Move More Pack research

Research to explore reactions to the Move More pack and name of the physical activity programme with people living with and beyond cancer

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Background

The Macmillan Move More pack was developed in 2011 in order to help cancer survivors to become more active. It aims to support cancer survivors through information, motivational tasks and progress tracking, either as a standalone or as part of a wider Macmillan activity programme.

In accessing both the pack and the programme, patients are commonly told about it by their cancer nurse. If the patient is interested then the cancer nurse will either go through the pack with them or refer them on to the physical activity project lead, who will make an appointment to go through the pack with them. Based on their answers they will then be supported to find an appropriate activity to reach their goals. The pack is also accessible in Boots pharmacies and can be ordered online. It is targeted at those whose treatment is coming to an end, but is available to people however long it is since they had cancer.

In 2012 Make Sport Fun conducted research with those who had ordered the pack online and received very positive feedback. However, as over 90% of the people who ordered the pack were 46-65 year old women, it is important to gauge the opinions of other demographic groups as well. In particular, Macmillan is interested in discovering how appealing the pack is to men, people from lower socio-economic groups, younger people, and BME groups. Macmillan is considering changing elements of the look, feel and contents of the pack and developing additional resources in order to support people in using the pack. To this end, new research was required in order to feed into the development of a revised pack, which is due to be completed in the middle of 2015.
Aims and Objectives
The research was designed to test the appeal, the potential usage, and the name of the pack with different groups.

Appeal
When looking at appeal, the research sought to explore initial reactions to the pack including the look and feel of it, and the likelihood to pick up. This was particularly pertinent when discovering how likely different groups are to pick up the pack when coming across it, particularly as Macmillan had already ascertained that online ordering was largely limited to one demographic group. In addition, it was important to explore how appealing the pack was when looked at in more detail, and to identify which parts of the pack were strongest and which would benefit from further development.

Usage
The key objectives here were to:
- explore comprehension and any areas which are more/less easy to understand
- explore how appealing the case studies are
- assess intended usage and how cancer survivors would anticipate using the pack
- identify any areas of improvement including website versions, apps or inserts

Name
A final consideration was testing two names for the whole physical activity programme. Macmillan is currently using two different names – ‘Move More’ and ‘Get Active Feel Good’ – but would like to develop a more consistent branding moving forward. The research thus explored initial reactions and appeal of the names, how the names alone affected expectations of the programme and pack, and how the names fitted with the scheme once it had been explained.
Overview of approach

Methodology
To ensure we achieved all the research objectives we used a qualitative mixed methodology approach of focus groups and follow-up telephone depth interviews. The focus groups allowed us to first explore the initial appeal of the pack and programme and its names with different demographic groups. Using telephone depth interviews, we were then able to explore in greater depth how respondents used the pack once they had had time to engage with it more fully.

Sampling: Group Discussions
The focus groups were conducted in October 2014 and consisted of six 90-minute sessions in three locations; London, Glasgow and Leeds.

All respondents:
- Had been diagnosed with cancer in the last five years
- Had been diagnosed with a mix of cancer types
- Could be classified as inactive - none took more than 30 minutes of moderate intensity activity on more than two days a week
Sampling: Telephone depth interviews
Following the groups, eighteen 60-minute telephone depth interviews were conducted over two weeks following the groups. Respondents were chosen based on their responses at the groups, allowing us to cover the spectrum of opinion on the pack. Age, gender, social grade and cancer type were also taken into account in order to obtain the broadest possible demographic. The time between the focus groups and telephone depth interviews gave respondents the opportunity to read the pack in greater detail, to use different features of the pack, and to implement changes to their lifestyle, if motivated to do so. Between the focus groups, respondents were given short task books to fill out, facilitating deeper reflection on the pack and programme and prompting the discussion during the interview.

The interviews were conducted with on average three respondents from each group. Below is a breakdown of the respondents interviewed by group:

**London, Male, 55+ C1C2DE**
- Male, D, age 65
- Male, D, age 68
- Male, C1, age 55

**London, Mixed gender, Mixed Socio Economic Groups, 18-30**
- Male, C1, age 27
- Male, C1, age 25
- Female, B, age 21

**Glasgow, Mixed gender, ABC1, 55+**
- Female, C1, age 65
- Female, C1, age 67

**Glasgow, Mixed gender, Mixed Socio Economic Groups, 31-55**
- Female, C1, 51
- Male, D, 49
- Female, B, 55

**Leeds, Female, C2DE, 55+**
- Female, C2, age 55
- Female, C2, age 58
- Female, C2, age 57
- Female, C2, age 64

**Leeds, Female, Mixed Socio Economic Groups, BAME, 55+**
- Female, C2, 54
- Female, D, 64
- Female, C2, 54
General attitudes to health and physical activity

Awareness of the need to stay active is top of mind for all, often driven by an increased focus on health matters since diagnosis. This is especially pertinent for those whose activity levels have dropped significantly since their diagnosis and receiving treatment. Many, particularly within the mid age range (35-51), express an eagerness to return to the pre-diagnosis activity levels and previous sports they’d enjoyed.

For many there is an understanding that their current level of physical activity is low, expressing feelings of guilt and a sense that they should be doing more. As a result there is openness towards any means to help them get more active. In doing this it is important to be aware that some cancer survivors can have a lack of confidence in their own abilities; they may have lost their routine of activity, lost strength and even suffered a period where physical activity has not been an option. The more time lapses post treatment, the more difficult it can seem to get back to activity, particularly if coupled with feelings of anxiety about what are the ‘right’ levels of activity for that person and their condition.

“Any exercise you have to build up to slowly” – Glasgow, Female, ABC1, 55+

For many, cancer is not the only health matter on their mind. Especially for the older generation, age is arguably as big a factor and a hindrance to doing regular physical activity as cancer. Many feel they simply don’t have the stamina, or are restricted by other ailments such as arthritis, and feel more prone in general to aches and pains than when they were younger. However, for some, age is as big a motivator towards doing more physical activity as cancer. Many refer to being driven by the phrase, ‘use it, or lose it’ based on friends they know who’ve lost some of their physical ability with age.

“It keeps you going, doesn’t it” – Leeds, Female, C2DE, 55+
“I feel the less I do, the worse I feel” – Leeds, Female, C2DE, 55+
“Cancer or no cancer… use it or lose it!” – Glasgow, Female, ABC1, 55+

Many express a desire to not let cancer define them and to make sure they aren’t constantly attending events specifically related to it, which may pose a potential barrier to accessing the programme and pack. This is particularly evident in the younger groups that we spoke to (18-30 years), who appear to be more distanced from their cancer, seeing it as in the past and in some cases believing that they would only access cancer focused resources and programmes should they get cancer again.

Positivity towards physical activity is heavily dependent on levels of activity previously undertaken. Those who had been more active pre-diagnosis express greater awareness of the ‘feel good’ aspect of physical activity than those previously more inactive. Some express annoyance at their current physical activity levels and are therefore arguably more receptive to any means to help them get back to being active again.

“[Physical activity] is an alien concept in my life” – Glasgow, Female, ABC1, 55+
For most, physical activity is predominately self-motivated and self-administered. Few mentioned following specific programmes beyond occasional gym classes. As such there is openness to direction and new ideas to help them get more active.

“You could lie about the house and feel sorry for yourself… but if you were going to go the gym… that gets you out the house” – Glasgow, Male, Mixed SEG, 31-55

However, currently, across all ages, there is a preference towards physical activity being as accessible and straightforward as possible, such as walking more. It is important therefore to bear this inclination in mind in terms of activities suggested within the pack.

“Since reading the pack I get up earlier now and build activity into my day. For the last 3 weeks I have been walking 20-30 minutes a day. I just realised that I could do more if I prioritised. Laziness stopped me before and I just thought I didn’t have time in the working day. Now I set my alarm earlier and go for a walk before work.” London, Male, C2DE, 55+

Motivators to doing physical activity
This research indicates both physical and emotional motivations to participating in physical activity, which could be leveraged in any communications.

- 'Feeling good' in both mind and body is expressed as a key benefit of being physically active. Getting outside and walking in the fresh air is preferable in this regard for allowing people the opportunity to also clear their mind.
- Moving forward, whether that is simply in terms of 'keeping going', or 'returning to normal', is a main aim of many. Within this is also a desire to see results (i.e. weight loss, or improvements in their abilities).
- Some also mention the social and competitive elements driving their interest in group physical activities. This appears to be more down to the individual than any age/gender differences.
- For some, it is simply a vague awareness that any physical activity undertaken will be beneficial in the future. Many mentioned it helping their mental well-being and negating other health implications (weight etc.). Others feel an increased public awareness of the benefits of physical activity has made it harder to make excuses not to exercise.
- Importantly, very few reference cancer as a motivator to do more activity – either to prevent their cancer returning or to speed up recovery. They simply aren’t aware that physical activity has a positive impact on their condition. When they learnt about these benefits they felt they had missed out by not hearing about them during their treatment.
- For some tracking results was a useful motivator, and they wanted to see what progress they were making, both physically and emotionally.
Barriers to doing physical activity

- Both emotional and rational reasons are feeding into the barriers to physical activity and can potentially be addressed in the pack.
  - Rational reasons for not doing physical activity are often more top of mind and more easy to express. Many mention weather, monetary and time constraints to doing more physical activity. One of the issues with time constraints was that many people were not sure how to fit activity into their routine.
  - Another key barrier is the side effects of the treatment, whether that is in terms of damage to certain organs, or loss of energy. This fits very closely with a large number of other pieces of research which have shown that for over 55s and even more for over 65s that health problems are their main reason for not getting active.
  - Age is also a hindrance for older people who aren’t physically able to undertake some of the sports they used to enjoy. The over 55 groups particularly talked about arthritis, aches and pains as barriers to getting active.
  - Furthermore, some feel unsure of where they can currently find opportunities for physical activity, or increasingly feel the demands of their routines as time lapses post treatment.

“I didn’t take too long before I was back doing a lot of the things I used to, picking up the grandchildren etc. I don’t know how I could fit in physical activity right now”- Glasgow, Female, ABC1, 55+

Emotional reasons are often just as keenly felt, but can be hidden behind more rational barriers to physical activity. For example, some admit simply not enjoying physical activity as their biggest barrier regardless of any other constraints. Some also feel embarrassed about their level of ability and body shape; others are frightened about pushing themselves without understanding their capabilities and damaging their recovery.

This concern about side effects of treatment and a lack of confidence of what is the right level of activity is in line with various other pieces of research. There is a proven need for reassurance that getting active is safe, that activity doesn’t have to be strenuous and what is a safe level of activity.

“It’s quite scary if you’ve never been before” – Leeds, Female, C2DE, 55+
The ‘ideal’ physical activity pack

When looking at what is expected and desired from a physical activity pack there are five requirements. These five requirements were identified in the analysis of what people wanted from the pack. The ‘ideal’ pack must be supportive, informative, digestible, achievable and relevant to encourage use and motivate a behaviour change. This is in line with the “Physical activity insight” research which showed that marketing of activity to cancer survivors should be supportive, informative, personalised and should position activity as their choice.

**Figure 1: The ‘ideal’ physical activity pack**

**Supportive**

For most the idea of increasing their level of physical activity can be daunting. Some are anxious that they will struggle and not achieve this, whilst others would like to start but are unsure how to do so. The pack should not assume a certain level of activity or knowledge and it is important that the tone is encouraging and supporting rather than patronising. This will help reassure the reader rather than becoming off-putting.

This tone is very hard to get right, but the “physical activity and cancer treatment” leaflet does it very well. This suggests we can use the expertise of the Information team to get the tone of voice right in the rest of the pack.

**Informative**

It is important that any information is either new/reminder information. If the pack is received at the early stages of the cancer journey, at diagnosis or soon after treatment, information on how cancer can affect activity levels would be appreciated. In hindsight the impact on activity levels and fatigue caused by the cancer are underestimated by some cancer survivors, therefore there is a sense that this information would have been useful. This meant people weren’t prepared for how little energy they would feel, this led to them feeling
guilty, and some people didn’t maybe manage to minimise their sedentary behaviour, as they would have done if they had understood the situation. They would have appreciated something that let them know that they’d feel tired, and provided suggestions of how to deal with it - little things to do so they don’t feel guilty they’re not doing more. They want to know that Macmillan understands it’s a difficult time.

Information and guidance on appropriate activities together with a range of possible options would be appreciated by all. This is especially important for those who wish to increase their activity levels but are not sure how to achieve this. There is some of this in there, and that’s appreciated. But critically it’s immediately what people thought should be in the pack, so is obviously a vital element, and we might need to make more of it.

Achievable
The range of possible activities suggested need to be feasible at current activity levels and consider the physical impact the cancer treatment may have caused, for example fatigue or muscle pain. The majority want to see options tailored to their circumstances and which can be done at their own pace. Goals need to be realistic as if overloaded they can feel daunting especially for those with lower activity levels.

Digestible
The pack must be easy to read and understand as it otherwise it can appear overwhelming and they won’t engage with it; it therefore must not contain medical or sporting jargon. Most people said there was too much in the pack for them to go through in one sitting, and they appreciated the clear layout with distinct sections, as it allowed them to ‘dip into’ different sections at different times if required.

Relevant
The pack must recognise different situations and experiences whilst feeling appropriate for people of different ages and cancer diagnosis. This must come to a large extent from the case studies and photos.

Timing of when the pack is received can affect how relevant the pack can feel and whether readers feel the pack is aimed at them. After treatment is felt to be the most suitable time for many, acting as almost a signpost for moving on and being ready to ‘feel good’ again. It is at this stage where a physical activity pack may feel the most relevant.

Prior to that many felt their focus is elsewhere, or that the pack may get lost in the multitude of other information booklets they received at this stage in their cancer journey.

The longer the time period after treatment the more likely it is felt that people may have returned to some of their previous activities and that new issues (health related or otherwise) would become more of a focus. However, whilst it becomes less relevant as time moves on very few people felt it had become completely irrelevant to them, even five years after
treatment. Images need to be relatable to enable the reader to picture themselves increasing their own physical activity and progress towards their goals.
Names of the physical activity programme

The two tested names both receive positive feedback, yet reactions are very much dependent on the interpretations of different words within the names.

The ‘Move More’ name

Positively for some, ‘Move More’ is seen as more personal and less strenuous than ‘Get Active, Feel good’, as it seems more achievable to simply increase everyday movement. Most feel the name conveys simply ‘moving more’ in their everyday lives e.g. walking to the shops instead of going in the car, or getting off the bus one stop earlier. There are no mentions of it feeling particularly part of any programme; it instead feels like it simply relies on individual’s taking responsibility to move a little more. In that regard, it feels less in keeping with a physical activity programme where support is of key appeal.

Additionally, negatively for others the word ‘move’ feels heavy handed, off-putting and more like an order. It also can negatively imply a lack of movement in their current levels of activity. They know that this is probably true, but they don’t want it pointed out too bluntly.

Overall this name was felt to be more achievable, but slightly less supportive.

“It’s not too hard” – Leeds, Female, C2DE, 55+
“IT feels like a command” – Glasgow, Female, Mixed SEG, 31-55
“It feels like the assumption is being made that I’m not active to start with” – Leeds, Female, C2DE, 55+

The ‘Get Active, Feel Good’ name

Positively this name has appeal, particularly for those who focus on the ‘feel good’ element – this is seen as very important in emphasising the motivation and result of doing more physical activity, and ‘feeling good’ extending beyond the physical. Feeling good was the most important motivator for getting active, physically, mentally and emotionally, so this fits well.

“It’s true – you do feel good after you exercise” – Glasgow, Male, ABC1, 55+
“You’re low, you’re depressed… you want to feel good again” – Glasgow, Female, ABC1, 55+

However, for those who initially focus on the word ‘active’ this name can appear daunting and ‘getting active’ more of a difficult task and long term aim than simply ‘moving more’. Others interpret it more negatively in terms of insinuating that ‘getting active’ is the only way they can ‘feel good’, especially if they are struggling to get over any of the barriers to physical activity.

Most recognise the link between the two parts of the name and that it is more in keeping with a programme in terms of its emphasis on the result.
The pack

Initial thoughts on the pack

Upon introduction to the pack reactions in the main are very positive, driven by the overall look of quality and visual appeal. The strong, positive brand image of Macmillan comes across clearly through the colour and font used on the front cover and makes it stand out. In addition to this many feel encouraged by the 'Feel Good' phrase, emphasising the benefits of physical activity on the pack cover, and feel that it gives the pack a welcoming and attractive exterior. In fact the word welcoming was used by multiple people when describing the pack.

The fact that people instantly understand the pack is by Macmillan gives the content a sense of kudos from the outset. Many express that they feel Macmillan are a trusted organisation with the right experience to deliver content on cancer related issues. As a result many feel more open and interested in the pack content as they feel it will be particularly relevant to their situation and that the pack will be positioned in an understanding and sympathetic manner.

Many feel the pack itself looks to be of a good quality and something that they could imagine keeping to refer back to or passing on to others in a similar situation. The spiral ring binder style and pull-out elements are felt to add to its appeal as a sturdy reference book that they could use to easily go to different sections. Its appearance and layout greatly add to its perceived usefulness with many commenting that its different detachable sections will allow them to dip into the pack in different ways and use it at different times.

However, for some, particularly the younger age group, its size and weight is initially off-putting, with some feeling overwhelmed so much so that some anticipate they wouldn’t even attempt to read it.

“It is as big as my George Bush autobiography I am reading, it doesn’t look like something you could just dip in and out of” – London, Male, Mixed SEG, 18-30

Some of this group also felt they wouldn’t see Macmillan as a source for physical activity advice because their cancer diagnosis is too far in the past.

“I wouldn’t go to Macmillan for this kind of information.” – London, Male, Mixed SEG, 18-30
**Intention to use**

Despite this positive initial reaction to the pack, intention to use is mixed. The younger groups are more hesitant and are unsure whether they would feel the need to use the pack. Whilst the younger group do appreciate the concept of the pack, they are more confident in their own ability to start physical activity and find help if needed. As expected based on previous research conducted, intention to use is most encouraging in the older female group. This group were looking for this kind of support, don’t know other avenues to get it, and appreciate it being brought to them.

However a key challenge remains around how to gain awareness of or access to the pack. Overall, a greater proportion feel they would have been more likely to use the pack if they had received it at the middle or end of treatment when they have more time to reflect and are looking towards future changes. The majority are typically now back in their routine, and whilst they understand the importance of physical activity, are less likely to make time to increase current levels.

This research uncovered different levels in which people claim they will engage with the pack:

![Figure 2: Ways in which readers claim they will engage with the pack](image)

*Figure 2: Ways in which readers claim they will engage with the pack*
Taking each in turn:

- The majority questioned their likelihood to pick up a pack on its own and most would prefer to be given it, particularly by a health care professional. The main selling point of the programme is the one to one coaching and tailored activities that are conveyed through the programme description; many feel that this didn't come across within the pack.
- For some, the pack is predominately a reference book and they'll only look to use certain sections of interest upon occasion.
- Yet, those who have a particular interest in tracking their progress feel they'll use the pack regularly, particularly the diary feature.
- Only a minority feel the pack is eye catching and motivating enough to pick up.

There is a clear challenge, therefore, in terms of getting people to engage with and pick up the pack on its own. And the decision should be made as to whether to focus on this at all, or whether to focus on getting the pack distributed by health professionals and project leads.

Distribution of the pack
As referred to previously a key challenge remains around how people feel they will come across the pack. It is important to appreciate that some feel the need for outside guidance on the pack, whilst others prefer the pack to be a more personal tool that they can use at their own pace. Furthermore, there is a potential challenge in engaging the target audience to pick up a pack without guidance. Despite them showing an interest in being more active, current inactivity levels and perceived barriers may indicate that they need more support to change behaviour.

For many their preference would be to be given the pack and talked through the programme by a health care professional to engage with the one-to-one support and understand fully the pack contents. However, there is some conflict around who exactly would be best placed to do this. For some, whilst they go to their GP more regularly, particularly post-treatment, there is some uncertainty around the amount of time they feel GPs would be able to devote to careful explanation given their workloads. For others, the cancer specialist makes sense in relation to the pack content, however many feel they are more geared up to talk about specifics related to your treatment rather than lifestyle changes.

Macmillan representatives are spontaneously suggested as they feel best placed to know the content. However, there is some concern around resource being taken from those more deserving given Macmillan's association for some with end of life care. This is particularly the case for those who have moved on since their cancer and feel less attached. People tend to think of Macmillan as providing support during the treatment stage, so the longer since treatment the less connection they feel. Further emphasis on the importance of physical activity in the recovery process may help people to feel less guilty in this regard and more open to taking the support.
Additionally there is an assumption by most that they would come across the pack in a medical environment due to its focus on health matters and are not anticipating coming across it in a retail environment. With this lack of awareness of the availability of the packs in different settings, some questioned their likelihood to be, or linger post treatment in a medical environment where they assumed they’d pick it up.
Detailed reactions to the pack

Whilst the pack as a whole is viewed positively by most, some sections stand out more than others in terms appeal, especially the guide to physical activity and cancer treatment and the case studies.

Below illustrates overall perceptions of the different sections by the five key elements detailed earlier and we have also included a column for overall appeal of the concepts.

If there is a question mark and a tick then it means that element is polarising, but that if it was changed that might make it more appropriate.

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Figure 3: Overview of reactions to the pack
Guide to physical activity and cancer treatment

Many find the guide to physical activity and cancer treatment appealing and view the execution positively in terms of being supportive, informative, achievable, digestible and relevant. The guide is overall the most positively received section of the pack both initially, and upon later reflection. Furthermore, it is perceived to be supportive and achievable through highlighting the impact cancer treatment may have and appropriate activities to try.

It feels informative either as new information or as a reminder. Those who’d had longer with the pack acknowledged the value of this section in helping frame activity ideas and motivations post cancer.

This section feels relevant to all given coverage of a variety of cancer diagnosis and treatments. Including specific information on financial and work related support increases the feeling of relevance further for those who have been though similar situations. Particular sections that appeal are repercussions of the different treatments (p.18-21), table of physical activity options (p.16-17) and treatment side effects (p.6-7) for providing reassurance, motivation and information. Its credibility and usefulness remains amongst those who’d had the pack for longer and is the section most feel they would continue to refer back to. Even for the younger group, arguably the least warm to the pack overall, see the benefit of this section as a portable reference tool that gives it value in the long term.

The format of the detachable booklet is appreciated as it makes the guide smaller and easier to carry around if they wished to do so. It is easy to read and does not use medical or sporting jargon, whilst not appearing too basic or patronising. In the follow up interviews this section is commonly referred to for being both informative and digestible. In fact Maria, who was very disengaged in the group read this guide, carried it around with her and showed it to one of her colleagues.

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Overall, this section feels like it provides both the breadth and depth of content. People would then often appreciate more of the same format of information (for example, either expanding on information based on cancer stages, or what certain physical activities involved). This could possibly be provided via follow up booklets about specific elements, or website links at the end of each section.
“I don’t think you realise when you go into it… how you’re going to be at the end” – Leeds, Female, C2DE, 55+
Case studies

Many view the case studies positively in terms of being supportive, digestible, informative and achievable. They also like the photo and story format. However the case studies can lack relevance to all audiences. However, those who’ve had time to reflect with the pack refer to the case studies being very motivational in terms of providing role models and ideas of physical activities to try, particularly when they can relate to the case studies.

In that respect readers view Mariette’s case study (p.14) less warmly as it is seen as emphasising more of a niche sport and someone who is previously very active to a high standard (fencing for England) and therefore less relatable. The case studies can resonate and make the reader feel less alone, whilst emphasising the variety of experiences people may have. Many appreciate that the imagery looks like ordinary people and therefore can feel even more relatable.

Whilst readers like the case studies, the execution could be more inclusive as some readers do not perceive the case studies to be relevant to them. Particularly to younger readers, the current imagery can make the pack feel like it is aimed at an older audience than themselves and there is a desire for some younger and more ethnically diverse imagery to be included in the pack to recognise different situations and experiences.

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"It’s always quite interesting to read about someone who has been through it and survived and come out the other end, enjoying life and keeping active. They are nice to have, the only issue with them is once you’ve read them you’re unlikely to do so again" – London, Male, C2DE, 55+
Activity Diary

The diary aspect feels motivational to most and many welcome the idea of tracking their progress to see how far they have come. However, there is low intention to use, particularly in its current format. The majority are unsure whether they would make written notes in the booklet and feel that a busy schedule and limited free time may act as a barrier from doing so. As a result the diary is the most polarising aspect of the pack initially and upon reflection, as people remain in a similar mind-set in terms of whether they’d ever use it or not.

Despite this even those who feel they wouldn’t use the diary could see it would be a good visual reminder and those who’d had more time with it liked the motivational quotes. The time frame of 12 weeks set within the diary feels like a good motivational and achievable starting point. An important aspect of the diary is that it allows people to visually track how they are feeling and refer back to good days in particular; in that regard the questions it prompted, around how they felt before/after physical activity is welcomed.

“12 weeks seems do-able why not give it ago for 12 weeks see if I can make a change and if I don’t it’s only been 12 weeks” Glasgow, Female, 35-54

The goals aspect feels like it overcomplicates the diary and makes it too long and onerous to fill in. There is a consensus that the number of goals included is too many and as a result may not be achievable. Especially for the younger age groups its size makes it feel less appealing and portable. It is felt in many cases to be spread over too many pages and certain quotes are felt to add nothing extra, or motivational. The one on page 17 was specifically mentioned in this negative light.

An app/online version of this section would be welcomed, especially amongst younger readers (18-30 year old groups), but this may not be appropriate for all ages and levels of technology capability.

This was part of pack that people felt they’d most appreciate being taken through by someone else.

“Once I’ve started doing something I don’t need the diary, you know what you can do yourself without having to write in down” – Leeds, Female, C2DE, 55+

“Things like that give you a positive attitude” – Glasgow, Male, ABC1, 55+
**Getting started**

The getting started section of the pack receives a positive response for being digestible, but there is uncertainty around whether this section is relevant, supportive or achievable. For many it gets lost as a distinct section in itself and their view is they would only use it once and not refer back to it. Overall there is a muted response with the majority feeling quite indifferent towards this section. It does not always feel necessary and many would welcome a more condensed version.

However there are a number who view this section positively as a reminder and motivation to start increasing their activity levels. In the follow up interviews some mention liking the questions (page 10) even if they hadn’t filled them in yet it got them to think about it. No-one actually filled in prompts on page 10. Given the title of this section it is perhaps unsurprising that this is the first section reader’s mention going to when they came to re-read the pack and helps to explain initial positive responses.

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<tr>
<th>Section</th>
<th>Relevant</th>
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<td>Getting started</td>
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“Even if you don’t write your answer down, the question makes you think about what you would like to do” – Leeds, Female, C2DE, 55+
Setting Goals (p20)

The execution of the setting goals section (p20) received a positive response in terms of being relevant, supportive, digestible, informative and achievable. Most feel it will be most useful as a tool to track progress.

However, appeal for the section is mixed and it is difficult to gauge actual intention of using this section. Some claim they would write down their goals in this section, however others may use it as a reminder, particularly those who are short of time. After having more time with the pack some refer to being more likely to use the setting goals pages in the activity diary as they feel it is more in keeping with that. However, few of those who spent time with the pack had written in the setting goals section in either. Therefore, whilst nice in terms of prompting thoughts it hadn’t impacted on many in terms of behaviour.

Whist setting goals is personal, some would like support and guidance in terms of the type of goal to set and what is achievable. Ideally this would be in the form of a face-to-face assessment and discussion, however if that isn’t possible then a phone conversation would also be appropriate.

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I’ve written out my goal in the front section of the diary. I think it makes sense to have them there as it helps keep reminding you. It’s where I will be referring back to most regularly anyway” - Glasgow, Female, C2DE, 35-54
Contact Details

Many view the included contact details sheet as digestible, but there is uncertainty around whether they are relevant, supportive, informative or achievable. Especially those seeking additional help and guidance in addition to the pack welcome the contact details. Those who currently do not wish for additional guidance are happy with the contact details included and appreciate there may be a time in the future where they may need guidance or help. For the younger groups this section feels unnecessary as they feel they already have other means to access this information online.

The Macmillan contact details and contact details for the physical activity programme feel like they are missing, especially for those who find the programme appealing and motivating. This was the feedback even though the Macmillan details were on page 16 along with more information on searching for local activities. This may be to do with the format – the pull out section pulls the eye to the right hand page, and people miss page 16.

There appear to be issues once people have tried to use the contact details, some examples are stated below:

- **Out of date contacts**: One gentleman had tried to use the ‘paths for all’ contact details for walks in his local area and found it out-dated; as a result he didn’t check any other details.
- **Not flexible enough in terms of methods of contact**: Many feel there should be more telephone numbers available and there is currently too much focus on online.
- **Missing the local element**: For many the contact details currently feel too broad and generic.

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<tr>
<th>Contact details</th>
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“The contact details are of no use to me, I would just go online to look, there isn’t enough information there that you need to look elsewhere anyway” Male, London, Mix SEG, 18-30
Top 10 tips

The majority view the top ten tips positively in terms of being relevant, supportive, digestible and achievable. However there is uncertainty around whether the top ten tips are informative.

Generally views of the top ten tips are positive, as a good reminder for what readers should be doing. However, there are mixed views amongst a minority who feel the tips are too basic and patronising especially due to their simplicity. Additionally there are some who find the tips completely off-putting as they don’t like to be instructed.

With increased time with the pack some had detached the tips from the pack and stuck them up somewhere visual, yet the majority had ignored them as they are felt to repeat information elsewhere in the pack.

“I just think it’s too obvious really, I don’t know if you need it all” – London, Male, 55+

“It gives you an idea of how to start and what to do. I don’t agree with all of them but most of them make sense” – Leeds, Female, 55+

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<th>Top 10 Tips</th>
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Top 10 Tips to Get Active and Stay Active

Getting active may be a big lifestyle change for you. But settling clear goals, recording your progress and having support can all help. Becoming active for the first time or returning to activity during or after a condition like cancer may not be easy, so here are our top 10 tips on how to get started and keep going:

1. Keep in mind the benefits of becoming more active, and what you hope to achieve.
2. Set goals you can achieve at your own pace. Whether that’s being more active around the house, going for a walk or participating in a class, make sure it’s the right goal for you.
3. Gradually build up how much you do.
4. Keep a record of how active you’ve been and how you feel after being active so you can see your progress. Try using the activity diary included in this pack to help.
5. Share your plans with other people who are supportive.
6. Try being active with other people, such as family or friends, or join a group or a club.
7. Make sure the activities you do are fun and enjoyable.
Readership and Usage of the pack

To help assess the impact of the pack we have assessed readership, usage and whether the pack has motivated the individual to increase their physical activity levels. As a result of this we have established four different types of cancer survivors.

Of the 18 follow up telephone interviews conducted, we have provided an indication as how these are distributed across the four categories. Whilst this is only qualitative research, it does provide an overview. From this we can see that **over half of the interviews conducted felt more motivated as a consequence of reading the pack. Furthermore 5 of these had actually changed their behaviour as a consequence of using the pack.** Positively looking at the 5 who changed their behaviour there is a mix of gender and all ages. Whilst the largest group is group 1 who did not read the pack at all, this is made up of males (either 18-30 or 55 plus).

1 Not read, not motivated, not changed: 6 respondents
2 Read, not motivated, not changed: 2 respondents
3 Read, motivated, not changed: 5 respondents
4 Read, motivated, changed : 5 respondents
Case study 1

Alex– Male 18-30, diagnosed with non-Hodgkin lymphoma

In September 2011 Alex was diagnosed with non-Hodgkin lymphoma. It took 6 months to get his prognosis and in this time he had severe muscle pain and found any activity difficult. Prior to this he was active at least once a week, enjoying cycling, swimming and yoga. The main benefit he felt he got from physical activity at that point was relaxation after work.

Alex felt that the group itself made him think how useful it would have been when going through treatment to have had someone talk to him about the benefits of increasing physical activity and to go through the pack with him, but he felt that at this point in his life the pack had little relevance. There are two main reasons for this:

1. Alex feels removed from his cancer experience:
   “It would have been more relevant three years ago when cancer was such a massive part of my life, I would only pick this up if I got cancer again and fingers crossed that isn’t going to happen”.

Linked to this, Alex feels that if he wants information and support on becoming more active he would go elsewhere, for example a local gym.

2. The pack itself:
   “It is fairly bulky which puts me off and it just doesn’t feel like it is aimed at the younger generation, for example all of the case studies are people over 55, it would be nice to see a broader spectrum of people and people who have survived and come out the other end”

As a consequence Alex had not looked at the pack in detail at all since receiving it, it had stayed in his bag and he hadn’t been motivated to read any more than what he had initially glanced at during the group discussions.
Category 2 Cancer Survivor
Read the pack, not motivated and not made a change
With this type of person is difficult to know how much the research influenced their readership. Yet there is a group of people who are most likely to use the pack as a reference tool rather than it having any lasting impact. We think these people are less likely to be motivated solely by the pack and need more personal encouragement and clearer links between the pack and the programme. As a result they may have kept the pack, but it is unlikely to have a lasting, or regular impact on their physical activity levels.

Case Study 2

Moira- Female 55+, diagnosed with breast cancer

At Christmas last year Moira found a lump in her breast, however as the cancer was caught early she received no chemotherapy treatment for which she counts herself very fortunate. She remarked to feeling ‘a fraud’ in comparison to other cancer sufferers as whilst all-consuming at the time she doesn’t feel she was ever out of her old routine for long (2-3 weeks). She referred to herself as a couch potato as she doesn’t play any sport, or go to the gym. However, she did feel ‘active’ in other ways such as, walking to the shops, or running around after her grandchildren. Her main motivator to physical activity is age, yet she struggled to find time and inspiration to get active.

Moira felt the group itself motivated her to sit down and think about what she actually does, but she doesn't feel her attitude to physical activity and cancer has changed since. She did however, like the pack as a reference tool that she enjoyed reading ‘from cover to cover’ as she liked to be clued up on cancer information in general, but she hadn’t looked at it again since the first time.

She commented that she was ‘unsure what she would have done’ as a result of reading the pack as it asked her to do too much on her own. She ultimately felt she lacked confidence towards physical activity and would welcome someone to guide her through it with suggestions of something different to try to ‘shake her into action’.

As a consequence Moira didn’t think the pack on its own was something she would use for two reasons:

- She didn’t currently feel she needed it, or had been ill enough at the time of her treatment to be deserving of help in her recovery
- She didn’t feel the pack on its own was enough to motivate her; the personal touch was felt to be missing

However, she wouldn’t throw the pack away and would keep it as a tool to refer back to. Also – she has friends who’ve got cancer sometimes go to her for advice, so she’s keeping this as a reference for passing information on to friends, despite it not being personally motivating enough for her.
Case Study 3

Gillian- Female, BAME, 31-54, diagnosed with breast cancer

In August this year Gillian was diagnosed with breast cancer and is currently undergoing chemotherapy. Since she started treatment she can already tell the difference in her energy levels. Prior to diagnosis she describes herself as active, but not fit. Through working two jobs she was previously constantly on her feet and enjoyed walking, but always did physical activity with a set goal in mind such as an upcoming event.

Gillian felt the group helped remind her of the little things you can do to be physically active and that it has prompted and inspired conversations in her household of things she can do once she feels more able. At the moment as she is off sick she has had time to look at information booklets and has actively looked for stories, resources and contact details not just about physical activity, but cancer in general. This seems to be an example of the “teachable moment” in practice.

“I’ve had a look at the pack with my children and it’s really inspired them and me. It’s made me think- what am I going to as soon as I feel better? And because they don’t want to see me feeling down the pack helps them help you and gives them something to focus on.”

However, at the moment although she is motivated and keeps the pack near her bed with ‘other books I use frequently’ she doesn’t feel it is quite relevant for her to put it into action yet. Given her fluctuating energy levels she doesn’t feel her body is always able and currently the priority is getting through the chemotherapy.

“The pack is really positive. It’s made me feel as if there is light at the end of the tunnel and that after treatment it will be onwards and upwards.”

Category 3 Cancer Survivor

Read the pack, motivated and not made a change

This type of person is more likely to have rational barriers that have stopped them making changes to their physical activity levels such as illness or time pressures from job/family life. They are more likely to have shown and spoken about the pack and to have been looking for ideas to spur them on in their physical activities. For these people the pack has acted as a reminder and motivator in the long term. The pack is yet to have an actual physical impact, but for many it has already had a emotional impact.
Case Study 4

Olga – Female, over 55, diagnosed with skin cancer

Before her diagnosis Olga wasn’t very active. She had a busy life and described herself as lazy in terms of physical activity. She classed physical activity as going to the gym and other strenuous activities which felt overwhelming and daunting.

Once she had received the pack, Olga read it cover to cover. She found it inspiring and motivational and as a result understood that physical activity could be about ‘moving a bit more’ rather than just going to the gym.

As a result Olga has increased the amount of physical activity she does by increasing the length of her walks and has bought a dance physical activity DVD.

"It changed my mind-set, rather than being satisfied with what I’m doing I now realise I can do more, I should do more and I will do more so I think the pack has encouraged me in that way."
Conclusions

- This research indicates openness for support in becoming more physically active, particularly amongst the older (55+ age group). In fact many people had been actively looking for support around cancer, and this fitted the bill precisely for them, so they were very appreciative of it.
- Amongst our sample it is apparent that minimal guidance and support around physical activity has been given at time of cancer diagnosis or treatment, and in hindsight this would have been beneficial and appreciated.
- People were well aware that they should be more active, but were not aware of the benefits related to cancer.
- The feel good factor of physical activity is a key motivator and something which all groups can empathise with.
- However, particularly amongst the older groups, other health /age related issues can act as a barrier to increasing physical activity. This means that cancer survivors can lack confidence in their own abilities and knowledge of what is safe for their fitness levels (again highlighting receptiveness to the pack/support).
- Amongst the younger groups a desire to not let cancer define them is evident. This has key implications in terms of engagement with the pack as the more time elapses post treatment the less likely they will want to engage with cancer services.
- Amongst all, the timing of receiving this pack is critical. Amongst our sample many felt that it may have been more relevant if they had received it mid cancer treatment. At this point they feel that motivation levels are high and existing barriers such as time and routine are less of an issue.
- It is going to be difficult to get people to pick the pack up if it’s not given to them by a health professional, as people aren’t expecting this kind of thing in different settings (e.g. pharmacy)
- The ideal pack is described as informative, supportive, achievable, digestible and relevant:
  - Informative – contains new/reminder useful information
  - Supportive – encourages readers to increase activity at their own pace
  - Achievable – suggested activities must be feasible and realistic
  - Digestible – easy to read and understand
  - Relevant – recognises different levels and abilities
- Overall initial reactions to the pack are positive as it is feels digestible, of a high quality and the format is visually appealing. However intention to use is mixed.
- From our follow up telephone interviews, we have categorised four groups depending upon readership and usage of the pack. These are those who have:
  - Not read the pack, are not motivated and have not changed behaviour: 6 respondents
  - Read the pack, are not motivated, have not changed behaviour: 2 respondents
  - Read the pack, are motivated but have not changed behaviour: 5 respondents
  - Read the pack, are motivated and have changed behaviour: 5 respondents
- This indicates that over half of the interviewees feel more motivated as a consequence of reading the pack. Furthermore 5 of these had actually changed their behaviour as a consequence of using the pack.
- Whilst the largest group is group 1 who did not read the pack at all, this is made up of males (either 18-30 or 55 plus). This helps to confirm that both initially and after follow up, as suspected, the pack has most appeal amongst older age groups, particularly for females.
- Standout features of the pack in terms of appeal are the practical guide to physical activity and cancer treatment and the case studies. However the case studies could increase relevance and appeal to all ages by including a wider range of people.
- The diary concept is liked by all as a way of tracking progress and goals, however in its current format it is not felt to be user friendly. There are spontaneous suggestions for app or online versions across groups. There were also several suggestions to cut down the number of goals as it was felt to be unmanageable. This was also felt to be the area that they'd most appreciate someone going through with them.
- On using the pack, the majority feel that they would welcome the support and motivation offered if the pack was to be handed out by a healthcare professional. Overall Macmillan nurses are seen to be the most appropriate to give out this information, however there is concern about taking up this useful and valuable resource. This is a major concern, as it will stop people from taking up support that they need.
- People would also hugely appreciate someone going through the pack with them, and filling it in together. Many people felt they wouldn’t fill it in unless this happened.
- The two tested names both receive positive feedback, yet reactions are dependent upon interpretations of different words within the names.
Recommendations
There are several elements of the pack that are currently working successfully and these are important to maintain when developing the pack. It will be key to bear in mind the principles identified for the ‘ideal’ pack. These are:

- **Informative** – contains new/reminder useful information
- **Supportive** – encourages readers to increase activity at their own pace
- **Achievable** – suggested activities must be feasible and realistic
- **Digestible** – easy to read and understand
- **Relevant** – recognises different levels and abilities

Improvements/additions could focus around these principles:

**Informative**

- Additional content people would like to see within the pack included information on diet and its link to physical activity and also more on mental well-being as it is feels in keeping with the general ‘feel good’ emphasis of the pack.
- Raising the awareness of and including more local contact details to provide practical solutions for helping people increase their physical activity. This section needs to have more attention drawn to it, as currently people are missing it. It would seem to make sense to take the useful info on page 16, and make that the pull out part.
- People would often appreciate more information on certain topics for whoever wants it. This could be in the format of extra packs about people with specific cancer types, different ages and split by men and women, or website links to case studies mentioned at the end of each section. This could also possibly be available as a series of emails via an “autoresponder” email.

**Supportive**

- Flagging further the support available (either in person/over Skype/email/phone), especially for those less confident in their abilities. This would also be welcomed for ongoing support and motivation in using the activity diary.
- To help motivate further some feel it would be useful to include within the case studies examples of people who had used the diary.
- Work closely with the information team on best way to word the top tips, and other parts as people really liked the writing in the leaflet. They felt it was neither patronising nor complicated.

**Digestible**

- Overall the pack is positively received in terms of how easy to understand the information is and therefore it is important to maintain this.
- In its current format the diary is not digestible for all. There is some interest, particularly from the younger group for an app/online version of the pack and more interactivity in the form of either text/email push notifications, tips of the day and congratulations message when a goal is reached. Many feel these would act as a
helpful reminder and make it even easier for people to track their progress and keep motivated. There is also a desire for the diary to be slimmer so people can take it with them. At the moment it’s the same height and length as the booklet, but is much thicker, and people much prefer the format of the booklet.

- Edit some sections and simplify formatting. For example:
  - the images on page 25 are confusing to people because there’s no context to explain them
  - the text at the beginning of the top 10 tips is repetitive of the tips themselves, and is not needed
  - the tear out page about how to find physical activity in your area is good, but the formatting means that no-one notices the information on page 16, which is in some ways more helpful.

Relevant

- Increasing the diversity of images and case studies used, for example including some younger cancer survivors to appeal to a broader age group.
- Figure out how to get the right case studies to the right people. This could be by having extra leaflets with age or treatment specific case studies, or bundles of them on card or an automated series of emails to be sent out to people based on their age, gender or treatment type, or a website link for them to go and read more case studies.

Decide whether to focus on the promotion of the pack as a standalone resource. Everyone is agreed that it works much better with someone else taking them through it, so maybe we should prioritise that, and not focus on people using it on their own.