individual stories and the types of activities on offer.

A spotlight on... engaging professionals

In Berkshire, clinical nurse specialists (CNSs) have been invited to join in with some of the activities offered by the physical activity service. This helps them to understand how safe they are and encourages them to refer patients to it.

In Shropshire, the project has developed a memorandum of understanding (MOU) with the acting CNS lead, the cancer value stream chief and both cancer commissioners from Telford and Shropshire clinical

commissioning groups.

The MOU includes an agreement to pilot physical activity training and resources for healthcare professionals, and for the professionals to work with the project so it meets its targets. CNSs raised particular interest in the consultants using the British Medical Journal's physical activity and cancer online resources, which they felt would help boost referrals.

Cancer support groups

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 direct. 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, often only a few people will sign up to the programme; others may then sign up after hearing feedback about your service.

As well as recruiting individuals through local healthcare professionals and other professionals, it is essential that individuals can self-refer into your physical activity service. However, not everyone who wants to join the programme will feel confident to just turn up.

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.

Getting referrals to the programme

It's useful to consider the variety of ways you can encourage people to get involved with your programme. Over time, you will learn what works best for your service and the local people you're targeting. Both professional and individual led referrals should be considered.

Text number service

You could encourage people to text an existing mobile number or five-digit short code if they're interested in attending your physical activity service. Short codes can be more memorable and are often used in promotional materials. If you wish to set up a short code, speak to your organisation's IT team.

Online form

It may be useful to set up an online form on your service's website that asks for the details of people interested in attending your service. It's best to ask for a minimum amount of information to increase the number of people who fill it in. Therefore, only ask for people's name and phone number or email address and make sure you reply to requests promptly.

To set up an online form, you will need to speak to your organisation's IT team.

Freepost reply form

From experience, we know many older people prefer to get in touch via post rather than phoning, texting or going online. Setting up a freepost address for your service will cost a yearly amount, plus a cost per reply. To do this, you will need to set up a Freepost Standard Handwritten licence. Details of how to do this and the application form is available on the Royal Mail website.

Free introductory session

Research shows that if the first session of physical activity is free, it will increase uptake; but making further sessions free has a negligible effect on participation levels. Therefore, avoid giving people too many free sessions. This will also save you a lot of money in the long run.

Socialising opportunity

Current projects have found that 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.



Keeping in touch

Macmillan's Physical Activity team has developed a number of tools and resources to support your services and steering groups. These will aid development and sustainability.

You can access all of these tools and resources, which include templates and case studies, from from our Teamspace, which is a Macmillan website for us to share documents, encourage discussion and facilitate learning from across the services. Please contact the Physical Activity team at physicalactivity@macmillan.org.uk about this.

Resources for people affected by cancer and professionals

We have developed a number of resources for people affected by cancer, including a Move More behaviour change pack and gentle exercise DVD. Evidence reviews, insight research and fact sheets on specific topics are available for professionals.

Knowledge exchange

Every few months, our Physical Activity team hosts a knowledge exchange workshop in the UK. They give people who are leading physical activity services the opportunity to meet and share

experiences and best practice, and work together to find solutions to challenges they're facing.

Communications

Our Physical Activity team produces a monthly newsletter and a weekly blog to update projects and partners on the physical activity work taking place across the UK. If you would like to receive these updates, please contact the team at physicalactivity@macmillan.org.uk. You can also follow the team on Twitter [@MacMoveMore](https://twitter.com/MacMoveMore)

Sustainability

As outlined throughout this guide, we can provide support to services from the proposal stage to achieving sustainability and gaining long-term funding.

Through our knowledge exchange workshops, lessons learnt log and evaluations, we will also share with you what works, in what situation and for who. By doing this, we hope to support local services to develop a stronger case for long-term funding.

Please do speak to your local Macmillan development manager and the Macmillan Physical Activity team about all of the support that's available to your service.

References

- 1 Macmillan Cancer Support Cured, *but at what cost?* 2013
- 2 Macmillan Cancer Support. Worried sick: *The emotional impact of cancer.* 2006.
- 3 Macmillan Cancer Support. Cured – *but at what cost?* 2013
- 4 Macmillan Cancer Support. Online survey of 1,019 people living with cancer. 2010.
- 5 World Cancer Research Fund. *Food, nutrition, physical activity and the prevention of cancer: A global perspective.* 2011. London.
- 6 Macmillan Cancer Support. *The importance of physical activity for people living with and beyond cancer: A concise evidence review.* 2012.
- 7 Macmillan Cancer Support. *Intervention to promote physical activity for people living with and beyond cancer: Evidence-based guidance.* 2012.
- 8 Denmark-Wahnefried, et al. Riding the crest of the teachable moment: Promoting long-term health after the diagnosis of cancer. *Journal of clinical oncology: Official journal of the American Society of Clinical Oncology.* 23(24): 5814–30. 2005.
- 9 American College of Sports Medicine *roundtable on exercise guidelines for cancer survivors.* 2010.
- 10 Department of Health. *Start active, stay active: A report on physical activity from the four home countries' Chief Medical Officers.* 2011.
- 11 Macmillan Cancer Support, YouGov. Online survey of 1,740 UK adults living with cancer. Survey results are unweighted. Stats quoted here are based on people who have completed treatment for cancer within the last year. 2010.
- 12 Walkington L. *Patterns of breast cancer recurrence and associated health care costs of 1,000 patients treated in Leeds: A longitudinal study.* Submitted as a research abstract to the National Cancer Intelligence Network's Cancer Outcomes conference. June 2012.
- 13 Department of Health. *Long-term conditions compendium of Information: Third edition.* 2012.
- 14 Let's Get Moving physical activity care pathway is based on the principles of the NICE public health guidance 2006. Let's Get Moving, Commissioning Guidance A new physical activity care pathway for the NHS, Department of Health, 2009.

When you have cancer, you don't just worry about what will happen to your body, you worry about what will happen to your life. Whether it's concerns about who you can talk to, planning for the extra costs or what to do about work, at Macmillan we understand how a cancer diagnosis can affect everything.

No one should face cancer alone. So when you need someone to turn to, we're here. Right from the moment you're diagnosed, through your treatment and beyond, we're a constant source of support, giving you the energy and inspiration to help you take back control of your life.

For support, information or if you just want to chat, call us free on **0808 808 00 00** (Monday to Friday, 9am–8pm) or visit **macmillan.org.uk**

**WE ARE
MACMILLAN.
CANCER SUPPORT**