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**Exploring cancer survivors' views of health behavior change': *"Where do you start, where do you stop with everything?"***

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## Abstract

### Objective

Physical activity (PA) and a healthy diet can improve the well-being of cancer survivors. However, cancer survivors often do not engage in these behaviours. This study aimed to explore barriers and facilitators to engaging in these behaviours following cancer treatment.

### Methods

During the development of a web-based intervention to enhance health-related quality of life in cancer survivors, 32 people who had completed treatment for breast, colon or prostate cancer were presented with an intervention for PA and healthy eating. In-depth think-aloud and semi-structured interviewing techniques were used to elicit perceptions of both behaviours. Data were analysed using thematic analysis.

### Results

Some individuals reported implementing positive health behaviour changes to maintain health and prevent recurrence, or to help them to move forward after cancer. However, others reported feeling abandoned, and many did not report an intention to engage in lifestyle changes. Individuals discussed contextual and health-related barriers that were specifically linked to their situation as post-treatment cancer survivors: individuals described uncertainty about how to implement adaptive changes and perceived a lack of support from healthcare providers. Others viewed behaviour change as unnecessary or undesirable, with some arguing that non-modifiable factors contributed more to their cancer diagnosis than lifestyle-related factors.

### Conclusions

For many participants, the period that follows treatment for cancer did not represent a 'teachable moment'. A variety of complex and heterogeneous factors appeared to impact motivation, and may limit cancer survivors from engaging with diet and PA changes.

### Background

Survival from cancer in many countries is rising [1]. Despite this, many cancer survivors may experience poorer health-related quality of life (HRQoL) following cancer treatment. An increase in physical activity (PA) and the consumption of a healthy diet can enhance the wellbeing of cancer survivors and reduce risk of cancer recurrence [2-5]. The period after cancer treatment has been proposed as a teachable moment, which may motivate individuals to adopt risk-reducing healthy lifestyle changes [2, 6]. However, only a small proportion of cancer survivors implement or maintain lifestyle changes after treatment [3]. It remains unclear why some are motivated to make healthy lifestyle changes during and after cancer, while others are not [7].

Common barriers to PA and healthy eating in cancer survivors include a lack of motivation or self-efficacy, inadequate knowledge, concerns about pre-existing comorbidities, environmental factors such as bad weather, and lack of resources such as time or money [8-11]. Many of these issues are barriers to behaviour change across diverse health conditions [12-15] and could affect any motivational impact of the 'teachable moment' prompted by the completion of cancer treatment. In a study about cancer survivors' beliefs about diet quality, responses did not differ based on cancer type, age, or gender [16]. Similar findings were reported in a study on

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attitudes towards, knowledge of and seeking of information on PA [17]. While cancer survivors share some generic reasons for not engaging with lifestyle changes which are found across a variety of health conditions, they are also likely to have unique physical and emotional reasons specific to their survival or experience of cancer which influence engagement with these behaviours.

Understanding cancer-specific barriers to adopting a healthy lifestyle among cancer survivors could help improve the development of targeted interventions for this group [18]. During the development phase of a web-based intervention to enhance HRQoL in cancer survivors, participants were presented with a website that included modules on PA ("*Getting Active*") and healthy eating ("*Eat for Health*"). This presented an opportunity to explore potential cancer-specific reasons for engaging (or not) in diet and PA changes. We conducted qualitative interviews to explore facilitators and barriers to engaging with recommendations for lifestyle behaviour change following cancer.

### **Methods**

#### ***Design***

This study was part of a research programme that aimed to develop a digital intervention to support cancer survivors in making behaviour changes in order to improve HRQoL [19]. We obtained approval from NHS (Ref no. 191936) and University of Southampton ethics committees (Ref no. 17658) prior to data collection. The study was reported according to the consolidated criteria for reporting qualitative research (COREQ) [20].

#### ***Recruitment and procedure***

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We included breast, colon and prostate cancer patients because they are common types of cancer with large numbers of survivors [21], and were the target group for the intervention being developed.

Participants were recruited primarily through GP practices in Southern England. Potential participants identified via searches of GP databases were screened based on study inclusion criteria. Individuals who wanted to gain information about making healthy behaviour changes or coping with difficult feelings returned a reply slip to express interest in participating. The study was also advertised through cancer charities (Breast Cancer Care, Prostate Cancer UK, and PCaSO Prostate Cancer Network).

Interested participants were screened for eligibility and provided informed consent prior to the interview (See Appendix1). Interviews were conducted by trained postgraduate students and two qualitative researchers (TaC, LW). Individual interviews took place between May 2016 and January 2017 either at the University of Southampton or at a location that participants preferred (e.g. their private homes).

We used in-depth qualitative think-aloud interviewing techniques [22]. Using the Person-Based Approach [22], we elicited participants' perceptions of the intervention, as well as their thoughts about implementing behaviour changes after cancer. Semi-structured questions were asked before and after the think-aloud section of the interviews. Participants were asked about how they perceived the intervention (what they found useful, interesting, or helpful, what they were less keen on, and what they would change) and how they felt about PA and healthy eating.

### ***Analysis***

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All interviews were audiotaped and transcribed verbatim. Thematic analysis was used to analyse the data [26]. Saturation was considered reached; participants in later interviews did not indicate any significant new concerns or barriers to engagement with PA or diet. We conducted line-by-line open coding and an initial coding manual was developed by TaC. This coding manual was refined with TeC (qualitative researcher with experience in area of cancer survivorship) and updated regularly to reflect the ongoing analysis of the data. All of the data were coded, but our analysis was specifically focused on identifying patterns within participants' accounts related to behaviour change in the specific context of cancer survivorship.

Final codes, and themes were agreed between TeC, AMM (a PA specialist), KB, and LY (experienced qualitative researchers and Health Psychologists). Themes were clusters of codes that were related to similar aspects of the data. Deviant cases not consistent with the overall trend of the data were identified to explore the limits of the analysis and to ensure all relevant data were included in the analysis process. The findings were discussed with the wider research team (including cancer survivors and clinicians with cancer expertise), to ensure clarity of the themes and aid interpretation of the findings.

### **Results**

Thirty-two participants agreed to participate. Demographic and clinical characteristics are reported in Table 1. There were no patterns in the themes in relation to gender, age, cancer type, or time since treatment.

Many individuals cited non-cancer specific reasons for not engaging in behaviour change (see Appendix 3). Participants described the influence that their experience of cancer had had on their perceptions of behaviour change. Some of the comments



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reflected the 'teachable moment' after cancer as described previously [3]. Others suggested that there may be an opportunity for a 'teachable moment' that is not always capitalised on. Individuals discussed barriers and facilitators to change that were unique to their status as post-treatment cancer survivors. These themes can be seen in Appendix 4 and are discussed in detail below.

Table 1. Demographic and clinical characteristics of study participants

<b>Age in years</b>	
Mean	68.84
SD	10.76
Range	44-90
<b>Sex</b>	
Male	18
Female	14
<b>Type of Cancer</b>	
Prostate	13 (5 on active surveillance)
Breast	11
Colon	8
<b>Years since treatment<sup>1</sup></b>	
Mean	3.81
SD	2.60
Range	0-9
<b>Education level</b>	
No education	2
Secondary school	9
College/sixth form (post-secondary)	10
Undergraduate	4
Postgraduate	7

<sup>1</sup>Excluding five participants on active surveillance

### Motivation to change behaviour leads to behaviour change

Some cancer survivors were motivated to change their health behaviours after cancer treatment. Participants described how they had adopted a healthier lifestyle in order to maintain health and prevent cancer recurrence.

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*“You think about what went wrong with you and to try and keep yourself healthy so it doesn't happen again, really, isn't it? That's the thing. Yeah, just try and look after yourself the best you can.”* (Prostate, 6 years post-treatment).

The drive to feel better after treatment helped individuals to persevere with behaviour change despite persistent treatment-related side effects. Others did not want to be seen as a victim and felt that adopting a healthy lifestyle helped them to feel better, empowered, and able to move on after cancer.

### **Motivation, but no behaviour change**

Most participants recognised that lifestyle changes could be beneficial after cancer. However, many described reasons for not changing their behaviour. These are outlined in the two sub-themes below.

#### Absence of support from healthcare professionals (HCPs) after cancer ends

Despite recognising the potential health benefits of behaviour change, many felt motivation was hampered by HCPs failing to understand the experience of cancer survivors. Many were uncertain about how to adopt lifestyle changes after cancer, describing a perceived lack of advice and support following treatment completion.

*“Yes they were helpful when you're there, but that's not usually the time that you're having any problems, that's just having your particular treatment at that time. When you have to deal with it by yourself, when you're at home and not at the hospital... I didn't feel that they were assisting in what you needed once you've left”.* - Prostate cancer, 78, 3 years after treatment

The timing of support right after treatment was considered especially important for participants.

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*"Nobody ever told me...I had to work that out over time...Whereas if somebody had given me that list [of healthy foods] at the beginning, that would have been an idea."*

(Prostate, active surveillance)

Participants were concerned about making behaviour changes because they felt that they had figured out what worked best for them and worried about what the impact of these changes might be on their body.

*"I've got a fear of changing the diet I eat... if I try a new eating plan, it's going to throw my body out."* (Colon, Male, 7 years post-treatment)

A number of participants explored various sources of information to find answers and support regarding lifestyle change. Many were confused by contradictory advice, or information that was difficult to understand.

*"you shouldn't eat this, you shouldn't eat that', and there's just too much... out there that conflicts. Where do you start, where do you stop with everything?"* (Breast, female, less than a year since treatment)

Occasionally, due to a perceived lack of support from HCPs, participants reported feelings of uncertainty about how to approach lifestyle changes *"I think they give you this treatment and then they send you home and you're just left... you don't know what you can do and what you can't do."* (Prostate, active surveillance)

### Recognition of treatment side effects and a need to be realistic about behaviour change

Cancer and treatment side-effects were frequently seen as a barrier to implementing behaviour change.

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*"I know that exercise will help improve my lifestyle. But how do you exercise when your body won't allow you to?" (Prostate, 2 years post-treatment).*

Participants suggested that cancer treatment and medications made it more difficult to make changes. Some noted that cancer had led to muscle-loss that they believed would not be regained through exercise. Others spoke about weight-gain due to therapies. This was seen as difficult to change due to ongoing hormonal therapies.

*"I do think tamoxifen has a lot to answer for. I can't seem to shift the weight as easy as I used to. So I'd rather take it and be overweight than not take it." (Breast, female, 3 years post-treatment).*

Many argued that acceptance of and adaptation to physical limitations due to cancer was a key first step when trying to change behaviour.

*"We have got physical limitations and the drugs have caused us joint problems and all the rest of it. And it's about accepting that, and not making a big deal out of it ... just that's how it is." (Breast, <1year post-treatment).*

*"I think the key thing is realising you can't do you as much as you used to do. I used to go swimming with my kids and now after twenty minutes I'm tired. I'll just sit at the side while you two carry on. Whereas I used to be able to have a couple of hours, quite happily." (Breast, <1year post-treatment)*

A number of people felt that post-cancer wellbeing campaigns often failed to include realistic role-models. Many had been exposed to health promoting materials that failed to recognise the impact of cancer and its treatment. Examples of perceived 'high achievers' or 'over-achievers' who had accomplished successful health behaviour change were viewed as intimidating. Participants suggested that this

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resulted in reduced motivation to engage in behaviour change and that they would prefer interventions that acknowledged the difficulties faced by those after cancer treatment.

*"...you read so many stories of people that have overcome all sorts, but then they've gone so much bigger and better than I could ever dream of. I couldn't even have done before I had treatment, let alone after. And that is actually quite demotivating"*

(Breast, female, 2 years post-treatment).

### Decision not to change health behaviours after cancer

#### Rejection of the link between cancer and behaviour

Many felt confident that they had led a healthy lifestyle before cancer, and therefore did not need to change behaviour.

A number decided not to change their health behaviours, stating that they did not wholly accept the link between health behaviour and cancer. Participants often reported that their health behaviours were not implicated in causing cancer or cancer recurrence.

*"I think you could eat fruit and veg all day long but it's not going to stop you getting cancer..."* (Prostate, active surveillance).

Some were uncertain or unconvinced that changing their behaviour could have a substantial effect on their health:

*"Eating foods, healthy, it might make you feel good but you still have cancer. You might feel better in yourself but no way are you ever going to get back to normal."*

(Prostate, 6 years post-treatment).

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Participants sometimes compared themselves to others and concluded that their behaviour had not led to their cancer. Some described individuals who they perceived as having healthy lifestyles who had nevertheless had cancer or who had died at a young age. Others cited examples of those with unhealthy behaviours who had lived for many years.

*“Now, I smoked for forty-seven years, – they say smoking destroys your heart, meat destroys your heart, and lack of exercise destroys your heart. I’ve survived seventy-eight years on what I’ve been doing. I was older than my mother and father when they died, you know? So, my lifestyle hasn’t been that bad.”* - (Colon, Male, 2 years post-treatment)

A few participants seemed to find acknowledging a link between behaviour and cancer too challenging, as it induced feelings of guilt.

*“I would feel very guilty if I thought that our eating habits had caused me to have cancer. I just put it down to a kick in the teeth by life, that's just one of the things that happens. It's bad enough having it. My attitude is not ‘Why me?’, but ‘Why not me?’  
But now this is saying ‘It's your fault.’* (Breast, female, 3 years post-treatment).

### Other factors people take into account when considering/rejecting behaviour change

Individuals felt it was difficult to change their behaviour due to comorbidities they had had prior to the onset of cancer. Some were afraid that making lifestyle changes could affect self-management of pre-existing comorbidities.

*“It hasn’t been just after the cancer, I’ve always had back and joint problems. I use the stair lift because my knees are so painful going up and down the stairs, I did try*

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*to use it less, but I was frightened of falling.” - (Breast, female, 3 years post-treatment).*

*“I think you should, when you’ve got multiple problems like me, check with the doctor. Before you overdo it” – (Breast, female, 2 years post-treatment).*

Cancer had led many participants to reappraise their life and priorities. Newfound priorities were not always linked to changing health behaviours. Some felt that they would restrict or limit themselves by focusing too much on lifestyle changes.

Participants also referred to a newfound awareness that life is short and a need to enjoy it to the fullest. Some explicitly contradicted the view of cancer being a teachable moment for behaviour change, stating that the cancer experience had led to reduced motivation to change behaviour.

*“All those years I was watching the weight. When they tell you you’ve got cancer, you think oh for God’s sake, to Hell with it all, you know? If I want something I have it now.” (Breast, 5 years post-treatment).*

Another participant spoke about prioritising family-time, saying

*“if it suddenly said oh you’ve got to go and do three hours running a day, no... that’s three hours away from my family. They had enough time away from me while I was ill...” (Breast, female, less than 1 year post-treatment).*

## Conclusions

We have highlighted cancer-specific barriers to lifestyle change that are particular to the experience of post-treatment cancer survivors. We have also extended the existing literature that has often focused on barriers to behaviour change which are

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generic across conditions but are not unique to the experience of cancer survivors [12-15]. Participants varied greatly in the extent to which they chose to make lifestyle changes after treatment, due to their idiosyncratic needs and the experience of having cancer. This study offered a novel insight into the decision-making and prioritisation that people engage in when asked about changing health behaviours.

In keeping with existing literature that proposes that coming to the end of successful cancer treatment might represent a 'teachable moment'[6], some people reported implementing positive lifestyle changes. Beeken et al [16] noted that behaviour change was often motivated by a desire to remain generally healthy rather than to prevent recurrence. Survivors reported making or attempting some changes after cancer, with diagnosis often serving as an impetus for lifestyle change [16]. In contrast, we found that for most individuals, there appeared to be many other issues likely to negatively impact on behaviour change, and would have to be addressed to make it a teachable moment. Most interviewees could see the benefits of behaviour change but described generic (Appendix 3) and cancer-specific barriers that had prevented change. As with previous research [8, 9], a lack of confidence and support were often cited as reasons for not changing behaviour. Participants also reported uncertainty about whether any changes they had made were appropriate or sufficient for cancer survivors and did not want to make changes without explicit guidance from their HCP. Previous studies have also reported that participants received little information from health professionals relating to engaging in PA, with participants searching for information via media and websites[17]. Confusion about how to implement changes is likely to reduce motivation to make lifestyle changes [23]. It appears that (for many) there is the potential for a "teachable moment", but this



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opportunity to promote behaviour change is not always promoted by HCPs in a timely and context-specific manner.

Another common view was that behaviour change was unnecessary or undesirable. Many were confident that they had led a sufficiently healthy lifestyle before the onset of cancer. Scepticism regarding the influence of behavioural factors in causing cancer could be influenced by a belief that their diet was healthy prior to cancer [24]. Participants in the current study frequently mentioned the role of non-modifiable factors such as family history of cancer or chance. Beliefs that health is controlled by luck or chance are negatively associated with engaging in health-promoting lifestyle [25]. Over-estimation of the influence of non-modifiable factors may be part of a coping strategy to avoid a sense of blame [12]. In our sample, cancer survivors reported they would feel indirectly blamed for their cancer and potentially experience guilt if they were to believe that cancer was possibly “their fault” and attributable to their lifestyle. Perceived overly optimistic expectations of cancer survivors portrayed in the media sometimes led to feelings of stress, or feeling that they should be able to do more. In an intervention setting, this could potentially lead to participants becoming defensive or rejecting the advice given [26].

Behaviour change also appeared impeded by cancer-related side-effects and the influence of the cancer experience on the management of pre-existing comorbidities. Similar findings have been reported elsewhere [17, 27]. Cancer survivors with comorbid diseases often prioritize one chronic condition or symptom over another and many struggle to integrate various self-care strategies into their routine [28]. The current study highlighted that health-related concerns can pose genuine barriers to behaviour change even when cancer survivors are motivated to engage in lifestyle changes. Some of these issues are summarised in Appendix 2 which outlines

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identified barriers, and suggested actions that HCPs could take to potentially enhance engagement with lifestyle change.

### **Strengths and Limitations**

Participants were presented with a digital intervention for PA ("*Getting Active*") and healthy eating ("*Eat for Health*") to elicit perceptions about the websites and about both behaviours. The discussions surrounding barriers to behaviour change may have been more realistic than if participants had been asked their thoughts on hypothetically making behaviour changes, rather than discussing the content presented in the intervention.

Individuals who were not interested in behaviour change may have been less likely to participate. However, we found that people often took part for altruistic reasons, suggesting that the behaviour change aspect of the intervention was not a deterrent. The intervention also included a module that focused on stress management, which may have attracted some participants (data focussing on perceptions of this module is not presented here). As evident in the themes, some participants were not interested in behaviour change, providing an insight into this group. Our findings are therefore transferable as they could be applicable to those who did not self-select to take part.

When using multiple interviewers, there are likely to be discrepancies between styles, potentially leading to variation in information disclosed by the participant. Efforts were made to reduce this by producing an interview schedule. All interviewers took part in a training workshop led by KB to promote consistency.

### **Clinical implications**

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Our research has highlighted barriers to behaviour change following treatment for cancer that may be important to consider when developing interventions to support lifestyle changes in cancer survivors. Our findings highlight a need to acknowledge and respect genuine health-related barriers, as well as conflicting priorities of cancer survivors. Overly positive expectations for behaviour change may be rejected as unrealistic and unwanted. It cannot be assumed that cancer will lead to motivation to change; rather than a 'teachable moment', the period after cancer may be better conceptualised as an opportunity to engage in a dialogue about behaviour change priorities, preferences and needs for behaviour change support.

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### **Conflict of interest**

Teresa Corbett, Tara Cheetham, Andre Matthias Müller, Joanna Slodkowska-Barabasz, Laura Wilde, Adele Krusche, Alison Richardson, Claire Foster, Eila Watson, Paul Little, Lucy Yardley, and Kat Bradbury declare that they have no conflict of interest.

### **Author Contributions**

Teresa Corbett and Tara Cheetham should be considered joint first author. All authors made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data.

Kat Bradbury and Lucy Yardley led and supervised the study. Tara Cheetham, Andre Matthias Müller, Joanna Slodkowska-Barabasz, Laura Wilde, and Adele Krusche were involved in the planning of the study and conducted the interviews. Alison Richardson, Claire Foster, Eila Watson, and Paul Little contributed clinical expertise.

Teresa Corbett, Tara Cheetham, Andre Muller, Kat Bradbury, and Lucy Yardley drafted the manuscript. Each of the authors were involved in revising the manuscript critically for important intellectual content. All authors have given final approval of the version to be published.

**Appendices**

Appendix 1. Eligibility criteria for participation

Inclusion criteria:	Exclusion criteria
<ol style="list-style-type: none"> <li>1. Be identifiable from GP case records</li> <li>2. Not receiving palliative care</li> <li>3. Have internet access;</li> <li>4. Have poorer HRQoL: as assessed using the 2 item quality of life subscale of European Organization for Research and Treatment of Cancer) QoL questionnaire C30 instrument (version 3)[20] (EORTC) (i.e. scoring 4 or less out of 7 )</li> <li>5. Have at least one self-reported issue likely to be helped by the intervention, and</li> </ol>	<ol style="list-style-type: none"> <li>1. Has not had breast cancer, prostate cancer or colorectal cancer;</li> <li>2. Have finished primary treatment within the last 3 months or longer than 10 years ago;</li> <li>3. Currently receiving palliative care;</li> <li>4. Current serious mental health problem (such as schizophrenia, bipolar disorder, major depressive disorder with or without suicidality, major alcohol or drug problems, obsessive compulsive disorder);</li> <li>5. No internet access</li> </ol>

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<p>interested in using web-based support to improve diet or physical activity.</p>	<p>6. Do not have poor HRQoL: as assessed using the 2 item QoL subscale of EORTC*[20] (i.e. scoring greater than 4 out of 7 on average )</p>
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Appendix 2. Overcoming cancer specific barriers to behaviour change	
Potential barriers to behaviour change	How barriers might be overcome
Feeling blamed or pressurised into making changes after cancer	<ul style="list-style-type: none"> <li>• Avoid discourses which might be viewed as blaming the individual for their cancer (e.g. highlighting link between cancer and behaviour).</li> <li>• Positively framing messages that focus on wellbeing, rather than illness management discourses or risk of disease could enhance health messages. For example the wider benefits of making behavioural changes (such as increased energy, improved mood or memory) could be drawn on.</li> <li>• Facilitate choice of behaviour changes and respect the autonomy of individuals. In some cases individuals may choose not to make changes, or may only want to make changes in a specific area.</li> </ul>
Behaviour change in conflict with other priorities after cancer	<ul style="list-style-type: none"> <li>• Interventions could include discussion about cancer survivors' priorities to tailor suggestions to the values of participants as much as possible.</li> <li>• It might be useful to carefully consider enjoyable participation in valued roles and activities as an important feature of cancer survivor's HRQoL. This could be achieved by lessening the focus on "health" and emphasising the social or enjoyment benefits that could be achieved.</li> </ul>
Perceived absence of support from HCPs after cancer ends leads to uncertainty about how to adopt lifestyle changes	<ul style="list-style-type: none"> <li>• At discharge, cancer patients could be given brief written information or links to digital resources which provide advice and support for making healthy behaviour changes. It is likely that healthcare practitioners endorsing these resources would persuade patients of their credibility[29, 30].</li> <li>• Train HCPs in signposting to existing support services after cancer treatment, as well as highlighting how these might complement existing support resources.</li> <li>• Digital interventions or HCPs could discuss concerns that patients have about changing routines after cancer and engaging in healthy behaviours.</li> </ul>
Confusion due to contradictory advice or information that is difficult to understand	<ul style="list-style-type: none"> <li>• Clear guidance and information from credible and reputable sources could be provided in an easily accessible format. Interventions may include content designed to challenge misinformation relating to post-cancer care. HCPs recommending such resources, explicitly acknowledging the vast amount of advice out there and noting that this</li> </ul>

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	<p>resource is the most sensible approach for the patient would enhance credibility of such guidance.</p> <ul style="list-style-type: none"> <li>• Where possible, individuals could also be encouraged to discuss any confusion about their health and lifestyle changes with a HCP.</li> </ul>
<p>Cancer treatment, pre-existing comorbid diseases and medications made it more difficult to make changes</p>	<ul style="list-style-type: none"> <li>• Interventions might be improved by acknowledging genuine health-related barriers that people may face and showing how these can be overcome, or in many cases helped by engaging in health behaviours (e.g. pain, fatigue, depression can be helped by PA).</li> <li>• Carefully designed interventions could be tailored to address age-related or QoL issues. These could acknowledge problems that people may face and providing support to overcome these where possible.</li> <li>• Acceptability may be enhanced by including strategies that may also benefit overlapping symptoms and facilitate self-management of ongoing side effects and pre-existing comorbidities.</li> </ul>
<p>Perceived unrealistic expectations about what a cancer survivor should be able to achieve after cancer</p>	<ul style="list-style-type: none"> <li>• Avoid perpetuating unrealistic messages about cancer survivorship by promoting achievable changes that people can build on to accomplish their goals.</li> <li>• Appropriate role models and case studies could be used to avoid promotion of unrealistic messages about cancer survivorship, to acknowledge difficulties with change and model how people overcome such barriers.</li> </ul>



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Appendix 3. Non-cancer specific barriers and facilitators for behaviour change cited by participants.		
Theme	Code	Explanation of code
<b>Mistrust of experts and advice</b>	Doubt about information from experts and research evidence	Includes discussion of: <ul style="list-style-type: none"> <li>• Contradictions between health guidance and reality</li> <li>• Uncertainty about research evidence</li> <li>• Evidence from 'them' isn't trusted – who are they?</li> <li>• Personal experience that contradicts information from experts</li> <li>• Evidence/guidelines change over time so people lack trust in them               <ul style="list-style-type: none"> <li>○ Research can be biased by researcher's assumptions or aims</li> <li>○ Guidelines always changing</li> </ul> </li> </ul>
	Information from the media (websites/newspapers/TV) is trusted	Includes discussion of: <ul style="list-style-type: none"> <li>• Trusted sources of information online or in the media, as well of sources that are not considered useful.</li> <li>• Focuses on media coverage of health behaviour topics such as being more active or what constitutes a healthy diet.</li> </ul>
<b>Personal beliefs and knowledge</b>	Personal knowledge of healthy eating and exercise affects beliefs and behaviour	Includes discussion of: <ul style="list-style-type: none"> <li>• Knowledge about the benefits of health behaviour change</li> <li>• Influence of past experience of health behaviour change, comparison to people who haven't had similar past experiences</li> <li>• A wide range of beliefs have been coded relating to specific food types discussed, e.g. alcohol, dairy, fish, meat, processed foods, superfoods, wholegrain foods</li> </ul>
	Beliefs about outcomes of behaviour change	Negative outcomes of unhealthy lifestyle <ul style="list-style-type: none"> <li>• Obesity as a consequence of unhealthy eating</li> <li>• Inactivity can lead to obesity and further health problems</li> </ul> Positive outcomes of healthy lifestyle <ul style="list-style-type: none"> <li>• Activity can make you feel energised rather than tired</li> <li>• Benefits of healthy eating include living longer and feeling better</li> <li>• Exercise and tiredness as a vicious circle: Not doing enough exercise weakens your body, making it hard to get back into exercising</li> </ul>

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<b>Perceived need to change behaviour (or not)</b>	Already has changed/ Could do more	<ul style="list-style-type: none"> <li>• Belief that they already have a healthy lifestyle</li> <li>• Wants to do more/ Motivated to change</li> </ul>
<b>Perceptions of others</b>	Feels they are different to other people	<p>Includes negative perceptions of what it means to 'be healthy' or who can/should change behaviour</p> <ul style="list-style-type: none"> <li>• Likes exercise and thinks maybe other people don't</li> <li>• Negative perception of someone who eats healthily</li> <li>• Inactive people as couch potatoes</li> <li>• Social comparison (e.g. spouse, peers etc.)</li> </ul>
	Barriers as false or non-existent	<p>Includes positive perceptions of what it means to 'be healthy' or who can/should change behaviour:</p> <ul style="list-style-type: none"> <li>• Anyone can do more activity: Any barriers given are just excuses</li> <li>• There is a right and wrong state of mind to have</li> </ul>
<b>Support to have a healthy lifestyle</b>	Social support as beneficial for health behaviours and lack of support as detrimental to health	<p>Includes discussion of factors that are likely to lead to successful behaviour change including:</p> <ul style="list-style-type: none"> <li>• To make health behaviour changes you need the right information and encouragement.</li> <li>• Positive/supportive influence of other people and support groups               <ul style="list-style-type: none"> <li>○ More likely to change with other people than on your own</li> </ul> </li> <li>• Spousal support and motivation</li> <li>• Electronic tools such as Wii fit programme as motivational support</li> </ul>
<b>General barriers to behaviour change</b>	Non cancer-specific barriers to behaviour change	<p>Barriers cited included:</p> <ul style="list-style-type: none"> <li>• Cost: Healthy eating as expensive</li> <li>• Ageing:           <ul style="list-style-type: none"> <li>○ Behaviour change just for young people (e.g. Vegetarianism)               <ul style="list-style-type: none"> <li>▪ Perception that younger people more likely to change their habits</li> </ul> </li> <li>○ Age impacts their desire to try new foods</li> <li>○ Perception that older people who have disabilities can't be more active</li> </ul> </li> <li>• Motivation/ lack of motivation           <ul style="list-style-type: none"> <li>○ Dislike of healthy eating/exercise</li> <li>○ Change as too hard/too much effort</li> </ul> </li> </ul>

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		<ul style="list-style-type: none"> <li>• Fear of harm: Worries about pain and harm to self</li> <li>• Comorbidities/ other illnesses</li> <li>• Lack of time</li> </ul>
<b>Overcoming barriers to behaviour change</b>	Overcoming barriers by using behaviour change techniques	<ul style="list-style-type: none"> <li>• Traffic light system to help participants to make healthier choices (Foods are categorised as green, amber, or red to show users at a glance if a food is has low, medium, or high amounts of fat, saturated fat, sugars and salt, helping them to achieve a better balance).</li> <li>• Recipes give people ideas – overcoming the barrier of not knowing how to eat healthily</li> <li>• Reminders could help people to overcome barriers such as forgetting about their activity goals</li> <li>• Goal setting and monitoring progress are helpful             <ul style="list-style-type: none"> <li>• Goals give you something to aim for</li> <li>• Monitoring goals is good as you can track progress and see if you feel better</li> </ul> </li> </ul>
	Discipline and self-motivation important for behaviour change	<ul style="list-style-type: none"> <li>• Discipline and self-motivation to exercise</li> <li>• Importance of moderation in changing behaviour</li> <li>• The role of habits             <ul style="list-style-type: none"> <li>○ Bad habits are hard to break but having a healthy habit helps keep up healthy behaviour</li> <li>○ Easy to get into the habit of being inactive but hard to break out of the habit</li> </ul> </li> </ul>

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Appendix 4. Summary of identified themes		
Theme	Sub-theme	Explanation of code
Motivation to change behaviour reported as leading to behaviour change		This theme addresses cases where people described making changes after cancer and illustrated an understanding of the importance of changing behaviour after/because of having had cancer.
Motivated to change behaviour but do not make behaviour change	Absence of support after cancer ends	This sub-theme refers to reports of people feeling alone after treatment and in need of advice and support. This includes discussions of finding information conflicting and confusing.
	Recognition of treatment side effects and a need to be realistic about behaviour change	This sub-theme describes comments by participants who reported physical limitations, side effects, and emotional consequences that are attributed to cancer and its treatment. This incorporates concerns about behaviour change after cancer specifically, as well as the impact of comorbidities as barriers to attempts to change behaviour.
Decision not to change health behaviours after cancer	Rejection of the link between cancer and behaviour	This theme refers to patients' understandings of what causes cancer and how these perceptions are likely to influence their responses to advice regarding behaviour change.
	Changing behaviour and life after treatment ends	This theme describes comments relating to how participants had reappraised their life and priorities after cancer. The theme includes beliefs about perceived conflicts between recommendations to change and priorities relating to social life and family. The theme also includes references to beliefs about the implications of cancer on what is possible and/or what is a priority.

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### References

1. Maddams, J., M. Utley, and H. Møller, *Projections of cancer prevalence in the United Kingdom, 2010–2040*. *British journal of cancer*, 2012. **107**(7): p. 1195-1202.
2. Ligibel, J.A., et al., *American Society of Clinical Oncology position statement on obesity and cancer*. *Journal of clinical oncology*, 2014. **32**(31): p. 3568-3574.
3. Blanchard, C.M., K.S. Courneya, and K. Stein, *Cancer survivors' adherence to lifestyle behavior recommendations and associations with health-related quality of life: results from the American Cancer Society's SCS-II*. *Journal of Clinical Oncology*, 2008. **26**(13): p. 2198-2204.
4. Cramp, F. and J. Byron-Daniel, *Exercise for the management of cancer-related fatigue in adults*. The Cochrane Library, 2012.
5. Buffart, L., et al., *Evidence-based physical activity guidelines for cancer survivors: current guidelines, knowledge gaps and future research directions*. *Cancer treatment reviews*, 2014. **40**(2): p. 327-340.
6. Demark-Wahnefried, W., et al., *Riding the crest of the teachable moment: promoting long-term health after the diagnosis of cancer*. *Journal of Clinical Oncology*, 2005. **23**(24): p. 5814-5830.
7. Rabin, C. and B. Pinto, *Cancer-related beliefs and health behavior change among breast cancer survivors and their first-degree relatives*. *Psycho-Oncology*, 2006. **15**(8): p. 701-712.
8. Hardcastle, S.J., et al., *A qualitative study exploring health perceptions and factors influencing participation in health behaviors in colorectal cancer survivors*. *Psycho-Oncology*, 2017. **26**(2): p. 199-205.
9. Hefferon, K., et al., *Understanding barriers to exercise implementation 5-year post-breast cancer diagnosis: a large-scale qualitative study*. *Health education research*, 2013: p. cyt083.
10. Ottenbacher, A.J., et al., *Exercise among breast and prostate cancer survivors—what are their barriers?* *Journal of cancer survivorship*, 2011. **5**(4): p. 413-419.
11. Ventura, E.E., et al., *Barriers to physical activity and healthy eating in young breast cancer survivors: modifiable risk factors and associations with body mass index*. *Breast Cancer Research and Treatment*, 2013. **142**(2): p. 423-433.
12. Jerant, A.F., M.M.v. Friederichs-Fitzwater, and M. Moore, *Patients' perceived barriers to active self-management of chronic conditions*. *Patient Education and Counseling*, 2005. **57**(3): p. 300-307.
13. Bayliss, E.A., et al., *Descriptions of Barriers to Self-Care by Persons with Comorbid Chronic Diseases*. *The Annals of Family Medicine*, 2003. **1**(1): p. 15-21.
14. Leslie, J.H., et al., *Factors Affecting Healthy Eating and Physical Activity Behaviors Among Multiethnic Blue- and White-collar Workers: A Case Study of One Healthcare Institution*. *Hawai'i Journal of Medicine & Public Health*, 2013. **72**(9): p. 300-306.
15. Musaiger, A.O., et al., *Perceived Barriers to Healthy Eating and Physical Activity among Adolescents in Seven Arab Countries: A Cross-Cultural Study*. *The Scientific World Journal*, 2013. **2013**: p. 232164.
16. Beeken, R., et al., *"What about diet?" A qualitative study of cancer survivors' views on diet and cancer and their sources of information*. *European journal of cancer care*, 2016. **25**(5): p. 774-783.
17. Smith, L., et al., *Cancer survivors' attitudes towards and knowledge of physical activity, sources of information, and barriers and facilitators of engagement: A qualitative study*. *European Journal of Cancer Care*, 2017.
18. Stull, V.B., D.C. Snyder, and W. Demark-Wahnefried, *Lifestyle interventions in cancer survivors: designing programs that meet the needs of this vulnerable and growing population*. *The Journal of nutrition*, 2007. **137**(1): p. 243S-248S.

## Exploring cancer survivors' views of health behavior change

19. Bradbury, K., Steele, M., Corbett, T., Heber, E., Payne, L., Singh, K., Geraghty, A., Richardson, A., Watson, E., Foster, C., Little, P., Yardley, L., *Planning an intervention for cancer survivors: an evidence, theory and person-based approach*. In preparation.
20. Tong, A., P. Sainsbury, and J. Craig, *Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups*. International journal for quality in health care, 2007. **19**(6): p. 349-357.
21. Allemani, C., et al., *Global surveillance of cancer survival 1995–2009: analysis of individual data for 25 676 887 patients from 279 population-based registries in 67 countries (CONCORD-2)*. The Lancet, 2015. **385**(9972): p. 977-1010.
22. Yardley, L., et al., *The person-based approach to intervention development: application to digital health-related behavior change interventions*. Journal of medical Internet research, 2015. **17**(1): p. e30.
23. Julian-Reynier, C., et al., *Risk communication strategies: state of the art and effectiveness in the context of cancer genetic services*. European journal of human genetics, 2003. **11**(10): p. 725-736.
24. Anderson, A.S., R. Steele, and J. Coyle, *Lifestyle issues for colorectal cancer survivors—perceived needs, beliefs and opportunities*. Supportive Care in Cancer, 2013. **21**(1): p. 35-42.
25. Frank-Stromborg, M., et al., *Determinants of health-promoting lifestyle in ambulatory cancer patients*. Social science & medicine, 1990. **31**(10): p. 1159-1168.
26. Deimling, G.T., K.F. Bowman, and L.J. Wagner, *Cancer survivorship and identity among long-term survivors*. Cancer investigation, 2007. **25**(8): p. 758-765.
27. Fisher, A., et al., *Perceived barriers and benefits to physical activity in colorectal cancer patients*. Supportive Care in Cancer, 2016. **24**(2): p. 903-910.
28. Zulman, D.M., et al., *Quality of care for patients with multiple chronic conditions: the role of comorbidity interrelatedness*. Journal of general internal medicine, 2014. **29**(3): p. 529-537.
29. Yang, Q. and M. Beatty, *A meta-analytic review of health information credibility: Belief in physicians or belief in peers?* Health Information Management Journal, 2016. **45**(2): p. 80-89.
30. Avery, E.J., *The role of source and the factors audiences rely on in evaluating credibility of health information*. Public Relations Review, 2010. **36**(1): p. 81-83.