LIFESTYLE INFORMATION FOR CANCER SURVIVORS

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A thesis submitted for the degree of Doctor of Philosophy

UNIVERSITY COLLEGE LONDON
DECLARATION

I, Kate Alice Williams, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.
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ABSTRACT

With increasing numbers of people surviving cancer, research attention has turned to how best to improve the health of cancer survivors. A healthy lifestyle, including not smoking, being physically active, having a healthy diet, drinking alcohol in moderation, and maintaining a healthy weight, has the potential to improve outcomes in this population. However, there are a number of unanswered questions regarding the health behaviours of cancer survivors in the United Kingdom (UK), and the lifestyle information available to them. This thesis used a range of methodologies to try and address some of these gaps in the literature. Study 1 showed that on a population level, there is little evidence that cancer survivors make positive changes to their lifestyle following their diagnosis. Study 2 found that cancer survivors think lifestyle is important, but receive little information to help them make changes. Study 3 found that only a minority of statutory and charity sector organisations and cancer centres provided sufficient information about lifestyle for cancer survivors on their websites, and the majority recommended that they seek professional advice. However, Study 4 revealed that awareness of lifestyle guidelines among health professionals is suboptimal, and although the majority reported giving lifestyle advice to their patients, there were also a number of barriers to giving such advice. Study 5 highlighted that cancer survivors and members of their social networks all thought that lifestyle advice for people diagnosed with cancer would be beneficial. Study 6 then showed that the proportion of cancer survivors meeting the recommended lifestyle guidelines is low, but encouragingly they think they need to change their lifestyle and are interested in advice to help them make these changes. Overall, these findings highlight a need for lifestyle information to be incorporated into the cancer care pathway, to ensure the best possible long-term outcomes for cancer survivors.
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<td>American College of Sports Medicine</td>
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<td>ADL</td>
<td>Activities of Daily Living</td>
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<td>ADT</td>
<td>Androgen-Deprivation Therapy</td>
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<td>AICR</td>
<td>American Institute for Cancer Research</td>
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<td>ASCOT</td>
<td>Advancing Survivorship after Cancer: Outcomes Trial</td>
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<tr>
<td>AUDIT-C</td>
<td>Alcohol Use Disorders Identification Test Consumption Questions</td>
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<td>BMI</td>
<td>Body Mass Index</td>
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<td>CI</td>
<td>Confidence Interval</td>
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<tr>
<td>CRN</td>
<td>Clinical Research Network</td>
</tr>
<tr>
<td>CR-UK</td>
<td>Cancer Research UK</td>
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<tr>
<td>DINE</td>
<td>Dietary Instrument for Nutrition Education</td>
</tr>
<tr>
<td>DoH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>DSM</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
</tr>
<tr>
<td>ELSA</td>
<td>English Longitudinal Study of Ageing</td>
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<tr>
<td>GEE</td>
<td>Generalised Estimating Equation</td>
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<td>Godin LTEQ</td>
<td>Godin Leisure-Time Exercise Questionnaire</td>
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<td>GPRD</td>
<td>General Practice Research Database</td>
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<tr>
<td>HBRC</td>
<td>Health Behaviour Research Centre</td>
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<td>HRS</td>
<td>Health and Retirement Study</td>
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<td>HSE</td>
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<td>IGF-1</td>
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<td>OECI</td>
<td>Organisation of European Cancer Institutes</td>
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LIST OF ABBREVIATIONS

SES: Socioeconomic Status  
SHBG: Sex Hormone Binding Globulin  
WCRF: World Cancer Research Fund  
WHEL: Women’s Healthy Eating and Living  
WINS: Women’s Intervention Nutrition Study
MY CONTRIBUTION TO THE RESEARCH IN THIS THESIS

I played a lead role in developing the thesis aims and designing each of the six studies, with input from my supervisors, Professor Jane Wardle, Dr Rebecca Beeken and Dr Abigail Fisher.

For Study 1, I was provided with data from the English Longitudinal Study of Ageing (ELSA), by Professor Andrew Steptoe, who directs the ELSA research group at UCL. I performed all the analyses myself, although I sought advice from a departmental statistician, Dr Ellen van Jaarsveld, on the most appropriate statistical methods to use.

For Study 2, qualitative interviews were carried out by myself (n=7), my supervisor, Dr Rebecca Beeken (n=6), and Dr Helen Croker (n=6), a colleague in the Health Behaviour Research Centre (HBRC) at UCL. I played a central role in designing the study materials and recruiting patients. The ethics application was completed by Dr Helen Croker. I independently developed the list of codes, coded the transcripts in NVivo and generated the themes. The list of themes was finalised with input from Dr Rebecca Beeken and Dr Helen Croker. I wrote the version of the study included in this thesis, and a separate version of the study, focusing only on diet, was written up for publication with me as a co-author.

I conducted all aspects of Study 3, but a selection of the websites (n=4) were checked by a student volunteer.

For Study 4, I designed the survey, developed the online questionnaire, applied for ethical approval and collected the data. This included contacting the organisations and asking them to send out my questionnaire. I designed and conducted all analyses independently.

Data for Study 5 were collected by an independent social research agency, as part of a larger survey. I developed the questions used for this study. The agency provided a file with the raw data. I designed and conducted all analyses independently.

Data for Study 6 were collected as part of a larger study (ASCOT) being conducted in the HBRC. I played a lead role in selecting and developing measures for use in this study.
completed the ethics and local research and development (R&D) applications myself and defended the study at the research ethics committee meeting. I met with the research sites to explain the study and recruited them to take part. I then delivered training on the study procedures and provided them with the study materials. I also developed the online version of the questionnaire. I coordinated the data entry of the paper questionnaires, but had help with inputting data from several students and members of staff in the HBRC. I cleaned the data and designed and conducted the analyses independently.
This PhD aimed to answer the following questions:

1. What are the health behaviours of cancer survivors, how do these change following a cancer diagnosis, and what factors are associated with meeting lifestyle recommendations?
2. Are cancer survivors aware of the potential benefits of a healthy lifestyle for their long-term health?
3. What lifestyle information is available to cancer survivors and what determines whether they receive such information?
4. Are cancer survivors interested in lifestyle information, what are their preferences regarding such information, and do cancer survivors and their social networks think lifestyle advice should be given to individuals diagnosed with cancer?
CHAPTER 1: CANCER SURVIVORSHIP

1.1 Defining ‘cancer survivorship’

The concept of cancer survivorship was first introduced in the 1980s in the paper ‘Seasons of survival: reflections of a physician with cancer’ in the *New England Journal of Medicine* (Mullan, 1985). Mullan, a cancer survivor himself, felt that defining cancer as cured or not cured did not fully capture the experience of many people living with cancer, for example, those undergoing treatment or living with cancer long-term. Instead he proposed the term ‘survival’ as this encompasses the many stages of the cancer experience. Various definitions of ‘cancer survivorship’ have been used by researchers over the years; however, major organisations typically use a broad definition in line with Mullan’s original ideology (American Cancer Society, 2015; National Cancer Institute, 2015a; WCRF & AICR, 2007). Therefore, for the purpose of this thesis I will adopt the definition of the World Cancer Research Fund (WCRF) and the American Institute of Cancer Research (AICR) which includes ‘all people who are living with a diagnosis of cancer, and those who have recovered from the disease’ (WCRF & AICR, 2007). In this definition, cancer survivorship begins at the point of diagnosis and includes those who are pre-treatment, receiving treatment, post-treatment and in recovery, as well as those with secondary cancers and second primary cancers.

1.2 Prevalence of cancer survivors

Data from the GLOBOCAN project\(^1\) indicate that in 2012 there were around 32.6 million people living with a cancer diagnosis worldwide (International Agency for Research on Cancer, 2012). In the UK, estimates from 2008 indicate that at this time there were around two million cancer survivors, equating to approximately 3% of the total population and 13% of the population over the age of 65 (Maddams et al., 2009). This figure is rising and recent estimates suggest that if current trends continue, almost a quarter of those aged 65 years and over in the UK will be living with a cancer diagnosis by 2040 (Maddams, Utley, & Møller, 2012). While these increases are partly due to

\(^1\) http://globocan.iarc.fr
increases in cancer incidence in recent decades (Jemal, Center, DeSantis, & Ward, 2010), they are also a testament to breakthroughs in cancer research including improvements in early detection and treatment that have led to many people now living for many years beyond their diagnosis.

The most common cancers in the UK are breast, lung, prostate and colorectal, accounting for over half of all new cases (13-15% each) (Cancer Research UK, 2014a). Of these, prostate and female breast cancers have been shown to be most prevalent, accounting for 31% and 46% of male and female cancers respectively (Maddams et al., 2009). However, despite its high incidence, lung cancer is among the least prevalent in the survivorship population as the one year survival is only 32.2% (Quaresma, Coleman, & Rachet, 2015). As a result, breast, prostate and colorectal cancer survivors are the most studied groups of survivors and the largest body of literature exists for these groups.

1.3 Impact of a cancer diagnosis

A cancer diagnosis can have a significant impact on a broad range of physical health and psychosocial factors. Although there are more than 200 different types of cancer and treatments vary considerably (Cancer Research UK, 2015), the majority of cancer survivors experience some adverse effects. These long-term and late effects can occur immediately after treatment or manifest themselves months or years later.

1.3.1 Physical health impact

1.3.1.1 Cancer recurrence

Cancer recurrence refers to a cancer that returns, usually after a period of time during which the cancer could not be detected (National Cancer Institute, 2015b). Cancer can recur in the same place as the original primary cancer or in another part of the body. When a cancer spreads to another part of the body this is called secondary or metastatic cancer. There are two main reasons why a cancer may recur (Cancer Research UK, 2014b). The first is because the original treatment did not successfully get rid of all the cancer cells and those which were left grew into another tumour. For example, this may happen if not all cancer cells are removed during surgery or if chemotherapy does not
successfully kill them all. The second reason why a cancer may recur is because some cancer cells had already spread to other parts of the body and had gradually formed a tumour there. All cancer survivors face a risk of cancer recurrence, but the extent of this risk depends on several factors including the type of cancer, the type of treatment and the time since diagnosis and treatment. In general, the more time that passes, the lower the risk of cancer recurrence.

1.3.1.2 Second primary cancers
An additional potentially serious adverse effect of a cancer diagnosis is an increased risk of second primary cancers. Distinct from cancer recurrence and secondary cancer, a second primary cancer refers to a new primary cancer that occurs in individuals with a history of cancer (National Cancer Institute, 2015c). The reasons for this increased risk are multi-factorial and include treatment effects, lifestyle, environmental and host factors, and interactions between these factors.

Radiotherapy is a common and highly effective therapy used to treat a wide range of cancers including breast, prostate and colorectal. However, despite its efficacy, it has also been associated with an increased risk of second primary cancers, usually solid tumours which occur close to the radiation site (Travis, Demark Wahnefried, Allan, Wood, & Ng, 2013). These most commonly occur among the survivors of Hodgkin Lymphoma (Hodgson et al., 2007) and testicular cancer (Travis et al., 2005), but increasingly data are becoming available for other sites including prostate and breast cancer. Analysis of data from the US Surveillance, Epidemiology and End Results (SEER) cancer registries found that 8% of second solid cancers were related to radiotherapy (Berrington de Gonzalez et al., 2011). However, given the observational nature of this study, there is the potential for confounding, for example, from other treatments or lifestyle factors (Berrington de Gonzalez et al., 2011). Also, as radiotherapy treatments have changed over recent years, this study included patients who had received older forms of radiotherapy and newer techniques may not pose the same risk.

The exact mechanisms linking radiotherapy with second primary cancers are not fully understood, but it has been proposed that radiation may damage DNA which may lead to gene mutations, followed by a malignant transformation of the radiated cells.
(Mullenders, Atkinson, Paretzke, Sabatier, & Bouffler, 2009). In addition, impairment to DNA repair proteins, which normally protect against DNA damage, has been shown to lead to increased sensitivity to radiation and increased susceptibility to cancer (A. M. R. Taylor & Byrd, 2005).

Chemotherapy has also been associated with second primary cancers, most commonly therapy-related myeloid neoplasms (Travis et al., 2013). For example, patients with multiple myeloma who receive lenalidomide maintenance therapy after high-dose therapy are at an increased risk of myelodysplastic syndrome and acute leukaemia (Attal et al., 2012; McCarthy et al., 2012). Data on solid tumours arising from patients treated with chemotherapy are more limited and are often the result of treatment for childhood cancers (Nottage et al., 2012; Veiga et al., 2012). Hormone therapies may also play a role; a recent meta-analysis of 20 trials found that Tamoxifen, a hormone therapy for treating oestrogen-receptor positive breast cancer, was associated with an increased risk of endometrial cancer among post-menopausal women (Early Breast Cancer Trialists' Collaborative Group (EBCTCG), 2011).

As with radiotherapy, the mechanisms linking chemotherapy with second primary cancers are not completely clear, but a number of pathways have been proposed. For example, the increased risk of myelodysplasia and acute myeloid leukaemia among the survivors of Hodgkin Lymphoma and ovarian cancer has been attributed to DNA damage caused by chemotherapy (J. Yang, Terebelo, & Zonder, 2012). Chemotherapy may also cause mutations in tumour suppression genes, hindering the body’s ability to prevent another cancer from developing (Travis, 2002).

In addition to treatment effects, genetic factors may also put cancer survivors at risk of second primary cancers. Women with breast cancer and a BRCA1 or BRCA2 mutation have been found to be at increased risk of developing ovarian cancer. In a study of 491 such women, the 10 year risk of developing ovarian cancer after breast cancer was 12.7% for BRCA1 carriers and 6.8% for BRCA2 carriers (Metcalfe et al., 2005). This study did not include a control group, but women with breast cancer who do not carry the BRCA genes have been reported to have no increased risk of ovarian cancer as a second
primary cancer (Travis et al., 2013). Although these results suggest an increased risk of second primary cancers due to genetic mutations, it is important to acknowledge the role of confounding factors, such as treatment effects. For example, in this study chemotherapy was associated with a non-significant decrease in ovarian cancer risk and Tamoxifen was associated with a non-significant increase (Metcalfe et al., 2005).

Lifestyle factors may also play an important role in the development of second primary cancers, although research in this area is still in its infancy. In a review and meta-analysis of observational studies examining outcomes for early stage lung cancer, continued smoking was associated with over four times the risk of a second primary cancer compared with those who quit smoking at diagnosis (Parsons, Daley, Begh, & Aveyard, 2010). However, as with all observational studies, it is not possible to rule out the possibility of confounding. Two of the included studies reported baseline differences, and the findings were limited to patients with early stage disease so outcomes may be different for those with advanced disease. The mechanisms linking lifestyle factors with cancer outcomes are discussed further in Chapter 2.

1.3.1.3 Fatigue

In addition to their increased risk of chronic disease and second primary cancers, cancer survivors face a range of physical symptoms both acutely after diagnosis and over the longer term. Fatigue is one of the most commonly reported cancer-related symptoms and has been defined as a persistent subjective sense of physical, emotional, or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and that significantly interferes with usual functioning (Mock et al., 2000). Fatigue has adverse consequences on both patients’ functional abilities and their quality of life (Wagner & Cella, 2004), and has been reported as one of the most important and distressing symptoms related to cancer and its treatment (Stone et al., 2000). However, it is difficult to determine the exact prevalence due to the heterogeneity of samples and the different definitions and instruments used to assess it. This has led to prevalence estimates of between 4% and 91% depending on the population studied (Lawrence, Kupelnick, Miller, Devine, & Lau, 2004).
While fatigue generally occurs during cancer treatment or immediately afterwards (Lawrence et al., 2004), there is evidence that it can persist for several years. A review of the prevalence of fatigue among disease-free breast cancer survivors found that some patients were experiencing significantly higher levels of fatigue to the general population up to five years post-treatment (Minton & Stone, 2008). Heterogeneity in the self-reported measures of fatigue used meant it was difficult to determine the severity of persistent fatigue, although some of the included studies suggested it decreased over time.

The causes of fatigue among cancer survivors are multi-factorial and are likely to vary according to the type of cancer, stage of disease and treatment received. There is some evidence that fatigue may be linked to the body’s immune response to cancer, as studies have found higher serum levels of several markers associated with pro-inflammatory cytokine activity among cancer survivors who were fatigued (Bower, Ganz, Aziz, & Fahey, 2002; Bower, Ganz, Aziz, Fahey, & Cole, 2003). There is some evidence that fatigue is associated with disruption to the circadian rhythm (Roscoe et al., 2002), as this has been shown to be altered by cancer (Mormont et al., 1998). Other symptoms and side effects of cancer and its treatment have also been shown to be associated with fatigue including pain, depression, sleep disturbances and anaemia (Ahlberg, Ekman, Gaston-Johansson, & Mock, 2003; Bower et al., 2000).

1.3.1.4 Pain

Cancer-related pain is a common problem among cancer survivors and can contribute to depression and decreased quality of life (Pachman, Barton, Swetz, & Loprinzi, 2012). A review and meta-analysis found that pain was most prevalent among cancer patients with advanced disease (64%), but approximately 33% patients continued to experience pain after curative treatment (van den Beuken-van Everdingen et al., 2007). In advanced disease pain is usually a result of the tumour, but cancer survivors who have received curative treatment tend to experience treatment-related pain (Pachman et al., 2012). A recent review found that the majority of cancer treatments have the potential to cause pain, including surgery, radiotherapy, chemotherapy, hormonal therapy and haematopoietic cell transplantation (Glare et al., 2014). However, as patients often
receive more than one type of treatment it can be difficult to determine the exact cause of their pain.

1.3.1.5 Cognitive impairments

Cognitive impairment has been defined as changes in cognition that have a negative effect on higher-order mental processes (Hess & Insel, 2007). A recent review found that between 17% and 75% of cancer survivors report some level of cognitive impairment, with deficits in memory, attention and concentration, speed of processing, and executive functioning being the most common (Von Ah, 2015). In one study examining the health profiles of a mixed group of 5,836 long-term cancer survivors, memory loss affected around 8% patients overall but was particularly common among those with gastrointestinal cancers (15.3%), acute leukaemia and lymphoma (both 14.7%) (Schultz, Beck, Stava, & Vassilopoulou-Sellin, 2003). However, this study did not examine the possible reasons for the higher levels of memory loss in these patient groups. Another study found that memory and attention concerns were more prevalent among cancer survivors who had received haematopoietic cell transplantation (20%) than among case-matched controls (7%) (Syrjala, Langer, Abrams, Storer, & Martin, 2005).

Cognitive impairments such as these are partly due to individual differences such as age, menopausal status, co-morbidities and medication use (Bender, Ergyn, Rosenzweig, Cohen, & Sereika, 2005), but may also be a consequence of some cancer treatments. The term ‘chemo-brain’ has been widely used by patients to describe perceived cognitive decline following chemotherapy, but evidence linking the two has been inconsistent (Kayl, Wefel, & Meyers, 2006). This may in part be due to differences in methodologies as the majority of studies to date have been retrospective, did not include pre-treatment measures of cognition, had heterogeneous samples or measures of cognition, or did not have a control group. However, it is possible that some groups of patients are adversely affected by cancer treatment whereas others are not.
1.3.1.6 **Physical function**

The presence of cancer and physical symptoms (as described above) may have an impact on cancer survivors’ physical functioning. In a study of health and disability among 4,878 cancer survivors and 90,737 controls who had no history of cancer, cancer survivors were more likely to report being in fair or poor health (29.8% vs. 10.5%), to have limitations in activities of daily living (ADLs) (11.3% vs. 3.2%), to have functional limitations (58.1% vs. 28.5%), and to be unable to work because of a health condition (16.8% vs. 5.0%) (Hewitt, Rowland, & Yancik, 2003). However, this study was cross-sectional so it was not possible to infer causal associations between a cancer diagnosis and physical limitations. The sample was also limited to non-institutionalised individuals so it is possible that there would be greater levels of impairment among those living in residential care or hospices. However, another study found that an even greater proportion of cancer survivors (75%) rated their health as fair or poor, which was significantly greater than those limited by cardiovascular disease or emotional problems (Richardson, Wingo, Zack, Zahran, & King, 2008). This study did not report data by cancer site and it is likely that levels of impairments may vary according to diagnosis and treatment.

1.3.1.7 **Cardiovascular disease**

Population-based studies have demonstrated that cancer survivors are at increased risk of cardiovascular disease compared with the general population. An analysis of 1.2 million cancer survivors in the SEER database found higher rates of circulatory malfunctions including cardiovascular disease among cancer survivors (B. W. Brown, Brauner, & Minnottte, 1993). More recently, a UK study used data from the General Practice Research Database (GPRD) to compare 26,213 breast, colorectal and prostate cancer survivors with matched controls (Khan, Mant, Carpenter, Forman, & Rose, 2011). They found an elevated incidence of heart failure (Hazard Ratio (HR) 1.95 [95% Confidence Interval (CI) 1.27-3.01]) and coronary artery disease (HR 1.27 [95% CI: 1.11-1.44]) among breast cancer survivors but no differences for the other cancer sites. However, due to a lack of information in the GPRD database, this study was unable to examine the possible causes of these increased risks. In particular, information about treatments was limited which may account for some of the incidences.
Cardio toxicity is a serious potential side effect of anticancer therapies and if not detected or treated promptly it can lead to increased mortality due to cardiac problems. A range of different cancer treatments have been associated with cardio toxicity, including several chemotherapy drugs and radiotherapy (Bovelli, Plataniotis, Roila, & ESMO Guidelines Working Group, 2010). Anthracyclines, a class of chemotherapy drug, have been shown to have a dose-response relationship with cardio toxicity. For example, in a pooled analysis of patients with breast cancer or small cell lung cancer, a 300mg/m\(^2\) dose of the anthracycline doxorubicin was associated with a 1.7% incidence of congestive heart failure, increasing to 4.7% at 400mg/m\(^2\), 15.7% at 500 mg/m\(^2\), and 48% at 650 mg/m\(^2\) (Swain, Whaley, & Ewer, 2003). The mechanisms surrounding this relationship are complex, but have been attributed to myocardial cell death during treatment and damage to the reparatory and homoeostatic mechanisms (Aleman et al., 2014).

Radiotherapy has also been associated with cardio toxicity. A recent review found an increased risk of morbidity and mortality from heart disease among those receiving radiotherapy for breast cancer (Aleman et al., 2014). However, this review included studies that used historic radiotherapy techniques and it is possible that the effect of newer techniques may be different. Radiation induced cardiovascular diseases are thought to be caused by injury to various structures and tissues of the heart. For example, radiotherapy has been shown to cause inflammation of the coronary arteries which can lead to premature coronary artery disease and atherosclerosis, which usually occurs around 10 to 15 years later (Bovelli et al., 2010).

There is mixed evidence for an increased risk of myocardial infarction and cardiovascular mortality following androgen-deprivation therapy (ADT) among men with prostate cancer (Saylor, Keating, & Smith, 2009). In this review, those studies which found no increased risk benefited from a randomised design and a long follow-up, whereas those which found an increased risk were observational studies with a relatively short follow-up. Nonetheless, the potential adverse impact of ADT should not be ruled out.

Metabolic syndrome is a term given to a group of cardiovascular disease risk factors that typically include decreased insulin sensitivity, hypertension, overweight and an adverse
lipid profile (Aleman et al., 2014). Many patients gain weight during cancer treatment (Kroenke, Chen, Rosner, & Holmes, 2005), which may in part explain their increased risk of cardiovascular disease, and highlights the importance of lifestyle post-diagnosis. In addition, cancer and cardiovascular disease share lifestyle-related risk factors such as smoking, which may account for some of the increased risk of cardiovascular disease among cancer survivors (Backer et al., 2003).

1.3.1.8 Osteoporosis

Osteoporosis is another common adverse effect of a cancer diagnosis. In the study which used GPRD data (described above), breast, prostate and colorectal cancer survivors all had an increased risk of osteoporosis compared with the general population (Khan et al., 2011). This was highest among prostate cancer survivors, which may in part be explained by the use of ADT, although limited treatment data were available. This hypothesis is supported by an earlier meta-analysis which found a 23% increased risk of fractures among men with prostate cancer who received ADT compared with those who did not (L. G. Taylor, Canfield, & Du, 2009). It is thought that this is because ADT depletes levels of circulating oestrogen and testosterone which are essential for maintaining bone mass (Hofbauer & Khosla, 1999; Pfeilschifter & Diel, 2000). Findings from a recent review suggest that Tamoxifen is associated with a loss of bone mineral density among women with pre-menopausal breast cancer, but appears to have the opposite effect in post-menopausal patients (Abdel-Razeq & Awidi, 2011). In addition to treatment effects, other factors such as suboptimal health behaviours including low levels of physical activity have been associated with increased risk of osteoporosis (Kesaniemi et al., 2001).

1.3.1.9 Type 2 diabetes

Cancer survivors have also been shown to be at an increased risk of type 2 diabetes, although much of the literature in this area has focused on the survivors of childhood cancers. In an analysis of 8,599 survivors in the Childhood Cancer Survivor Study, survivors were nearly twice as likely as their siblings to have diabetes (Meacham, Sklar, & Li, 2009). This appeared to be due to radiotherapy as the risk of diabetes increased among survivors who received total body irradiation (OR 12.6 [95% CI 6.2-25.3]),
abdominal irradiation (OR 3.4 [95% CI 2.3-5.0]), and cranial irradiation (OR 1.6 [95% CI 1.0-2.3]). Similar findings have been found for radiation to the pancreas (de Vathaire et al., 2012). A number of mechanisms have been proposed for the link between radiotherapy and diabetes, including the hypothesis that it causes damage to the pancreas which subsequently impairs insulin secretion (Meacham et al., 2009).

More limited research has been conducted among the survivors of adult cancers. A recent study found that two years after diagnosis, breast cancer survivors had a higher risk of diabetes compared with controls (HR 1.07 [95% CI 1.02-1.12]), and this was even higher 10 years after diagnosis (HR 1.21 [95% CI 1.09-1.35]) (Lipscombe et al., 2013). The mechanisms behind this increased risk were less clear, although the risk was highest in those who received adjuvant chemotherapy (HR 1.24 [95% CI 1.12-1.38]), suggesting that this may play a role. However, this dataset lacked information on hormonal treatments such as Tamoxifen which may also influence this risk. The analysis also did not control for body mass index (BMI) and this is likely to be an important factor given the known link between obesity and diabetes (Hartemink, Boshuizen, Nagelkerke, Jacobs, & van Houwelingen, 2006). This study also focused on post-menopausal breast cancer and as was shown above in relation to osteoporosis, findings may be different for pre-menopausal patients.

1.3.2 Psychosocial impact

As well as having serious physical health consequences, a cancer diagnosis is also associated with adverse psychosocial effects, including fear of recurrence, depression, employment issues, relationship issues, sexual dysfunction and impaired quality of life.

1.3.2.1 Fear of recurrence

Fear of recurrence is a near universal consequence of cancer survivorship that has been found to continue to affect cancer survivors for more than five years beyond their diagnosis (Koch, Jansen, Brenner, & Arndt, 2013). Prevalence estimates vary considerably as they have been found to be determined by a number of factors including age, cancer site, stage, and treatment type (Crist & Grunfeld, 2013). One study found that fear of recurrence was a top ranking problem experienced by cancer
survivors, but prevalence ranged from 48.8% among prostate cancer survivors to 74.2% among lung cancer survivors (F. Baker, Denniston, Smith, & West, 2005).

The severity of fear of recurrence has also been shown to vary depending on the population being studied. In a study of long-term breast cancer survivors, the majority of women reported low levels of fear (82%), but a considerable proportion experienced moderate (11%) or high (6%) levels of fear (Koch et al., 2014). Younger age was associated with higher levels of fear, similar to a previous study which found that 70% of breast cancer survivors aged 18-45 reported clinical levels of fear of cancer recurrence, diagnosed by clinical interview (Thewes et al., 2012). These findings suggest that fear of recurrence may be more severe among younger cancer survivors.

1.3.2.2 Depression

Depression is the most extensively researched emotional consequence of cancer, but there are considerable variations in prevalence estimates. A review of 85 studies published between 1965 and 2002, found that the prevalence of major depression ranged from 0% to 38% and the prevalence of depression spectrum syndromes ranged from 0% to 58% (Massie, 2004). This variation may be due to a number of factors including time since diagnosis, prognosis and cancer site. Different measures of assessment are also likely to play a role as the studies in this review used a variety of self-reported measures of depression (Massie, 2004). Self-reported measures have been found to result in higher prevalence estimates than those based on structured interviews (Fann et al., 2008).

Two recent systematic reviews and meta-analyses have attempted to overcome issues with heterogeneous measures by only including studies that used standard diagnostic criteria of depression defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM) (Mitchell et al., 2011; Walker et al., 2013). Walker and colleagues found that the prevalence of depression ranged from 5% to 16% in outpatients, 4% to 14% in inpatients, 4% to 11% in mixed outpatient and inpatient samples, and 7% to 49% in palliative care (Walker et al., 2013). Interestingly, although standard diagnostic criteria were used, estimates still varied according to the level of expertise by the health
professional administering the interview, with those with a higher level of expertise (e.g. a psychiatrist) reporting lower estimates of depression.

Mitchell and colleagues found that in a palliative care setting, the pooled prevalence of depression was 16.5% for DSM-defined major depression and 9.6% for DSM-defined minor depression (Mitchell et al., 2011). In oncology and haematology settings it was 14.9% for DSM-defined major depression and 19.2% for DSM-defined minor depression. These findings suggest that the prevalence of clinically diagnosed depression (according to the DSM) is highest among palliative care patients, which is unsurprising given the nature of their disease. However, a considerable proportion of cancer survivors outside of palliative care still report depressive symptoms and some have major depression. These findings are concerning, because cancer survivors who experience depressive symptoms have been found to have a 25% increased risk of mortality, rising to a 39% increased risk among those diagnosed with minor or major depression (Satin, Linden, & Phillips, 2009).

In a more recent meta-analysis, the prevalence of depression and anxiety in long-term cancer survivors was compared with healthy controls (Mitchell, Ferguson, Gill, Paul, & Symonds, 2013). This found that levels of depression did not differ between cancer survivors and controls (11.6% vs. 10.2%), but anxiety levels were significantly higher among cancer survivors (17.9% vs. 13.9%). This finding suggests that longer-term cancer survivors may be less affected by depression, but anxiety may be more of a problem. This could be related to the high prevalence of fear of cancer recurrence among longer term cancer survivors (Koch et al., 2013).

**1.3.2.3 Social factors**

The physical and psychological impact of cancer may mean that many cancer survivors experience a range of social problems including relationship, employment and financial issues. A systematic review of employment and work related issues among cancer survivors found that overall around 63.5% cancer survivors returned to work, although this ranged from 24% to 94% depending on the time since treatment completion (Mehnert, 2011). However, only a small proportion of studies in this review included
data on prevalence, and several did not specify the time since diagnosis and treatment and return to work, so it is possible that these figures may vary even more. A more recent review examined predictors of return to work and found that breast cancer survivors had the greatest chance of returning to work (van Muijen et al., 2013). This review also found that working in manual labour, receiving chemotherapy, older age, low education and low income were all negatively associated with employment. These findings highlight some socioeconomic disparities in work outcomes which are likely to be further compounded by financial strain through lack of employment.

Many different relationships may also be affected by a cancer diagnosis. A study of testicular cancer survivors and their spouses found that while cancer did not affect their marital satisfaction, there was a significant adverse impact on their sexual satisfaction (Tuinman, Fleer, Sleijfer, Hoekstra, & Hoekstra-Weebers, 2005). Sexual dysfunction is one of the most common and distressing consequences of cancer treatment and survivors face long-term effects such as treatment-induced menopause and erectile dysfunction (Bober & Varela, 2012). Non-romantic relationships may also be affected; one study found that women’s social support networks decreased, and their emotional support reduced in the five years following a breast cancer diagnosis (Bloom, Stewart, Chang, & Banks, 2004).

### 1.3.2.4 Quality of life

The adverse physical and psychosocial sequelae of a cancer diagnosis have been found to impact the quality of life of cancer survivors. In an analysis of the United States Health Interview Study, cancer survivors had a higher prevalence of poor physical and mental health-related quality of life (24.5% and 10.1% respectively) compared with those with no history of cancer (10.2% and 5.9%) (Weaver et al., 2012). In the UK, an analysis of the English Longitudinal Study of Ageing (ELSA) found that cancer survivors had poorer quality of life and happiness than those with no history of cancer (Wikman, Wardle, & Steptoe, 2011). However, as both of these studies are cross-sectional, it is not possible to know for certain if lower levels of quality of life are a direct consequence of a cancer diagnosis or the result of long-standing differences.
1.4 Summary

The evidence presented in this chapter suggests that even after successful treatment, many cancer survivors continue to experience a range of adverse physical and psychosocial effects of cancer. Many of these are inter-related, and can have a knock-on effect on other aspects of cancer survivors’ lives. It is the combination of these consequences that has resulted in cancer survivors generally reporting worse health and well-being than the general population. There has therefore been substantial interest in how to address the adverse outcomes experienced by the growing population of cancer survivors. The following chapter examines the role health behaviours might play in improving the health, well-being and survival of those diagnosed with cancer.
CHAPTER 2: HEALTH BEHAVIOURS IN CANCER SURVIVORS

2.1 Addressing the needs of cancer survivors

The previous chapter described how the number of cancer survivors is increasing and discussed the physical and psychosocial impact of a cancer diagnosis. Given this evidence, there is growing interest in how to improve outcomes in this population. In an attempt to address these issues, the Cancer Reform Strategy in 2007 highlighted survivorship as one of ten key priorities (Department of Health, 2007). This was followed by the launch of the National Cancer Survivorship Initiative, a joint venture between the Department of Health (DoH) and the charity Macmillan Cancer Support (Department of Health, 2010). This initiative acknowledged the role of both pharmacological and behavioural approaches to ensuring that cancer survivors live a long, healthy and active life.

One of the aims of the National Cancer Survivorship Initiative was for a shift from clinically led care to more supported self-management for cancer survivors. Supporting self-management involves educating people about their condition and equipping them with the tools to help them choose healthy lifestyle behaviours (de Silva, 2011). For health professionals, this shift means a change from a disease treatment model to a model of prevention (Murphy & Girot, 2013). This chapter discusses the role of a healthy lifestyle in cancer survivorship and how this may contribute to the behavioural approach of this initiative. In this context, lifestyle is defined as health behaviours, including diet, physical activity, smoking and alcohol, as well as body weight (WHO, 2015).

2.2 Health behaviours and cancer prevention

Interest in the potential link between health behaviours and outcomes in cancer survivors has stemmed from their role in cancer prevention. Smoking is a long established risk factor in the initiation and progression of lung cancer (Peto, 1994), and has also been implicated in the development of cancers of the bladder, pancreas, cervix,
upper digestive tract and respiratory tract (Engeland, Andersen, Haldorsen, & Tretli, 1996).

In 2007, the WCRF and AICR reviewed the evidence on the role of food, nutrition and physical activity in the prevention of cancer, the findings of which were published in their Second Expert Report (WCRF & AICR, 2007). As part of this review, they graded the evidence linking aspects of lifestyle with cancer as convincing, probable, limited-suggestive or unlikely. They found convincing evidence that excess body fatness (BMI≥25), high alcohol intake, and consumption of red and processed meat, were associated with an increased risk of several cancers. High levels of physical activity were associated with a reduced risk of colorectal cancer. Since this report, these findings have been continually updated as part of the Continuous Update Project.² This is funded by the WCRF and is a collaborative effort between over 100 researchers at universities worldwide. A summary of the latest evidence from the Continuous Update Project is shown in Table 2.1.

² http://www.wcrf.org/int/research-we-fund/continuous-update-project-cup
### Table 2.1: Lifestyle factors for which there is convincing* evidence of a link with cancer risk (2007 WCRF & AICR Second Expert Report and Continuous Update Project (CUP))

<table>
<thead>
<tr>
<th>Cereals (grains), roots, tubers and plantains</th>
<th>Decreases risk</th>
<th>Increases risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aflatoxins</td>
<td>-</td>
<td>Liver</td>
</tr>
<tr>
<td>Foods containing dietary fibre</td>
<td>Colorectum†</td>
<td>-</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Meat, poultry, fish, eggs</th>
<th>Decreases risk</th>
<th>Increases risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Red meat</td>
<td>-</td>
<td>Colorectum</td>
</tr>
<tr>
<td>Processed meat</td>
<td>-</td>
<td>Colorectum</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Water, fruit juices, soft drinks, hot drinks</th>
<th>Decreases risk</th>
<th>Increases risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arsenic in drinking water</td>
<td>-</td>
<td>Lung</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Alcoholic drinks</th>
<th>Decreases risk</th>
<th>Increases risk</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>-</td>
<td>Colorectum (men), breast (pre- and post-menopause), mouth, pharynx, larynx, oesophagus, liver†</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dietary constituents and supplements</th>
<th>Decreases risk</th>
<th>Increases risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beta-carotene supplements</td>
<td>-</td>
<td>Lung</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Physical activity</th>
<th>Decreases risk</th>
<th>Increases risk</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Colon</td>
<td>-</td>
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</table>

<table>
<thead>
<tr>
<th>Anthropometric factors</th>
<th>Decreases risk</th>
<th>Increases risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body fatness</td>
<td>-</td>
<td>Oesophagus, pancreas, colorectum, breast (post-menopause), endometrium, kidney, liver†</td>
</tr>
<tr>
<td>Abdominal fatness</td>
<td>-</td>
<td>Colorectum</td>
</tr>
<tr>
<td>Adult attained height</td>
<td>-</td>
<td>Ovarian†, colorectum†, breast (post-menopause)†</td>
</tr>
</tbody>
</table>

*For all other cancers there was probable, limited-suggestive evidence or no evidence
†Updated since the 2007 Second Expert Report as part of the CUP (2010-2015)
CHAPTER 2: HEALTH BEHAVIOURS IN CANCER SURVIVORS

Given the convincing evidence for the role of health behaviours in cancer risk, it seems logical that they may also play a role in the health of cancer survivors. In recent years this topic has received increasing attention by researchers looking for potential ways of improving the long-term health outcomes of cancer survivors.

2.3 Health behaviours and cancer survivorship

This section describes some of the mechanistic evidence for why health behaviours are thought to influence survival, followed by the evidence to date on their role in health outcomes for cancer survivors. This evidence comes from both observational and intervention studies. Observational studies are useful as they enable researchers to look at the impact of health behaviours in a large sample in the general population. However, they cannot determine causation as it is difficult to control for potential confounders which may also influence the outcome of interest. Intervention studies such as randomised controlled trials overcome this problem by having a control group. This makes it possible to determine the specific influence of health behaviours on outcomes.

2.3.1 Biological mechanisms linking smoking with cancer

Tobacco smoke is known to contain more than 60 carcinogens which increase the incidence of cancer (Hecht, 2002). The primary mechanism by which this occurs is by causing damage to DNA which leads to genetic changes that ultimately develop into cancer. Among individuals already diagnosed with cancer, smoking has been shown to reduce the effectiveness of chemotherapy drugs by preventing them from destroying cancerous cells (Dinicola et al., 2013). There is also evidence that it may promote tumour growth and metastases by increasing cell proliferation and preventing apoptosis of cancerous cells (Wong et al., 2007).

2.3.2 Evidence for smoking and health outcomes

Given the strong mechanistic evidence linking smoking with poorer health outcomes, a large number of observational studies have examined associations between smoking and outcomes among cancer survivors. A recent systematic review of head and neck cancer survivors found higher rates of recurrence and poorer survival rates among those
who continued to smoke following their diagnosis compared with those who quit smoking (van Imhoff et al., 2015). In a meta-analysis of nine observational studies conducted among breast cancer survivors, smoking at diagnosis was associated with a 33% increased risk of mortality from breast cancer compared to never smokers (Bérubé, Lemieux, Moore, Maunsell, & Brisson, 2014). Among colorectal cancer survivors, a meta-analysis of six observational studies found that current smokers had a 26% increased risk for all-cause mortality compared with never smokers (Walter, Jansen, Hoffmeister, & Brenner, 2014).

In addition to its impact on recurrence, mortality and survival; smoking following a cancer diagnosis can lead to an increased risk of other health conditions and treatment complications. Another meta-analysis of 10 observational studies found that continued smoking was associated with over four times the risk of developing second primary cancers among patients with limited stage small cell lung cancer, although only one of the included studies controlled for confounders (Parsons et al., 2010). Among upper aerodigestive tract cancer patients enrolled in a chemoprevention trial, continued smoking was associated with twice the risk of second primary cancers (Do et al., 2003). A recent review also found that smoking aggravates and prolongs radiotherapy induced complications, promotes tumour progression and increases resistance to chemotherapy (Florou, Gkiozos, Tsagouli, Souliotis, & Syrigos, 2014).

Continued smoking following a cancer diagnosis has also been associated with poorer psychological well-being, although the majority of studies have been conducted among head and neck cancer survivors. In a study of 209 post-treatment head and neck cancer patients, smoking at diagnosis was associated with an increased risk of long-term depressive symptoms, after controlling for patient, treatment and disease characteristics (Moubayed et al., 2015). Another study found that continued smoking at least one year post-treatment was associated with higher levels of depression among 211 patients diagnosed with squamous cell carcinoma of the head and neck treated with radiotherapy (A. M. Chen et al., 2013). Smoking has also been associated with anxiety among cancer survivors; in a mixed sample of 1,154 survivors, smoking at six months post-diagnosis was a significant predictor of co-morbid anxiety and depression at 12
months (Boyes et al., 2013). Among patients with smoking-related cancers of the upper aerodigestive tract, smoking following diagnosis has been associated with poorer outcomes on multiple domains of physical and mental health-related quality of life (Duffy et al., 2002, 2007).

Given the negative impact of continued smoking following a cancer diagnosis, it is unsurprising that smoking cessation has been associated with improved outcomes. The majority of these studies have been conducted among lung cancer survivors. A non-systematic literature review of smoking cessation during lung cancer treatment suggested that it was associated with improved cognitive function, psychological well-being, self-esteem, activity levels, performance status, appetite, sleep, and mood, and decreased fatigue and shortness of breath (Cataldo, Dubey, & Prochaska, 2010). This review also suggested that smoking cessation can decrease the risk of additional lung cancer tumours or second primary cancers. A review of observational studies among lung cancer patients in palliative care also found that smoking cessation was associated with improved pulmonary function and quality of life (Andreas, Rittmeyer, Hinterthaner, & Huber, 2013).

Although these findings present a strong argument for smoking cessation among cancer survivors, it is important to acknowledge some of their limitations. Smoking status was self-reported and standard measures were not used, so the included studies could be subject to varying degrees of reporting bias. All studies were observational, as conducting intervention studies is difficult because it would be unethical to prevent some groups of patients from quitting smoking. All studies were therefore subject to limitations common to observational studies, for example, many combined patients at different stages of disease and who had received different treatments making it difficult to compare across studies. This meant that although systematic reviews often identified multiple studies, meta-analyses could sometimes only be carried out on as few as three studies (van Imhoff et al., 2015). In addition, several of the included studies did not adjust for other health behaviours, such as physical activity, which may also influence outcomes (Bérubé et al., 2014; Walter et al., 2014).
2.3.3 Biological mechanisms linking alcohol with cancer

A number of potential mechanisms have been proposed for the link between alcohol and cancer. In breast cancer, oestrogen has been thought to be an important factor as alcohol has been associated with increased levels of circulating oestrogen in the blood (Singletary & Gapstur, 2001). Breast cancer cells require oestrogen for growth, so increased exposure to oestrogen may cause oestrogen-sensitive cells to become cancerous (Al-Sader, Abdul-Jabar, Allawi, & Haba, 2009). Another plausible mechanism is that the oxidation of ethanol (pure alcohol) in the body creates carcinogens such as acetaldehyde, which may inhibit DNA repair (Al-Sader et al., 2009). Chronic alcohol consumption has also been linked to increased circulation of the hormone insulin-like growth factor-1 (IGF-1), which has been associated with mammary carcinogenesis (Stoll, 1999). While interesting, these studies have all been conducted among breast cancer survivors, so there is a need for additional mechanistic studies in other types of cancers.

2.3.4 Evidence for alcohol consumption and health outcomes

Given that mechanistic studies linking alcohol consumption with health outcomes have been focused on breast cancer survivors, the majority of studies on the impact of alcohol consumption on cancer outcomes have also been conducted in this population. Although several studies have examined the relationship between post-diagnosis alcohol consumption and breast cancer outcomes, the evidence has been inconsistent.

A recent systematic review and meta-analysis of 11 observational studies examined the relationship between post-diagnosis alcohol consumption and prognosis among breast cancer survivors (Ali et al., 2014). When comparing moderate alcohol drinkers with never drinkers, they found that post-diagnosis alcohol consumption was not associated with all-cause mortality. However, not all studies identified by the review were included in the meta-analysis and the results across studies were heterogeneous. For example, one study found that increasing current alcohol consumption improved prognosis, with a 2% reduction in the risk of death per unit of alcohol consumed per week (Barnett et al., 2008). This may be because those who were consuming alcohol were generally healthier and were more able to drink alcohol socially. Another included study found that the results differed by menopausal status, with post-menopausal women who
regularly consumed more than six grams of alcohol per day having an increased risk of recurrence (Kwan et al., 2013).

The above meta-analysis had a number of limitations which should be considered when interpreting these findings (Ali et al., 2014). The included studies used a variety of different measures of alcohol and the standardisation of these may have biased the results. Those who consumed anything under two units of alcohol per day were classified as moderate drinkers, so it is possible that some were consuming too small amounts of alcohol to yield a result significantly different to those consuming no alcohol. The inclusion of heavier drinkers may have found a difference in outcomes. It has been found that samples of ‘never drinkers’ often include former heavy drinkers which may bias the results (Zeisser, Stockwell, & Chikritzhs, 2014). Many of the included studies did not stratify their results by oestrogen-receptor (ER) positive or ER negative tumours and it is possible that they may respond differently to alcohol.

Since the above meta-analysis was conducted, another large cohort study has examined the association between alcohol consumption and survival among breast cancer survivors (Newcomb et al., 2013). This study benefited from examining the impact of drinking varying amounts of alcohol (two or more/three to six/seven to nine or ≥10 drinks per week, compared with non-drinkers) post-diagnosis on disease-free survival, rather than focusing on highest versus lowest as had been done in previous studies. It found that none of the different levels of alcohol were associated with breast-cancer specific survival. However, compared with non-drinkers, breast cancer survivors who consumed higher levels of alcohol had better cardiovascular survival (HR 0.47 [0.24-0.91] for those consuming ≥10 drinks/week) and overall survival (HR 0.77 [0.60-0.98], 0.63 [0.45-0.88] and 0.64 [0.47-0.88] for those consuming 3-6, 7-9 and ≥10 drinks/week respectively).

A small number of studies have been conducted among other groups of cancer survivors. Among head and neck cancer survivors, alcohol consumption has been associated with negative outcomes. One study of 1,181 survivors of upper aerodigestive tract cancers found that continued alcohol consumption following diagnosis was
associated with increased risk of second primary cancers (Relative Risk (RR) 1.3 [95% CI 1.0-1.7]) (Do et al., 2003). Another study of patients with early stage head and neck cancers showed that even after adjusting for pre-diagnosis alcohol consumption, continued drinking following diagnosis significantly increased mortality risk compared with those who stopped drinking (RR 2.7 [95% 1.2-6.1]) (Mayne, Cartmel, Kirsh, & Goodwin, 2009). These findings are unsurprising given that alcohol consumption is a known risk factor in the development of head and neck cancers (Hashibe et al., 2007).

A few studies have examined the relationship between alcohol consumption and psychological well-being among cancer survivors but as with smoking, the majority have been conducted among head and neck cancer survivors. The study of 209 post-treatment head and neck cancer patients discussed above, also examined the relationship between alcohol consumption at diagnosis and risk of long-term depressive symptoms (Moubayed et al., 2015). This found that consumption of more than 14 alcoholic drinks per week at diagnosis was associated with an increased risk of depressive symptoms, after controlling for patient, treatment and disease characteristics. In contrast, another study of head and neck cancer survivors found that current alcohol drinkers had fewer depressive symptoms and better overall quality of life than former or never drinkers (Potash, Karnell, Christensen, Vander Weg, & Funk, 2010). However, post-hoc analyses revealed that social drinkers had the best scores whereas problem drinkers had the worst scores. Studies that examined the relationship between alcohol consumption and health-related quality of life among head and neck cancer survivors have failed to find a relationship between the two (Duffy et al., 2002, 2007).

Overall, these findings provide little evidence that moderate alcohol consumption is associated with poorer health outcomes among breast cancer survivors, although heavier consumption may be associated with an increased risk of recurrence and depressive symptoms. More research is required to determine the exact levels of alcohol that may lead to this increased risk, and whether a reduction in consumption would reduce the risk. In contrast, alcohol has been associated with an increased risk of mortality and second primary cancers among head and neck cancer survivors. However,
all research to date has been observational and no intervention studies have examined whether alcohol cessation may reduce the risk of mortality among cancer survivors.

### 2.3.5 Biological mechanisms linking physical activity with cancer

Several mechanisms have been proposed for the link between physical activity and cancer survival. Figure 2.1 shows a summary of some of these direct and indirect mechanisms (McTiernan, 2008). Permission to reproduce this figure has been granted by the Nature Publishing Group.
Figure 2.1 Hypothesised mechanisms linking physical activity with cancer (McTiernan, 2008)
One of the direct ways that physical activity may influence cancer outcomes is through sex hormones. As described in section 2.3.3, oestrogen may lead to breast cancer cell proliferation (Al-Sader et al., 2009), and high concentrations of oestrogen have also been associated with an increased risk of endometrial cancer (Kaaks, Lukanova, & Kurzer, 2002). In pre-menopausal women, there is evidence that physical activity may reduce lifetime exposure to oestrogen and the subsequent risk of cancer by delaying age at menarche and influencing the menstrual cycle (McTiernan, Ulrich, Slate, & Potter, 1998). In post-menopausal women, higher levels of physical activity have been associated with reduced levels of oestrogen, independent of BMI (McTiernan, 2008).

Among men, physical activity has been shown to increase the production of sex hormone binding globulin (SHBG), resulting in low free testosterone levels that may reduce prostate cancer risk (Zoeller, 2009).

Insulin is another mechanism by which physical activity may influence cancer outcomes. Insulin has been shown to increase cell proliferation and prevent apoptosis, resulting in an increased risk of several cancers (Kaaks & Lukanova, 2001). A meta-analysis of 14 trials (11 randomised, 3 non-randomised) found that physical activity improved insulin sensitivity, independent of changes in body weight, which could potentially translate to a decreased risk of cancer (Boulé, Haddad, Kenny, Wells, & Sigal, 2001). Increased levels of IGF-1 have been associated with an increased risk of several cancers (Kaaks & Lukanova, 2001), and physical activity has been found to reduce circulating IGF-1 among breast cancer survivors (Fong et al., 2012).

Physical activity may also influence cancer outcomes through its impact on inflammatory markers. Increased levels of pro-inflammatory markers, such as C-reactive protein, Interleukin 6, Tumour Necrosis Factor alpha, and decreased levels of anti-inflammatory markers, such as adiponectin, have been linked with increased cancer risk (Il’yasova et al., 2005). Physical activity has been shown to decrease these markers of inflammation, which may help reduce cancer risk (Campbell & McTiernan, 2007).

In addition to those described above, there are a number of other mechanisms through which physical activity may influence cancer outcomes. The immune system may play
an important role as physical activity has been shown to enhance natural killer cell function, which may help eliminate cancer cells (Carmichael, Daley, Rea, & Bowden, 2010). Physical activity has been shown to decrease gastrointestinal transit time, potentially reducing exposure to carcinogens in the gut which may decrease the risk of colorectal cancer (Zoeller, 2009). There is evidence that physical activity may help prevent cancer at the cellular level by activating DNA and protein repair systems that reduce damage to cells (Carmichael et al., 2010). Physical activity may also influence survival indirectly through its effects on obesity. These mechanisms are discussed in more detail in section 2.3.10.

There are a number of plausible mechanisms behind the link between physical activity and fatigue among cancer survivors. As described previously, fatigue has been associated with higher levels of inflammatory markers (Bower et al., 2002, 2003) and physical activity may help reduce these (Campbell & McTiernan, 2007). Physical activity improves cardio-respiratory fitness among cancer survivors and this may make them better able to cope with fatigue (Fong et al., 2012). Fatigue and depression are known to be correlated among cancer survivors so it is plausible that the same mechanisms may apply in reducing depression in this population (Jacobsen, Donovan, & Weitzner, 2003). In addition, several mechanisms have been proposed for the beneficial effects of physical activity on depression, although these are not specific to a cancer population. These include the endorphin hypothesis which predicts that physical activity reduces depression due to the release of endorphins which enhance positive mood (Craft & Perna, 2004).

2.3.6 Evidence for physical activity and health outcomes

Given that oestrogen is thought to be an important mechanism linking physical activity with cancer, it is perhaps unsurprising that much of the evidence on physical activity and cancer outcomes comes primarily from observational studies of breast cancer survivors. A recent meta-analysis summarised the findings of 22 prospective cohort studies examining the relationship between physical activity, recurrence and mortality among breast cancer survivors (Lahart, Metsios, Nevill, & Carmichael, 2015). This found that compared with those with the lowest level of recreational physical activity post-
diagnosis, those with the highest had a 48% reduced risk of all-cause mortality, a 41% reduced risk of breast cancer mortality and a 21% reduced risk of breast cancer events. More interestingly in terms of the practical application of the findings, this study also found that those meeting the recommended physical activity guidelines post-diagnosis had a 36% and 33% reduced risk of all-cause and breast cancer mortality respectively. Subgroup analyses found that those who were overweight (BMI ≥ 25 kg/m²) had the greatest risk reduction in breast cancer mortality (compared with those with a BMI < 25 kg/m²). In addition, those who were post-menopausal had the greatest risk reduction in all-cause mortality.

Although the literature is largely focused on breast cancer survivors, recent studies have also examined associations between physical activity and long-term outcomes among colorectal cancer survivors (Je, Jeon, Giovannucci, & Meyerhardt, 2013; Schmid & Leitzmann, 2014; Van Blarigan & Meyerhardt, 2015). A recent meta-analysis of 23 observational studies found that compared with those with the lowest levels of physical activity, those with the highest had a 42% reduced risk of colorectal cancer mortality and a 39% reduced risk of all-cause mortality (Schmid & Leitzmann, 2014). This also found a dose-response relationship between post-diagnosis physical activity and total mortality, with five, 10, or 15 metabolic equivalent task (MET) hours per week being associated with 15%, 28% and 38% reductions in total mortality respectively. This is particularly encouraging as it suggests even a small amount of physical activity may be beneficial, although five MET hours is still more than the recommended guidelines so many survivors may not achieve this. One of the studies included in this meta-analysis found that an increase in physical activity levels after their cancer diagnosis was associated with a 52% lower risk of colorectal cancer-specific mortality, independent of how physically active they were before their diagnosis (Meyerhardt et al., 2006). This finding provides a good argument for promoting lifestyle change among survivors, even among those who may think it is too late.

Research is more limited for other groups of cancer survivors, although a couple of studies have examined the relationship between physical activity, survival and mortality among prostate cancer survivors. One used data from 4,623 men diagnosed with
prostate cancer between 1997 and 2002 and followed-up until 2012, to examine the relationship between post-diagnosis physical activity (of varying types) and mortality (Bonn et al., 2015). This found that physical activity was associated with a 26% to 37% reduced risk of all-cause mortality, compared with less active men within each activity type. Men who walked or cycled for at least 20 minutes per day, and those who exercised for at least one hour per week, had a 39% and 32% reduced risk of prostate cancer mortality respectively. This finding is encouraging as it suggests even a minimal amount of physical activity could have health benefits. However, a major limitation of this study is that participants were not recruited until 5-10 years following their diagnosis. The study is therefore unlikely to include many men with advanced disease, limiting the generalisability of these findings. In another study, vigorous physical activity (at least 3 hours per week) was associated with a 49% reduced risk of all-cause mortality and a 61% reduced risk of prostate cancer mortality (Kenfield, Stampfer, Giovannucci, & Chan, 2011). Non-vigorous activity (at least 90 minutes walking per week) was associated with a 46% reduced risk of all-cause mortality only.

Although these studies provide convincing evidence that physical activity is beneficial for cancer survivors, there are a number of limitations that are inherent in this literature. The meta-analyses found considerable heterogeneity in the results across the included studies so the findings should be treated with caution (Lahart et al., 2015; Schmid & Leitzmann, 2014). This heterogeneity may be because different measures of physical activity and different cut-offs were used when comparing highest versus lowest levels of physical activity. Both meta-analyses also reported evidence of publication bias, so it is possible that there may be unpublished studies which did not find the same benefits of physical activity. All of the studies used self-reported measures of physical activity which are prone to recall and social desirability bias. Studies using objective measures such as accelerometers are needed to confirm these results. All of these studies were observational so the possibility of confounding cannot be ruled out.

The current evidence suggests that physical activity is beneficial for cancer survivors and that it may have a dose-response relationship with mortality. However, there are still a number of gaps in the literature as it is not clear what mode, frequency or duration of
physical activity is required to achieve the maximum health benefits. Large randomised controlled trials with a long-term follow-up are required to determine the impact of specific physical activity programmes on survival. Such trials are extremely resource intensive, requiring collaboration across multiple centres or even countries. Although none have been completed to date, one is currently being conducted by the National Cancer Institute of Canada. The Colon Health and Life-Long Exercise Change (CHALLENGE) trial aims to determine the effects of a structured physical activity intervention on disease-free survival among 962 high-risk stage II or stage III colon cancer survivors (Courneya, Booth, et al., 2008). This three year intervention includes supervised physical activity and behavioural support delivered in person and by telephone. Disease-free survival is being assessed every six months for three years then annually for up to 10 years. As of the latest update from the trial in December 2013, 250 patients had been randomised from cancer centres in Canada (n=20) and Australia (n=26), with further expansion planned (Courneya et al., 2014).

Although there is not yet any trial evidence on the impact of physical activity on survival among cancer survivors, a large number of trials have examined the impact of physical activity on symptoms and psychological well-being. As fatigue is one of the most commonly reported symptoms among cancer survivors, it is one of the most widely used outcome assessments in trials of physical activity interventions in this population. Studies have consistently found that physical activity is associated with improvements in fatigue among cancer survivors (Cramp & Byron-Daniel, 2012; Fong et al., 2012; Speck, Courneya, Masse, Duval, & Schmitz, 2010). A meta-analysis by the Cochrane Collaboration identified 56 randomised controlled trials examining the impact of exercise interventions on cancer-related fatigue (Cramp & Byron-Daniel, 2012). This showed that an exercise intervention delivered either during or post-cancer treatment was more effective at reducing cancer-related fatigue than a control. However, a breakdown of the results showed that although exercise was effective for reducing fatigue among breast and prostate cancer survivors, it was not for those with haematological cancers. However, only four studies examined haematological cancers and the sample sizes were very small (N ranged from 22 to 122 for each study), so they may have been underpowered to find an effect. However, a more recent meta-analysis
of five randomised controlled trials found that among colorectal cancer survivors, found that exercise interventions were not associated with short term improvements in fatigue relative to a control (Cramer, Lauche, Klose, Dobos, & Langhorst, 2014). This suggests that continued exercise may be required to have an effect on fatigue.

The current evidence suggests that while physical activity may reduce fatigue among some groups of cancer survivors, these findings may not be universal. However, these differences could be attributed to variation in the exercise interventions and in the measures of fatigue used. Often participants were allowed participants to choose their preferred type of aerobic activity, but walking, yoga and cycling were also commonly prescribed. Most studies used a validated measure of fatigue, but these varied considerably which may lead to bias in the results. Some studies also included mixed groups of cancer survivors at varying stages of treatment making it difficult to compare across studies.

Depression is also a commonly assessed outcome in physical activity intervention trials and studies have consistently shown an inverse relationship between the two (J. C. Brown et al., 2012; Craft, VanIterson, Helenowski, Rademaker, & Courneya, 2012; Fong et al., 2012). One meta-analysis identified 40 physical activity intervention studies including 2,929 cancer survivors (J. C. Brown et al., 2012). Overall this found that cancer survivors who were assigned to a physical intervention were significantly more likely to have reduced depressive symptoms than control groups. Among the high quality trials, this was found to be a dose-response relationship, with larger reductions in depressive symptoms for each increase in weekly volume of aerobic physical activity.

Although these findings are encouraging, their generalisability is limited due to the majority of studies being conducted among breast cancer survivors. Another major limitation of this meta-analysis is that the majority of studies had depressive symptoms as a secondary outcome (J. C. Brown et al., 2012). This means the studies were not designed nor powered to focus on depressive symptoms and patients were not recruited on this basis which may affect the results. In addition, many of the included
studies had methodological limitations such as small sample sizes and inconsistent assessment of baseline levels of depressive symptoms.

Given that physical activity has been shown to have a positive impact on physical and psychological health, it is unsurprising that it may also have an impact on quality of life. A large number of intervention studies have examined the relationship between physical activity and quality of life among cancer survivors. A systematic review and meta-analysis conducted by the Cochrane Collaboration identified 40 randomised controlled trials on the topic with 3,694 participants (Mishra et al., 2012). Thirty trials included patients who had completed treatment for cancer, and the remaining 10 included patients both during and post-treatment. Overall the results showed that exercise had a positive impact on global health-related quality of life relative to a control group at 12 week and six month follow-ups. Exercise was also associated with improvements in specific domains of health-related quality of life including self-esteem, emotional well-being and social functioning. However, these positive results should be interpreted with caution as again there was considerable variation in the exercise interventions and the measures of health-related quality of life used.

In summary, these findings provide convincing evidence that physical activity can improve fatigue and psychological well-being among cancer survivors. However, as the majority of studies have been conducted among breast cancer survivors, further research is required among other groups of survivors. There is also a need for randomised controlled trials with homogenous samples and standard outcome measures in order to determine the optimal mode, frequency and duration of physical activity.

2.3.7 Biological mechanisms linking diet with cancer

The relationship between diet and cancer is complex and it is likely that dietary patterns, such as those low in fat or high in fibre, are more important than specific foods. This is because foods contain many different nutrients and chemicals that may affect cancer. Some of the potential mechanisms linking dietary components with cancer outcomes are described below.
Given that there is probable evidence that foods containing dietary fibre can reduce the risk of colorectal cancer (WCRF & AICR, 2011), a number of mechanisms have been proposed for this link. Although these relate primarily to risk of developing cancer, they could plausibly apply to outcomes for cancer survivors as well. Fibre has been shown to dilute faecal contents, increase stool weight and decrease gastrointestinal transit time, potentially reducing exposure to carcinogens (WCRF & AICR, 2007). Dietary fibre may also lead to the production of short-chain fatty acids in the colon, which have been shown to promote apoptosis, potentially reducing the risk of cancer developing (WCRF & AICR, 2011).

Fruit and vegetables contain a range of nutrients which may help prevent cancer and could potentially improve outcomes among those already diagnosed with cancer. These include carotenoids, folate, vitamin C, vitamin E, selenium, flavonoids, and various other phytochemicals (chemicals found in plants) (WCRF & AICR, 2007). The WCRF and AICR report found that carotenoids, vitamin C, and vitamin E act as antioxidants, which can protect DNA from damage that may lead to cancer. It also found that selenium and flavonoids have anti-inflammatory properties which could plausibly help reduce cancer risk. Folate was found to play an important role in DNA repair (WCRF & AICR, 2007).

As shown earlier in this chapter in Table 2.1, there is convincing evidence that red and processed meat are associated with an increased risk of colorectal cancer (WCRF & AICR, 2007). Several mechanisms have been proposed for this relationship, including that red meat may cause the stomach to produce potentially carcinogenic N-nitroso compounds. Processed meats often contain nitrates in the form of preservatives and these may contribute to the production of N-nitroso compounds. Red meat also contains iron and iron overload can activate pro-inflammatory markers, potentially increasing cancer risk (Huang, 2003).

The mechanisms linking dietary fat intake with cancer outcomes are not well understood but are thought to be related to sex hormones such as oestrogen. Dietary fat intake has been shown to increase levels of oestrogen in the blood, which may promote the development of breast cancer in women (Wu, Pike, & Stram, 1999).
Energy-dense diets, which are typically high in fat, have been shown to lower the age of menarche (WCRF & AICR, 2007). Early menarche is an established risk factor for breast cancer, most likely because it increases lifetime exposure to oestrogen. Among prostate cancer survivors, a small-scale randomised controlled trial found that men who received a low fat diet had significantly decreased cancer cell growth relative to those who received a Western diet (40% of calories from fat) (Aronson et al., 2010). Another larger trial found that a low fat diet was associated with significant reductions in lipoprotein cholesterol which may play a role in reducing co-morbidities such as cardiovascular disease (Demark-Wahnefried et al., 2008).

2.3.8 Evidence for diet and health outcomes

In line with the mechanistic evidence linking fat intake with oestrogen levels, some of the earliest work on the association between nutrition and cancer survival examined fat intake among breast cancer survivors. In a review of 13 prospective studies among women diagnosed with breast cancer, all studies examined fat intake at diagnosis but the findings were inconsistent (Rock & Demark-Wahnefried, 2002). In five studies, total dietary fat was inversely associated with survival. However, three of these studies did not adjust for total energy intake, which has been found to correlate with fat intake (Rock & Demark-Wahnefried, 2002), making it difficult to determine the independent influence of fat intake. The other studies either found trends or found no associations between total fat intake and survival. None of the seven studies that examined the relationship between intake of dietary fibre and survival or recurrence found any associations. Of the eight studies that examined vegetable intake, three found inverse associations with risk of death. However, this review was limited by the fact that some studies used dietary data collected before a diagnosis. This is problematic as individuals may not only change their diet following a cancer diagnosis, but pre-diagnosis diet may affect survival differently to post-diagnosis diet.

Although the above review gave a useful early indication of the role of diet in breast cancer survival, the large number of studies and different dietary components assessed can make the findings difficult to interpret. In an attempt to overcome this, Patterson and colleagues conducted an updated review and meta-analysis of the epidemiological
evidence and examined associations between dietary patterns and breast cancer prognosis (Patterson, Cadmus, Emond, & Pierce, 2010). This identified seven observational studies examining the link between prudent and Western dietary patterns, and all-cause mortality or breast cancer mortality. This found that a prudent dietary pattern (characterised by a high intake of fruit, vegetables, whole grains, legumes, poultry and fish) appeared to be protective, and a Western dietary pattern (characterised by a high intake of refined grains, processed and red meats, desserts, high-fat dairy products and French fries) was associated with a trend towards an increased risk of mortality, although this was not statistically significant. However, this meta-analysis found substantial evidence of heterogeneity across the included studies, with some showing statistically significant associations between dietary components and mortality, and others finding trends or no link.

The promising results of these early observational studies led to two large randomised controlled trials to examine the impact of a dietary intervention on prognosis among breast cancer survivors. The Women’s Healthy Eating and Living (WHEL) study was a multi-site randomised controlled trial of the effectiveness of a high vegetable, low fat diet on reducing breast cancer recurrence and overall survival in women with stages I-III breast cancer in the United States (USA) (Pierce et al., 2002). The 3,088 women were randomised to an intensive dietary intervention or a comparison group between 1995 and 2000 and were followed up until 2006. The intervention comprised intensive telephone counselling, cooking classes and print materials to help improve the women’s dietary patterns. Women in the intervention group were encouraged to meet five daily targets including eating five servings of vegetables, 16 ounces (473 mls) of vegetable juice, three servings of fruit, 30 grams of fibre and obtain only 15-20% of their energy from fat. Outcome assessments were completed every six months and were verified with medical records.

The findings of the WHEL trial were published soon after the end of follow-up (Pierce et al., 2007). At baseline there were no between-group differences in any of the five daily dietary targets (described above). In the comparison group, these dietary targets remained relatively unchanged, although the relative intake of energy from fat
increased by 13%. In contrast, there were large changes in the intervention group and the between-group differences remained significant for all dietary targets across the six years. Over the study period, 16.7% of women in the intervention group and 16.9% of women in the comparison group experienced an invasive breast cancer event and this difference was not significant. Similarly, no difference was found for survival, with 10.1% of those in the intervention group and 10.3% of those in the comparison group dying during the study.

The Women’s Intervention Nutrition Study (WINS) was another large randomised controlled trial that was designed to assess the effect of a fat reduction intervention on relapse-free survival among women with resected, early-stage breast cancer (Chlebowski et al., 2006). The 2,437 women were randomly assigned to the dietary intervention group or a control group between 1994 and 2001. Women were included if they obtained at least 20% of their calories from fat and the goal of the intervention was to reduce this percentage to 15%. Participants in the intervention group were given a fat gram goal based on energy intake required to maintain weight. With the help of trained dietitians, they then implemented a low fat eating plan based on Social Cognitive Theory that included self-monitoring, goal setting, modelling, social support, and relapse prevention and management. At one year follow-up those in the intervention group were consuming significantly less fat than the control group (51.3g vs. 33.3g). After a median of 60 months of follow-up, those in the intervention group were less likely to have experienced a breast cancer recurrence at any site.

Given the similarities between the WHEL and the WINS interventions, it is important to try and understand why only the WINS intervention was successful in improving disease outcomes. Both studies were conducted in the US in the 1990s and included women diagnosed with early stage breast cancer, but they also had a number of important differences. First, the WINS study only included post-menopausal women aged 48 to 79 at diagnosis, whereas the WHEL included women aged 18 to 70. It is therefore possible that the dietary intervention may have impacted pre and post-menopausal women differently. Second, WINS enrolled women within one year of diagnosis, whereas WHEL enrolled women within four years of diagnosis. This means that relative to WINS, WHEL
would have underrepresented patients with recurrences occurring in one to four years following diagnosis. Third, the WINS excluded those with worse prognoses and a dietary intervention could potentially be more effective among those with earlier stage disease.

Another explanation for the differing results of the WINS and the WHEL may be related to weight. It is possible that the benefits of reducing fat intake shown in the WINS could be due to the weight loss that occurred in the intervention group (mean between-group difference of 6 pounds) rather than the dietary change itself (Chlebowski et al., 2006). The same weight reduction was not seen in the WHEL which could explain why this study found no effect (Pierce et al., 2007). The impact of weight loss on outcomes among cancer survivors is discussed in more detail in section 2.3.10.2.

To explore how these differences may have led to differing outcomes of the two studies, Pierce and colleagues compared the WINS sample with the post-menopausal sample of the WHEL (Pierce, 2009). This did not change the outcome of the WHEL study, suggesting that age and menopausal status were not contributing factors to the differing results. It did however highlight that the differences in the study outcomes were limited to between-group differences in the proportion of women who had local recurrences and new primary breast cancer events, with those in the intervention group of the WHEL experiencing more events than those in the WINS. The reasons for this may be due to some of the differences in the studies outlined above. Overall, given the conflicting results of the two studies, there is not sufficient evidence to conclude that changing dietary pattern will improve prognosis for breast cancer survivors.

Since the publication of the WINS and the WHEL results, several observational studies have been conducted to build on the existing evidence. One study attempted to determine which components of dietary fat may be associated with an increased risk of mortality among 4,441 women diagnosed with invasive breast cancer between 1987 and 1999 in the Collaborative Women’s Longevity Study (CWLS) (Beasley et al., 2011). This found that compared to those with the lowest intake, those with the highest intake of saturated and trans fat had a 41% and 78% increased risk of all-cause mortality respectively. Another study examined the relationship between dietary fibre and
prognosis among 688 women with stages 0 to IIIA breast cancer in the Health, Eating, Activity and Lifestyle (HEAL) study (Belle et al., 2011). This found suggestive evidence that fibre intake was associated with a reduced risk of breast cancer mortality and cancer recurrence but the results were not statistically significant.

In an attempt to determine how meeting dietary guidelines affected cancer outcomes, a recent study examined the relationship between diet quality and mortality among 2,317 post-menopausal women with invasive breast cancer in the Women’s Health Initiative (George et al., 2014). Diet quality was assessed with the Healthy Eating Index (HEI)-2005, which includes 12 dietary components (total fruit; whole fruit; total vegetables; dark-green vegetables, orange vegetables, and legumes; total grains; whole grains; milk; meats and beans; oils; saturated fat; and sodium) which align with the United States Dietary Guidelines for Americans (Guenther, Reedy, & Krebs-Smith, 2008; Guenther, Reedy, Krebs-Smith, & Reeve, 2008). This found that women who had a better quality overall diet had a 26% lower risk of all-cause mortality and a 42% lower risk of non-breast cancer mortality. There were no significant associations with breast cancer mortality. These findings suggest that having an overall healthy diet may be beneficial, even if there is no clear evidence for the role of specific foods. However, it is important to note that this study did not adjust for treatment type, which may also have an impact on mortality and may bias these results.

Although the literature is dominated by studies conducted among breast cancer survivors, a growing body of research has examined the relationship between dietary factors and prognosis among prostate cancer survivors, but evidence is limited to observational studies. In 2007, a review identified eight studies examining associations between diet and survival in this population (Berkow, Barnard, Saxe, & Ankerberg-Nobis, 2007). Six of these studies examined fat intake, four of which found that saturated fat was associated with negative outcomes including a higher risk of prostate cancer mortality, advanced prostate cancer and aggressive tumours. However, the majority of studies in this review had very small sample sizes, some relied on retrospective recall of dietary intake and not all adjusted for potential confounders. Interestingly, the only
large prospective study did not find any association between dietary intake and prostate cancer mortality (Hsing et al., 1990).

More recently, a prospective study examined the association between post-diagnosis consumption of processed and unprocessed red meat, fish, poultry and eggs and the risk of prostate cancer recurrence or progression (Richman et al., 2010). This found that compared to those with the lowest consumption, those with the highest consumption of eggs and poultry with skin had a twofold risk of prostate cancer progression. This remained the same even after adjustment for saturated fat intake. No associations were found for the other dietary factors, suggesting that processed and unprocessed red meat, fish, total poultry and skinless poultry are not associated with recurrence or progression.

Evidence for the role of dietary factors and outcomes among colorectal cancer survivors is limited to observational studies. One of the first studies examined associations between prudent and Western dietary patterns and disease-free survival among 1,009 patients with stage II colon cancer (Meyerhardt et al., 2007). This found that a higher intake of a Western diet was associated with worse disease-free survival (including recurrence and mortality). Compared to those with the lowest intake of a Western diet, those with the highest intake had over three times the risk of recurrence or death. In contrast, a prudent dietary pattern was not associated with cancer recurrence or mortality. These results are consistent with a study which found that consumption of red and processed meats (which are characteristic of a Western diet) were associated with an increased risk of colon cancer, even after adjustment for age, BMI, physical activity and total energy intake (Slattery, Boucher, Caan, Potter, & Ma, 1998).

More recently, a study examined the association between red and processed meat consumption on prognosis among 2,315 colorectal cancer survivors. This found that red and processed meat consumption after a colorectal cancer diagnosis were not associated with mortality (McCullough, Gapstur, Shah, Jacobs, & Campbell, 2013). However, those with a consistently high intake of red and processed meat before and after their diagnosis had a 79% increased risk of colorectal cancer mortality compared
with those with consistently low intakes. This is consistent with a study that found higher intakes of processed meat before a diagnosis of colorectal cancer were associated with an increased risk of recurrence and disease-specific mortality, even after adjustment for total energy intake and demographics (Zhu et al., 2013).

There are a number of important limitations to consider when interpreting these findings. All studies assessed diet using food frequency questionnaires which have been associated with a high level of systematic error and could lead to substantial bias and error in the results (Natarajan et al., 2006). Self-reported dietary assessment has been shown to underestimate energy intake, which may lead to bias in interpretation (Black & Cole, 2001; Johansson, Solvoll, Bjørneboe, & Drevon, 1998). There are also issues with interpreting data relating to the intake of specific dietary components as foods are not consumed in isolation and good or bad eating habits often correlate. For example, dietary fat intake typically correlates with energy intake and with obesity (Rock & Demark-Wahnefried, 2002). Unless the analysis is able to adjust for other aspects of diet and contributing factors, it can be difficult to isolate specific foods that may be associated with improved or worsened outcomes. This is even problematic in randomised controlled trials; as those who are instructed to follow a low fat diet may also be motivated to make other healthy changes. Therefore it can often be easier to interpret findings from studies which examine dietary patterns rather than specific foods. Such studies are also likely to be more representative of dietary intake in the general population.

In summary, the current literature is insufficient to make conclusions about the role of specific dietary components on outcomes among cancer survivors. However, the evidence does suggest that an overall healthy diet may be beneficial. Further large-scale randomised controlled trials, similar to the WINS and WHEL, are required to determine the impact of specific dietary components on survival among different groups of cancer survivors.
2.3.9 Biological mechanisms linking weight with cancer

Overweight and obesity, defined as excess body adiposity, have significant negative health consequences in the general population, so it is possible that similar mechanisms may link them with cancer outcomes. Several potential mechanisms have been proposed, for example, adipose tissue has been associated with an increased production of serum oestrogens (Key et al., 2003; Ligibel, 2011), which have been associated with an increased risk of breast cancer and progression (Kaaks et al., 2005; Lann & LeRoith, 2008; Ray, 2012). Obesity has also been associated with increased levels of several hormones and growth factors, including IGF-1, insulin and leptin, which have all been found to stimulate the growth of cancer cells (WCRF & AICR, 2007). Body fatness, particularly abdominal fatness is associated with increased insulin resistance, which can lead to hyperinsulinaemia. Hyperinsulinaemia, a condition related to excess insulin in the blood, has been associated with an increased risk of several cancers (Calle & Kaaks, 2004). In addition, obese people often have chronic low-level inflammation which can promote the development of cancer (WCRF & AICR, 2007).

Given the mechanisms linking obesity with cancer, it is possible that these biomarkers may be influenced by changes in weight. A handful of small trials have examined the impact of weight loss on biomarkers among cancer survivors, all of which have been conducted among overweight or obese breast cancer survivors. In the Breast Cancer Survivors Health and Physical Exercise (SHAPE) trial of 220 women, weight loss of at least 5% resulted in lower leptin and insulin levels (Rock et al., 2013). Among post-menopausal women, it also resulted in lower levels of oestrone, oestradiol and bioavailable oestradiol, but no differences were found among pre-menopausal women.

A smaller study of 90 women found that weight loss of one kilogram led to positive changes in biomarkers including SHBG, leptin, high-sensitivity C-reactive protein, and total cholesterol (Saxton et al., 2006; Scott et al., 2013). However, weight loss and reductions in waist circumference were associated with negative changes in insulin-like growth factor binding protein (IGFBP-3) and IGF-1 respectively. This could be due to a non-linear association between these biomarkers and weight.
These studies provide some evidence of plausible mechanisms linking weight loss with improved cancer outcomes among those who are overweight. However, they both had small sample sizes and relatively short follow-ups so the long-term impact of weight loss is unknown. It is also important to remember that although there may be plausible mechanisms; these findings do not necessarily translate to improved survival among cancer survivors.

2.3.10 Evidence for weight and health outcomes

2.3.10.1 Obesity and weight gain

The mechanistic evidence linking obesity with poorer health outcomes, and the fact that many people gain weight following a cancer diagnosis (Kroenke, Chen, et al., 2005), has led to increasing attention on how excess body weight may affect outcomes in cancer survivors. The majority of studies on this topic have been conducted among breast cancer survivors.

Studies have consistently shown that overweight and obesity are associated with poorer outcomes across different groups of cancer survivors. A meta-analysis of 43 observational studies of breast cancer survivors found that obese women had a 33% increased risk of both all-cause and breast cancer mortality, compared with non-obese women (Protani, Coory, & Martin, 2010). Obesity at breast cancer diagnosis has also been associated with an increased risk of second primary cancers including contralateral breast (37%), breast (40%), endometrial (96%), and colorectal (89%) (Druesne-Pecollo et al., 2012). Similar findings have been seen among prostate cancer survivors. A recent meta-analysis of 26 studies including 36,927 individuals with prostate cancer, found that every 5kg/m² increase in BMI was associated with a 16% increased risk of biochemical recurrence (Hu, Xu, Bai, Jiang, & Ding, 2014).

Several studies have examined the relationship between overweight and obesity and quality of life among cancer survivors. In a recent systematic review and meta-analysis of four observational studies of endometrial cancer survivors, obesity was associated with poorer outcomes on several domains of health-related quality of life including physical functioning, social functioning and role functioning (Smits, Lopes, Bekkers, &
Galaal, 2015). However, this systematic review did not find any differences in emotional or cognitive functioning. Similar results were seen in a study of 753 older, long-term breast, prostate and colorectal cancer survivors, which found that greater BMI was associated with poorer physical quality of life, including health perceptions, physical functioning, vitality, pain and role limitations (Mosher et al., 2009). Obesity has also been associated with poorer quality of life in other groups of cancer survivors including head and neck (Egestad & Nieder, 2015) and ovarian (Smits, Lopes, Das, Bekkers, & Galaal, 2015). In contrast, an observational study of 692 breast cancer survivors did not find that BMI was independently associated with quality of life, although all survivors in this sample were overweight or obese (Pakiz et al., 2015).

Each of these meta-analyses had a number of similar limitations. In some of the included studies, BMI was measured by the study investigators or taken from medical records, but in others it was self-reported. Studies have found that people typically overestimate their height and underestimate their weight, which may lead to systematic bias in studies which use self-reported measures (Gorber, Tremblay, Moher, & Gorber, 2007). There was also variation in the cut-points used for overweight and obesity, as some studies focused on BMI only and others also included waist circumference. Two of the meta-analyses reported evidence of heterogeneity across the included studies (Hu et al., 2014; Protani et al., 2010). This may partly be due to the different cut-points, but could also be attributed to confounding as studies did not consistently adjust for potential confounders such as the presence of metabolic syndrome.

In addition to the adverse outcomes associated with being overweight or obese at diagnosis, weight gain following a cancer diagnosis has also been associated with poorer prognosis. In a recent study of 1,436 women diagnosed with primary breast cancer, those who gained more than 10% of their body weight after diagnosis had more than double the risk of all-cause and breast cancer mortality, compared with those who maintained their pre-diagnosis weight (Bradshaw et al., 2012). Similar results were found in an earlier study but only among women who had never smoked (Kroenke, Chen, et al., 2005). Among prostate cancer survivors, studies have found weight gain to be associated with an increased risk of prostate cancer recurrence (Joshu et al., 2011).
and prostate cancer mortality (Bonn et al., 2014). Although obesity is associated with poorer outcomes among colorectal cancer survivors, weight gain following diagnosis has not been associated with poorer prognosis in this population (Otto et al., 2015).

2.3.10.2 Weight loss

In the general population, weight loss is typically associated with a substantial reduced risk of mortality among those who are overweight or obese (Wannamethee, Shaper, & Lennon, 2005; Williamson et al., 1995). This has led to interest in the potential for weight loss to improve outcomes for cancer survivors who are overweight or obese. Several observational studies have examined associations between weight loss and prognosis among cancer survivors, the majority of which have focused on breast cancer survivors.

In an analysis of two separate cohorts of breast cancer survivors (the Life After Cancer Epidemiology [LACE] and the comparison group of the WHEL study), women who lost greater than 10% of their body weight between pre-diagnosis and study entry had a 70% increased risk of recurrence and twice the risk of all-cause mortality compared with those who maintained their weight (Caan et al., 2008). Interestingly, this increased risk was particularly pronounced for obese women, suggesting that weight loss is not always beneficial in this population. These findings were replicated in a more recent analysis of 12,915 breast cancer patients in the US and China (Caan et al., 2012a). This found that weight loss of greater than 10% was associated with a 40% increased risk of all-cause mortality in the US and over three times the risk of mortality in China, independent of pre-diagnosis weight status.

Other studies have shown that cancer survivors who lose smaller amounts of weight may also experience negative outcomes. Among women with primary breast cancer, at least 5% weight loss was associated with over five times the risk of all-cause mortality and over seven times the risk of breast cancer mortality, even after adjusting for pre-diagnosis weight changes (Bradshaw et al., 2012). Another study found that breast cancer survivors who lost more than a kilogram of weight had a higher risk of mortality than those who maintained their weight (X. Chen et al., 2010). However, this analysis
was conducted on the total sample and not just those who were overweight. Similarly, the study above conducted in the US and China, found that moderate weight loss (5-10%) was only associated with an increased risk of mortality among women of a healthy weight and not those who were overweight (Caan et al., 2012a). These suggest that a small amount of weight loss may not be harmful for cancer survivors who are overweight or obese.

However, a small number of studies have examined associations between weight loss and outcomes for other cancer sites and these have generally found similar negative consequences of weight loss. In a study of 1,825 patients diagnosed with stages I to III primary colorectal cancer in Australia, weight loss of five kilograms or more was associated with higher colorectal cancer-specific mortality and all-cause mortality (Baade et al., 2011). El-Safadi and colleagues recently examined the medical records of 705 patients with endometrial cancer and found that patients who lost even a small amount of weight (less than or equal to one kilogram) had worse prognosis than those who gained weight (El-Safadi, Sauerbier, Hackethal, & Münstedt, 2012). More recently, a study found that prostate cancer survivors who lost at least five kilograms of weight had double the risk of all-cause mortality compared with those who maintained their weight (Bonn et al., 2014).

A limitation of all of these studies is that none distinguished between intentional and unintentional weight loss. Intentional weight loss may be expected among those who are overweight or obese who may want to lose weight for health reasons. In contrast, unintentional weight loss may occur in patients who are unwell, possibly due to their underlying cancer, which may explain the association with poorer outcomes in the majority of these studies. In addition, patients with advanced cancer frequently experience cachexia, a multi-factorial syndrome defined by an ongoing loss of skeletal muscle mass (Radbruch, Elsner, Trottenberg, Strasser, & Fearon, 2010). Patients with cachexia suffer from unintentional weight loss and appetite loss, as well as from a reduction in physical function, tolerance to anti-cancer therapy and survival (Radbruch et al., 2010). In observational studies it is very difficult to determine intentionality as even if an individual is attempting to lose weight, this is not necessarily the cause of
their underlying weight loss. Intervention studies are required to examine the impact of intentional weight loss on outcomes among cancer survivors.

In addition to not being able to determine intentionality, these studies had a number of other limitations. Two used objective measures of BMI (Caan et al., 2012a; X. Chen et al., 2010), but the majority relied on self-reported measures, which may be subject to bias (Gorber et al., 2007). Not all studies stratified by weight status and those that did sometimes reported different results for those who were normal weight or overweight (Caan et al., 2012a).

There has been relatively little intervention research into the effect of weight loss on cancer outcomes. Findings from the WINS study provide limited evidence of a suggestive favourable effect of weight loss on recurrence among breast cancer survivors (Chlebowski et al., 2006). However, this study was a dietary intervention and was not designed to focus on weight loss. Although no results have been published to date, a number of studies are currently underway to directly examine the impact of weight loss on recurrence or survival (Goodwin et al., 2014; Rack et al., 2010; Rock, Byers, et al., 2012; Sedlacek et al., 2011; Villarini et al., 2012). These are all being conducted among breast cancer survivors and aim to achieve weight loss through lifestyle interventions.

In summary, the available literature provides little evidence for a beneficial effect of weight loss among cancer survivors, even among those who are overweight or obese. However, the majority of studies are observational so it is possible that weight loss may be unintentional. Large-scale randomised controlled trials are required to examine the impact of intentional weight loss interventions on survival among cancer survivors.

2.3.11 Evidence for role of health behaviours in advanced disease

Although the majority of studies examining the role of health behaviours among cancer survivors have focused on patients with earlier stage disease, there is also some evidence that health behaviours play a role in patients with advanced disease. In a systematic review of 16 mixed types of studies examining physical activity in patients with advanced-stage cancer, physical activity was consistently associated with improved
vitality, fitness and health-related quality of life, and decreased symptoms (Albrecht & Taylor, 2012). There is also some evidence that diet management may improve the effectiveness of palliative care (Chaiviboontham, 2015), and that patients with advanced cancer may find it a useful strategy to help them manage their symptoms (Yeager et al., 2015). In a large study of 1,370 patients with advanced non-small cell lung cancer, those who continued to smoke did not have poorer overall survival than those who quit smoking (Tsao, Liu, Lee, Spitz, & Hong, 2006). However, rather than assuming there are no benefits of smoking cessation in this population, it is possible that those who quit did so because they were too ill to smoke.

2.4 Health behaviour guidelines for cancer survivors

Given some of the potential benefits of health behaviours for cancer survivors, several organisations have produced health behaviour recommendations for this population. In their 2007 Second Expert Report, the WCRF and AICR concluded that evidence was too limited to produce specific guidelines for cancer survivors but recommended they should follow their guidelines for prevention (WCRF & AICR, 2007). The evidence for the role of lifestyle in cancer prevention and cancer survivorship is regularly reviewed as part of the Continuous Update Project. In 2014, a report from this project was published outlining the updated evidence for the role of food, nutrition and physical activity in breast cancer survivors (WCRF & AICR, 2014). However, this concluded that breast cancer survivors should continue to follow the WCRF guidelines for cancer prevention. A summary of these guidelines is shown in Table 2.2. Although not specifically listed as a recommendation in the 2007 Second Expert Report, the panel emphasised the importance of not smoking and avoiding tobacco smoke, so this is included as an additional recommendation in the table. Adherence to these guidelines has been associated with a reduction of metabolic syndrome among breast cancer survivors, highlighting their clinical impact (Bruno et al., 2015).
Table 2.2 WCRF health behaviour recommendations for cancer prevention

1. **Body fatness**
   - Be as lean as possible within the normal range of body weight
   - Goal: BMI 18.5 to 24.9kg/m²

2. **Physical activity**
   - Be physically active as part of everyday life
   - Goal: Be moderately physically active for at least 30 minutes every day

3. **Foods and drinks that promote weight gain**
   - Limit consumption of energy-dense foods and avoid sugary drinks
   - Goal: Consume energy dense foods sparingly and avoid sugary drinks

4. **Plant foods**
   - Eat mostly foods of plant origin
   - Goal: Eat at least five portions of fruit and vegetables per day and eat relatively unprocessed cereals and/or pulses with every meal

5. **Animal foods**
   - Limit intake of red meat and avoid processed meat
   - Goal: Consume less than 500g red meat per week and have very little if any processed meat

6. **Alcoholic drinks**
   - Limit alcoholic drinks
   - Goal: Men to consume no more than two drinks per day and women one drink per day

7. **Preservation, processing, preparation**
   - Limit consumption of salt
   - Goal: Consume less than 6 grams (2.4g sodium) per day

8. **Dietary supplements**
   - Aim to meet nutritional needs through diet alone (avoid supplements)
   - Goal: Do not take dietary supplements for cancer prevention

9. **Tobacco***
   - Do not smoke and avoid exposure to tobacco smoke
   - Goal: Do not smoke

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*Not listed as a specific recommendation as the focus of the report was diet, nutrition and physical activity (WCRF & AICR, 2007), but this was also emphasised as important by the panel*
The American Cancer Society (ACS) has published similar guidelines to the WCRF on nutrition and physical activity for cancer survivors during and after treatment (Rock et al., 2012). These guidelines also emphasise that as soon as they are able, cancer survivors should follow the ACS guidelines for prevention. In addition, in 2010 the American College of Sports Medicine (ACSM) convened a roundtable to review the evidence for the role of physical activity on outcomes for cancer survivors (Schmitz et al., 2010). This recommended that cancer survivors should follow the US Department of Health and Human Services 2008 Physical Activity Guidelines for Americans (150 minutes per week of moderate intensity exercise or 75 minutes per week of vigorous intensity exercise or combination of the two) (US Department of Health and Human Services, 2008). They also advised that exercise programmes may need to be adapted according to the cancer patients’ disease and treatment.

These guidelines provide a useful summary of the types of lifestyle changes cancer survivors should aim for, but they also have a number of drawbacks. A problem with referring cancer survivors to the guidelines for prevention is that they do not always match with the evidence from studies with cancer survivors. Although weight loss may be beneficial for those who are overweight in the general population, as described previously, it is not associated with improved outcomes for cancer survivors (Caan et al., 2005, 2012b). In addition, as guidelines for cancer prevention are not specific to a cancer site, they may be difficult to interpret, particularly when there is conflicting evidence on a topic. For example, there is some evidence that a small amount of alcohol may be protective for breast cancer survivors (Barnett et al., 2008), whereas it is associated with poorer outcomes for head and neck cancer survivors (Do et al., 2003; Mayne et al., 2009).

Although health behaviour guidelines for cancer survivors exist in the academic literature, few have been translated into clinical guidelines for health professionals. The National Institute for Health and Care Excellence (NICE) have basic exercise guidelines for prostate cancer survivors which state that health professionals should “offer men who are starting or having androgen deprivation therapy supervised resistance and aerobic exercise at least twice a week for 12 weeks to reduce fatigue and improve quality

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of life” (NICE, 2014). However, there are no clinical guidelines in the UK for other cancer sites or for other health behaviours.

2.5 Prevalence of health behaviours among cancer survivors

The evidence presented in this chapter highlights some of the potential benefits of a healthy lifestyle for cancer survivors. In light of this evidence, recommendations have been developed with the aim of ensuring that cancer survivors are sufficiently informed about the role of lifestyle post-diagnosis. However, these guidelines focus on prevention and cancer survivors may not be clear on the guidelines relevant to them. Determining the prevalence of health behaviours in this population is an important step in assessing whether cancer survivors receive adequate information and support.

Surveys conducted among cancer survivors have found that they often report making positive changes to their lifestyle following their diagnosis. In one study of 250 women with breast cancer, 41% reported making dietary changes 12 months after their diagnosis, including decreasing meat (77%) and increasing fruit and vegetable consumption (72%) (Maunsell, Drolet, Brisson, Robert, & Deschênes, 2002). Another study of breast cancer survivors revealed similar results, with 38% reporting making dietary changes following their diagnosis (Salminen et al., 2002). In a mixed group of 352 cancer survivors, 47% reported making dietary changes and 46% smokers reported quitting as a result of their diagnosis (Blanchard et al., 2003, 2003). This study also found that 16% reported doing more physical activity following their diagnosis, but even more (30%) reported doing less. A study of breast, prostate and colorectal patients found similar results, with 40% reporting dietary changes and 20% reporting increases in physical activity (Patterson et al., 2003).

These reported lifestyle changes are in line with the ‘teachable moment’ hypothesis, where a significant life event such as a cancer diagnosis is thought to motivate individuals to make positive changes (McBride & Ostroff, 2003). In support of this hypothesis, a number of health-related life events have been shown to lead to positive health behaviour changes. For example, a colonoscopy has been associated with a spontaneous reduction in excessive alcohol consumption (Hubbard et al., 2014).
However, although these findings suggest that the health behaviours of cancer survivors may be fairly good, large-scale prevalence studies which include a control group are required to determine how they compare to the general population.

Several population-based studies have examined the health behaviours of cancer survivors relative to a control group, but findings have been inconsistent. One of the earliest studies used data from the United States National Health Interview Study to examine smoking, alcohol and the proportion of those meeting the ACSM physical activity recommendations, among 7,384 cancer survivors and 121,347 controls (Bellizzi, Rowland, Jeffery, & McNeel, 2005). In unadjusted analyses, this study found that cancer survivors were less likely to meet physical activity recommendations than those with no history of cancer (30% vs. 37%). However, when the analysis was adjusted for functional limitations, cancer survivors were 9% more likely than controls to meet these recommendations. No differences were found for smoking or alcohol. Similar results were found in a recent analysis of the United States National Health and Nutrition Examination Survey (NHANES) where cancer survivors were found to be more active than those with no history of cancer (Kim et al., 2013).

An analysis of a nationally representative sample of 114,355 adults in the Canadian Community Health Survey examined the prevalence of physical activity and obesity among cancer survivors and those with no history of cancer (Courneya, Katzmarzyk, & Bacon, 2008). This found that only 22% cancer survivors were physically active and 18% were obese. In the group analysis, prostate cancer survivors were more likely to be active and less likely to be obese, skin cancer survivors were more likely to be active, and obese breast cancer survivors were less likely to be active. A smaller study in Australia examined the prevalence of smoking, fruit intake, vegetable intake, alcohol use, overweight and obesity among 968 cancer survivors and 5,808 controls (Eakin et al., 2007). This found that cancer survivors were 35% more likely to be current smokers (21.3% vs. 18.9%) and 29% more likely to be former smokers (35.3% vs. 30.7%). This was highest for those aged 18-39 years (OR 1.69 [95% CI 1.14–2.50]) and women with gynaecological cancers (OR 2.37 [95% CI 1.70–3.29]). There were no overall group differences in physical activity, diet, alcohol or weight but these were suboptimal in both
groups. However, those diagnosed with melanoma or prostate cancer were more than twice as likely as the comparison group to report moderate alcohol consumption.

In the UK, an analysis of the English Longitudinal Study of Ageing (ELSA) compared the smoking, alcohol consumption and physical activity levels of 716 cancer survivors and 10,799 men and women with no diagnosis of cancer (Grimmett, Wardle, & Steptoe, 2009). In contrast to the studies discussed above, this found that cancer survivors were less likely to be moderately or vigorously active on more than one day per week compared with the control group (51% vs. 59%). There were no differences in current smoking (15% vs. 18%) or alcohol consumption (31% vs. 33%), but cancer survivors were more likely to be former smokers (52% vs. 46%).

Although these studies give a useful snapshot of the health behaviours of cancer survivors around the globe, they are subject to a number of limitations. Cancer diagnosis was self-reported in all studies and the lack of verification with medical records may have led to inaccurate prevalence estimates. Health behaviours were also self-reported which, as discussed previously in this chapter, are prone to both random and systematic error which may bias the results (Natarajan et al., 2006). A variety of different measures of health behaviours were used which may in part explain the conflicting results of the studies. In addition, not all studies had sufficient numbers to conduct group analyses, and it is likely that the findings could vary by cancer site, stage of disease and treatment type. There is also the possibility of confounding, as not all studies adjusted for additional factors which may influence health behaviours. Such confounders have the potential to significantly alter the results, as was shown by Bellizzi and colleagues when controlling for functional limitations (Bellizzi et al., 2005).

A few studies have attempted to overcome some of these limitations. One used data from the American Cancer Society’s Study of Cancer Survivors-II (ACS SCS-II) study to examine the prevalence of physical activity, diet and smoking among 9,105 cancer survivors (Blanchard, Courneya, & Stein, 2008). Participants for this study were identified through cancer registries which have information on cancer group, stage of disease and date of diagnosis, so this information is not self-reported. Only a minority of
cancer survivors were meeting the five-a-day (14.8% for skin melanoma to 18.2% for breast cancer) and physical activity recommendations (29.6% for uterine cancer to 47.3% for skin melanoma), but the majority were non-smokers (82.6% for bladder cancer to 91.6% for prostate cancer). However, this study did not have a comparison group so it is not possible to know how the prevalence of health behaviours compared to those with no diagnosis of cancer. More recently, a study used the 1995-2008 Scottish Health Surveys to compare fruit and vegetable consumption, physical activity, smoking and alcohol among cancer survivors and those with no diagnosis of cancer (Wang, McLoone, & Morrison, 2015). The surveys were linked to the Scottish Cancer Registry so information about cancer diagnoses were not reliant on self-report. This found that cancer survivors were more likely to eat five-a-day (21% vs. 15%) and have stopped smoking (43% vs. 33%), but were less likely to be physically active (35% vs. 45%) than those with no cancer diagnosis.

Another analysis of the NHANES data overcame the issue of self-reported health behaviours by using accelerometers to assess physical activity (Smith, Nolan, Robison, Hudson, & Ness, 2011). This study aimed to determine the proportion of cancer survivors and those with no history of cancer meeting the Centers for Disease Control (CDC) guidelines for physical activity. The results showed that the majority of participants were not meeting the CDC guidelines for physical activity. However, cancer survivors were 70% more likely to fail to meet these guidelines than those with no diagnosis (95.5% vs. 87.3%). Although objective measures of physical activity help overcome the limitations of self-reported data, they are not without their own limitations, for example, they are limited in what movement they can capture and are unable to record horizontal movements such as swimming.

Overall, evidence from these cross-sectional studies suggests that there is little difference between the health behaviours of cancer survivors and the general population. However, the findings are inconsistent, with some showing that cancer survivors have better health behaviours than those with no history of cancer and others showing worse. Regardless of diagnosis, the majority of participants in these studies were not meeting recommended guidelines, particularly for physical activity and diet.
These studies provide a useful snapshot of the prevalence of health behaviours among cancer survivors. However, their cross-sectional design means it is not possible to know if observed differences are a result of behaviour changes following a cancer diagnosis or long-standing differences. Longitudinal studies are required to determine if and how health behaviours change as a result of a cancer diagnosis.

A number of large-scale prospective population studies have now been conducted. Two analyses have used data from the Health and Retirement Study (HRS), a population-based cohort of older adults in the US. One specifically investigated smoking and found over three times the odds of quitting among 7,764 smokers who received a diagnosis of cancer than those without any serious diagnosis in the two years post-diagnosis (Keenan, 2009). The other examined the full HRS sample and found a greater reduction in smoking rates among individuals who had received a diagnosis of cancer within the previous two years (n=1,333; smoking prevalence dropped from 23.7% to 16.1%) than those without any new serious diagnosis (n=1364; from 22.8% to 20.8%), but little or no change in alcohol intake and a reduction in physical activity (Newsom, Huguet, McCarthy, et al., 2012). However, the comparison group was different from the cancer group in total diseases, making it difficult to determine the specific influence of a cancer diagnosis on health behaviours.

Another study examined smoking, diet, alcohol and physical activity in 5,404 adults aged 50 or older in the Canadian National Population Health Survey (NPHS) (Newsom, Huguet, Ramage-Morin, et al., 2012). This found that a cancer diagnosis was associated with reduced rates of smoking (from 17.2% to 13.5%) over an average of 12 years of follow-up, although significant reductions also occurred in the healthy comparison group (from 23% to 21%). No differences were found for diet, alcohol or physical activity.

Two studies have used data from the Danish Diet, Cancer and Health Study. The first examined changes in alcohol, tobacco and BMI among 126 men with prostate cancer, 297 men with a cancer other than prostate, and 20,488 who were cancer-free at baseline and follow-up (Karlsen et al., 2012). This found that men with cancers other than prostate were more likely to quit smoking (59% vs. 31%) and decrease their BMI to
normal (13% vs. 7%). Those with cancers other than prostate who drank more than three drinks per day were less likely than cancer-free men to reduce their alcohol consumption. The other study also examined changes in alcohol, tobacco and BMI, but this time among women with 449 breast cancer and 22,971 cancer-free women (Bidstrup et al., 2013). This found no difference in changes in alcohol, tobacco and BMI between the two groups.

More recently, an analysis of the Cancer Prevention Study-II Nutrition Cohort examined the association between a cancer diagnosis and smoking cessation at two and four year follow-ups (Westmaas, Alcaraz, Berg, & Stein, 2014). This found that smokers who were diagnosed with cancer were more likely to quit smoking at both two (31.3% vs. 19.5%) and four (43.0% vs. 33.8%) year follow-ups compared to those who did not receive a cancer diagnosis.

The prospective design of these studies meant that it was possible to examine how the health behaviours of cancer survivors and those with no diagnosis of cancer change over time. However, they were also subject to a number of limitations. The nature of these studies mean they are subject to survivor bias, as those who died or were too ill would have been lost to follow-up. Several studies used a ‘healthy’ comparison group that was not only free from cancer, but was also free from other conditions such as heart disease. As a result, the differences between the cancer and comparison groups may be inflated and will not show the specific impact of a cancer diagnosis. The majority of these studies only examined changes in health behaviours across two time-points, and it is possible that health behaviours may change over time as the short-term effects of cancer and its treatments diminish. Not all studies had sufficient numbers to analyse the results by group and it is possible that the results may vary according to cancer site, stage of disease and treatment. For example, a patient who has undergone chemotherapy may decrease their physical activity due to fatigue, whereas those who do not have this treatment may be better able to maintain or even improve their physical activity levels. These studies also had a number of similar limitations to the cross-sectional studies, including the use of self-reported measures, varied measures of health behaviours, and insufficient numbers to conduct group analyses.
Overall, the findings from these longitudinal studies provide some evidence that a cancer diagnosis is a trigger for smoking cessation. However, the evidence is more limited for other health behaviours, with some studies finding no difference between cancer survivors and controls and others finding that physical activity levels are reduced following a cancer diagnosis. No studies to date have examined changes in health behaviours from pre to post-cancer diagnosis among cancer survivors and controls in the UK, so this will be the focus of Study 1.

2.6 Summary

This chapter provides an overview of the evidence for the role of health behaviours in cancer survivors. The current evidence suggests that not smoking and being physically active are associated with improved survival among cancer survivors. There is also a wealth of evidence suggesting that physical activity is beneficial for symptom reduction and well-being. While conclusions cannot be drawn about specific dietary components, there is evidence that having an overall healthy diet and avoiding a Western dietary pattern may reduce risk of mortality. Both weight gain and weight loss are linked to poorer health outcomes, even among cancer survivors who are overweight or obese, suggesting that weight maintenance is preferable. However, no intervention studies have examined the impact of weight loss on survival. Evidence for alcohol consumption is more limited and seems to depend on cancer site. There are a number of plausible biological mechanisms linking all of these aspects of lifestyle with cancer but more research is need to establish the same evidence-base for survival as exists for cancer prevention.

Consequently, a number of organisations have produced lifestyle guidelines for cancer survivors, which suggest survivors should follow the recommendations for prevention. However, the prevalence of health behaviours among cancer survivors appears to be below recommended levels. This is concerning given the potential benefits of a healthy lifestyle in this population. It is currently unclear whether cancer survivors in the UK change their health behaviours following their cancer diagnosis, as no prospective longitudinal studies have been conducted across multiple time-points from pre to post-diagnosis.
CHAPTER 3: AIMS OF THE THESIS

The evidence summarised in Chapters 1 and 2 highlights some of the physical and psychosocial consequences of a cancer diagnosis and the potential benefits of a healthy lifestyle in this population. However, a number of questions about the current health behaviours of cancer survivors and the lifestyle information available to them remain unanswered. Therefore, this PhD aimed to address the following questions:

1) What are the health behaviours of cancer survivors, how do these change following a cancer diagnosis, and what factors are associated with meeting lifestyle recommendations?
2) Are cancer survivors aware of the potential benefits of a healthy lifestyle for their long-term health?
3) What lifestyle information is available to cancer survivors and what determines whether they receive such information?
4) Are cancer survivors interested in lifestyle information, what are their preferences regarding such information, and do cancer survivors and their social networks think lifestyle advice should be given to individuals diagnosed with cancer?

Specifically, Study 1 examined changes in physical activity, smoking and alcohol from pre to post-diagnosis among cancer survivors in the English Longitudinal Study of Ageing (ELSA). Following on from this, Study 2 examined cancer survivors’ beliefs about lifestyle and their sources of information in a qualitative interview study. Study 3 reviewed the lifestyle information that is available to cancer survivors online. Studies 4 to 6 all used survey data to examine the perspectives of cancer survivors, their social networks and health professionals on lifestyle information and advice for cancer survivors.
CHAPTER 4: STUDY 1: THE IMPACT OF A CANCER DIAGNOSIS ON HEALTH BEHAVIOUR CHANGE

4.1 Introduction

As outlined in Chapter 2, there have been no prospective studies examining changes in health behaviours from pre to post-diagnosis among people diagnosed with cancer in the UK. Existing prospective studies have been limited to North America (Keenan, 2009; Newsom, Huguet, McCarthy, et al., 2012; Newsom, Huguet, Ramage-Morin, et al., 2012) and Denmark (Bidstrup et al., 2013; Karlsen et al., 2012), and have used ‘healthy’ comparison groups who were free from multiple chronic conditions and not just cancer, therefore making it difficult to determine the specific impact of a cancer diagnosis on health behaviours. No studies to date have tracked health behaviour changes in cancer survivors and controls for any significant period beyond a cancer diagnosis.

4.2 Aim

The primary aim of this study was therefore to examine the effect of a cancer diagnosis on changes in physical activity, smoking and alcohol across three time-points (0-2 years before a cancer diagnosis, 0-2 years post-diagnosis and 2-4 years post-diagnosis) using data from a population-based sample in the UK. The comparison sample comprised individuals who had not received a diagnosis of cancer.

4.3 Methods

4.3.1 Design and participants

Data for this study were from waves 1-5 of the English Longitudinal Study of Ageing (ELSA) which were collected biennially between 2002 and 2010.

3 A version of this chapter has been published in the British Journal of Cancer (Appendix 4.1)
CHAPTER 4: THE IMPACT OF A CANCER DIAGNOSIS ON HEALTH BEHAVIOUR CHANGE

4.3.1.1 English Longitudinal Study of Ageing

ELSA is a population-based cohort of adults aged ≥50 years drawn from participants in the Health Survey for England (HSE) in 1998, 1999 or 2001. It is a ‘sister’ study to the Health and Retirement Study (HRS) in the US and has a partly harmonised data collection protocol (Steptoe, Breeze, Banks, & Nazroo, 2012). ELSA has received approval from various ethics committees, including the London Multi-Centre Research Ethics Committee, and full informed written consent has been obtained from all participants.

Six waves of ELSA have been carried out to date. At the time the analyses for this study were conducted, only data from waves 1 to 5 were available. At each wave, participants completed a range of assessments including a computer-assisted personal interview and a self-administered questionnaire. Refreshment samples were added at waves 3, 4 and 6; the first to maintain the representation of people aged 50-53 years, the second to include more individuals aged 50-75 years, and the third to include more individuals aged 50-55 years. In alternate waves, a nurse visit was carried out to collect objective measures of health status. Full details on the ELSA cohort and sampling methods are available elsewhere (Marmot, Banks, Blundell, Lessof, & Nazroo, 2003; Steptoe et al., 2012).

4.3.1.2 Analysed sample

The analysed sample included participants who reported a new cancer diagnosis in waves 2 to 4 and had provided data for both the previous and subsequent wave. A cancer diagnosis was defined as answering ‘yes’ to the question: ‘Have you ever been told by a doctor or other health professional that you had cancer or any other kind of malignancy’. The first wave in which they responded ‘yes’ became their ‘peri-diagnosis’ point (T1), the previous wave was their pre-diagnosis point (T0), and the subsequent wave was their post-diagnosis point (T2). Individuals reporting a cancer diagnosis at wave 1 or a new diagnosis at wave 5 were excluded from the analysis because of the absence of pre or post-diagnosis data respectively. For the comparison group, data from waves 2, 3 and 4 were used as T0, T1 and T2 respectively. This group comprised all individuals who had not received a cancer diagnosis in any wave. This was favoured
over a completely healthy control group as it enabled me to determine the specific influence of a cancer diagnosis independent of other chronic diseases. For both samples, I only included individuals with data available from three consecutive waves for at least one variable of interest (physical activity, alcohol or smoking). Figure 4.1 shows the flow of participants through the study.

Figure 4.1 Flow of participants through the study

4.3.2 Measures

4.3.2.1 Demographic

Age and gender were included as control variables, with household non-pension wealth used as an indicator of socioeconomic status (SES), because it has been identified as particularly appropriate to this age group (Banks, Karlsen, & Oldfield, 2003).

4.3.2.2 Cancer diagnosis

As described above, a cancer diagnosis was assessed with the question ‘Have you ever been told by a doctor or other health professional that you had cancer or any other kind of malignancy?’ (yes/no).
4.3.2.3 Smoking

Smoking status was assessed with a question adapted from the Health Survey for England: ‘Do you smoke cigarettes at all nowadays?’ (yes/no) (Craig, Mindell, & Hirani, 2009).

4.3.2.4 Alcohol

In wave 1, alcohol consumption was assessed with the question ‘In the past 12 months have you taken an alcoholic drink?’ with response options: twice a day or more/daily or almost daily/once or twice a week/once or twice a month/special occasions only/not at all. In waves 2 to 5, alcohol consumption was assessed with the question ‘On how many days out of the last seven did you have an alcoholic drink?’ with response options of one to seven.

The alcohol questions were already dichotomised in the dataset as I received it. Those who were daily (or almost daily) alcohol drinkers were categorised as heavy drinkers and all other categories combined were categorised as not heavy drinkers. Specifically, for the alcohol measure used in wave 1, those who responded ‘twice a day or more’ or ‘daily or almost daily’ were classified as heavy alcohol drinkers. For the alcohol measure used in waves 2-5, those who responded ‘five’, ‘six’ or ‘seven’ were classified as heavy alcohol drinkers. This threshold is consistent with the evidence showing that consuming an alcoholic drink every day is associated with poorer outcomes among breast cancer survivors (Kwan et al., 2013), and public health guidelines which recommend having at least two alcohol free days per week (NHS Choices, 2015).

4.3.2.5 Physical activity

Physical activity was assessed with three questions adapted from the Whitehall II study, one each on mild, moderate and vigorous activity: ‘Do you take part in any sports that are [vigorous/moderately energetic/mildly energetic]’ with response options: more than once a week/once a week/one to three times a month/hardly ever or never (Marmot et al., 1991). I was provided with the dataset with these questions already dichotomised into those who did moderate or vigorous activity at least once a week (active), and those who did less than this (inactive).
CHAPTER 4: THE IMPACT OF A CANCER DIAGNOSIS ON HEALTH BEHAVIOUR CHANGE

4.3.3 Analyses

Unless otherwise specified, all data in this thesis were analysed using IBM SPSS Statistics version 20 (IBM Corp., 2010). A two-sided $P$ value of <.05 was used as an indicator of statistical significance. Advice was sought from a departmental statistician on the most appropriate statistical tests to use.

4.3.3.1 Parametric assumptions

Throughout this thesis, where applicable I tested the parametric assumptions of the data. Parametric tests, such as $t$-tests in this chapter, assume that the data is normally distributed and that when groups are compared they should have equal variance. If an assumption is violated, using a parametric test may yield inaccurate results, so a non-parametric test should be used instead. To assess the normality of my data I used the Kolomogorov-Smirnov test, and examined histograms and skewness and kurtosis statistics (as a general rule, values between -1 and 1 were considered acceptable). Levene’s test was used to check for homogeneity (equality) of variance. Where these assumptions were not met I ran non-parametric tests. The results of the non-parametric tests are only reported if they differed from the parametric findings.

4.3.3.2 Descriptive data

Independent samples $t$-tests (for continuous variables) and chi-square tests (for categorical variables) were conducted to explore differences between the cancer and comparison groups in age, sex and wealth.

Separate analyses were also run to check how the analysed sample in this study compared with the total available ELSA sample. $T$-tests (for continuous variables) and chi-square tests (for categorical variables) were used to compare the demographic characteristics and health behaviours of the sample in this study, with ELSA participants who had data available for wave 2 but were later excluded because they did not meet my inclusion criteria (i.e. because they did not have data available from three consecutive waves for at least one variable of interest).
4.3.3.3 Main analyses

Generalised estimating equation (GEE) models were used to examine main effects of group (overall group differences in prevalence of smoking, heavy alcohol consumption, and physical activity independent of time), main effects of time (changes in behaviours over time independent of group), and group-by-time interactions (differences in behaviour change over time between groups). Age, sex and wealth were entered as covariates for all analyses. GEEs were chosen over a repeated measures analysis of variance, as they allow the correlation of outcomes within an individual to be estimated and taken into account (Burton, Gurrin, & Sly, 1998).

4.3.3.4 Sensitivity analyses

Where the pattern of results suggested there may be non-linearity across the three time-points, this was tested using a linear-by-linear association test. As non-linearity could have affected the analyses over the three time-points, I repeated the GEE analyses to examine group-by-time interactions across two time-points as applicable.

4.4 Results

4.4.1 Sample characteristics

The demographic characteristics of the analysed sample (N=5,146), comprising individuals with a new cancer diagnosis in waves 2-4 (n=433) and individuals with no cancer diagnosis in any wave (n=4,173) and data on at least one health behaviour for three consecutive waves, are shown in Table 4.1. The cancer group were older (69.9 years vs. 66.5 years; p<.001), and had a more equal gender balance than the comparison group (p <.05), but the groups did not differ in wealth (p =.935).

The analysed sample in this study were slightly younger, wealthier and had slightly better health behaviours (were less likely to smoke and were more likely to be physically active), than those who were excluded because they did not meet the inclusion criteria (have three consecutive waves of data for at least one variable of interest). The characteristics of both groups are shown in Appendix 4.2.
### Table 4.1 Demographic characteristics of sample

<table>
<thead>
<tr>
<th>Cancer group (n=433)</th>
<th>Comparison group (n=4713)</th>
<th>Mean ± SD</th>
<th>Mean ± SD</th>
<th>t(df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 69.92 ± 9.67</td>
<td>66.52 ± 8.97</td>
<td>-7.03(502.6)</td>
<td>.000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% (N)</td>
<td>% (N)</td>
<td>χ²(df)</td>
<td>p</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male 48 (207)</td>
<td>44 (2061)</td>
<td>5.42(1)</td>
<td>.020</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female 49 (210)</td>
<td>56 (2652)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wealth quintiles</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 (lowest) 18 (77)</td>
<td>18 (862)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>19 (80)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>22 (97)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>20 (87)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 (highest) 20 (88)</td>
<td>21 (998)</td>
<td>0.83(4)</td>
<td>.935</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Percentages were derived from the total sample so where numbers do not total 100% this is due to missing data.

### 4.4.2 Smoking

Figure 4.2 shows the proportion of smokers in each group at each time. There was no significant difference in the proportion of smokers by diagnosis status (Wald χ² (1) = 0.91, p=.34). In both groups, the proportion of smokers went down over time (Wald χ² (2) = 23.99, p<.001). Between T0 and T1, smoking rates dropped from 12.0% to 9.4% in the cancer group and 10.2% to 9.0% in the comparison group. Between T1 and T2, smoking rates increased from 9.4% to 9.9% in the cancer group and dropped from 9.0% to 8.3% in the comparison group. The group-by-time interaction over 3 time-points was not statistically significant (Wald χ² (2) = 3.58, p=.17).
4.4.3 Heavy alcohol consumption

Figure 4.3 shows the proportion of heavy alcohol drinkers in each group at each time. There was no significant overall group difference in the proportion of heavy alcohol drinkers (Wald $\chi^2 (1) = 0.47, p=.49$). The proportion of heavy alcohol drinkers went down in both groups, with an effect that approached significance (Wald $\chi^2 (2) = 5.67, p=.06$). Between T0 and T1, the proportion of heavy alcohol drinkers dropped from 22.9% to 19.2% in the cancer group and from 22.4% to 21.9% in the comparison group. Between T1 and T2, the proportion of heavy alcohol drinkers rose from 19.2% to 20.1% in the cancer group and dropped from 22.0% to 21.6% in the comparison group. The group-by-time interaction was not statistically significant (Wald $\chi^2 (2) = 3.25, p=.20$).
CHAPTER 4: THE IMPACT OF A CANCER DIAGNOSIS ON HEALTH BEHAVIOUR CHANGE

Figure 4.3 The proportion of heavy alcohol drinkers in each group at each time-point (adjusted for age, sex and wealth)

4.4.4 Physical activity

Figure 4.4 shows the results for being moderately or vigorously active at least once a week at each time-point. Overall, the cancer group were significantly less physically active than the comparison group (Wald $\chi^2 (1) = 11.95$, $p<.01$). In both groups, the proportion who were physically active reduced over time (Wald $\chi^2 (2) = 8.85$, $p<.05$). Between T0 and T1, rates of being physically active dropped from 13.2% to 9.4% in the cancer group and 15.9% to 15.1% in the comparison group. Between T1 and T2, physical activity increased from 9.4% to 9.9% in the cancer group and dropped from 15.1% to 14.4% in the comparison group. The group-by-time interaction was not statistically significant (Wald $\chi^2 (2) = 3.53$, $p=.17$).
4.4.5 Sensitivity analyses

The pattern of results in the main analyses suggested there may be non-linearity in the cancer group for smoking, alcohol and activity, with a trend towards slightly greater changes from T0 to T1 in the cancer group, followed by a small rebound from T1 to T2. The linear-by-linear association test failed to confirm linearity for smoking, alcohol and activity in the cancer group (Appendix 4.3). As this may have affected the analyses over the three time-points, I repeated the analyses to examine group-by-time interactions specifically for the T0 to T1 transition. These results showed consistent, near-significant, trends towards the cancer group making greater changes than the comparison group from T0 to T1: smoking ($p=.11$), alcohol ($p=.07$) and physical activity ($p=.07$).

Interactions over the T1 to T2 transition were not significant for smoking ($p=.14$), alcohol ($p=.55$) or activity ($p=.56$).
4.5 Discussion

Building on the existing literature discussed in Chapter 2, this study investigated the impact of a cancer diagnosis on health behaviour change in a population-based sample of older adults living in England. In comparison with participants not receiving a cancer diagnosis but not otherwise selected, this study did not find evidence that receiving a cancer diagnosis was associated with differential change in health behaviours. Although the pattern of results suggested that a slightly larger proportion of the cancer group quit smoking immediately after their diagnosis, the interaction with time was not statistically significant. Similarly no differences in heavy alcohol intake were observed. At all time-points a smaller proportion of individuals in the cancer group were physically active, but the changes in activity were not different in the group with a cancer diagnosis compared with the comparison group.

In contrast with previous research (Karlsen et al., 2012; Keenan, 2009; Newsom, Huguet, McCarthy, et al., 2012; Westmaas et al., 2014), this study did not find higher rates of smoking cessation in the cancer group. This is surprising given that motivation for smoking cessation is thought to increase following a cancer diagnosis (Gritz et al., 1993), and evidence of spontaneous quitting has supported the idea of a cancer diagnosis being a ‘teachable moment’ (Rabin, 2009). It should be noted that the higher quit rates in HRS may have been due to the comparison group being particularly healthy and free from any chronic conditions, not just cancer. One possible explanation for the lack of any excess quitting in the cancer group in this study is that UK adults are already getting excellent quitting advice due to the successful National Health Service (NHS) stop smoking services (Bauld, Bell, McCullough, Richardson, & Greaves, 2010). This would be consistent with the relatively low smoking rates in the sample overall. However, given that 75% of smokers with a cancer diagnosis failed to quit, a cancer diagnosis appears to be an underused opportunity for intervention. The need for assistance to quit smoking has been reported by patients with heart disease, and the same may apply to patients with cancer (Wilkes & Evans, 1999). Smoking rates did reduce over time in both groups; in line with other UK population data showing progressive reductions in smoking prevalence with advancing age (The NHS Information Centre, Lifestyles Statistics, 2011),
similar to the HRS and Canadian data (Newsom, Huguet, McCarthy, et al., 2012; Newsom, Huguet, Ramage-Morin, et al., 2012). Similarly, heavy alcohol consumption reduced over time in both groups, consistent with previous longitudinal studies that have found an age-related decline in alcohol consumption among men with or without a cancer diagnosis (Karlsen et al., 2012). Also consistent with previous cross-sectional studies, rates of alcohol consumption did not reduce (or increase) more in the cancer group over the time of diagnosis (Bellizzi et al., 2005; Coups & Ostroff, 2005; Eakin et al., 2007).

The sample as a whole had low levels of activity, and those who received a cancer diagnosis were even less active than the comparison group; consistent with findings from cross-sectional studies (Grimmett et al., 2009; Smith et al., 2011). There was no evidence of differential change in physical activity, in terms of cancer survivors getting either less or more active. This may be due to early symptoms of their cancer preventing them from being active, but is also consistent with the literature on the role of physical inactivity in cancer onset (Lynch, 2010). The finding that both groups became progressively less active over time highlights a need to increase the proportion of older adults who do at least some physical activity. Physical activity advice in the context of a cancer diagnosis could be particularly beneficial and contribute to improved long-term outcomes.

Overall, these findings provide little evidence that a cancer diagnosis is associated with spontaneous positive lifestyle changes over and above lifestyle trends in the older adult population. There were downward trends in smoking regardless of diagnosis. The slightly higher smoking rates among those who got a cancer diagnosis dropped to match the comparison group over time, but the differential change was not statistically significant in this sample. There was no sign that cancer survivors had become more active either in the first examination after diagnosis or two years after that.

Given that significant life events such as a cancer diagnosis are thought to motivate individuals to make positive lifestyle changes (Rabin, 2009), these findings raise the question of why such changes are not seen in this study. One explanation may be that
cancer survivors make some immediate, short-lived changes but return to their usual lifestyle before they next complete an ELSA questionnaire. However, it is also possible that they do not have access to appropriate information and advice about lifestyle and are unsure about what changes they should be making post-diagnosis. Cancer survivorship has been on the agenda in the US since the 1990s, whereas it really only rose to prominence in the UK following the Cancer Reform Strategy in 2007 (Department of Health, 2007). This could help explain why I did not find as large a reduction in smoking among cancer survivors as was found in HRS, although this could also be due to HRS using a healthy comparison group rather than a group that only differed by cancer diagnosis (Newsom, Huguet, McCarthy, et al., 2012).

4.5.1 Limitations

The findings of this study are subject to many limitations. All data were self-reported, including a cancer diagnosis. It is therefore possible that some individuals may have inaccurately reported that they had been diagnosed with cancer, for example, if they had a benign tumour. It is also possible that individuals in the comparison group could have received a cancer diagnosis but have responded incorrectly. The self-reported data on health behaviours may also be inaccurate, as research has shown that individuals typically under-report their smoking habits (Gorber, Schofield-Hurwitz, Hardt, Levasseur, & Tremblay, 2009) and over-report their physical activity levels (Prince et al., 2008). However, this means it is possible that the health behaviours of cancer survivors may be even worse than these results show; further highlighting a need to understand what influences lifestyle changes among cancer survivors.

Another limitation of this study is that it did not examine dietary intake. ELSA contains limited questions on fruit and vegetable intake but these were only asked in waves 3 to 5. Unfortunately the sample size from these three waves alone was too small to include in the analyses. No other measures of dietary intake are included in ELSA. Assessments of weight and height were only taken during the nurse visits in waves 2 and 4 so again, it was not possible to examine changes in BMI across three time-points.
CHAPTER 4: THE IMPACT OF A CANCER DIAGNOSIS ON HEALTH BEHAVIOUR CHANGE

The physical activity questions only asked about sports and not other aspects of physical activity so it was not possible to accurately describe the proportion of those meeting physical activity recommendations. It is possible that this may have led to physical activity levels being underestimated, although the physical activity levels in older adults are known to be low (Hallal et al., 2012). Conversely, the nature of the physical activity questions meant that participants were classified as active if they were moderately or vigorously active at least once a week, but once a week is still below recommended levels. This could have led to physical activity levels being overestimated. In addition, although the health behaviour measures had been widely used, they had not been formally validated so further studies using validated measures are required.

The analyses only included individuals who had three consecutive waves of data available for at least one outcome variable, and who answered the cancer diagnosis question at each wave. As a result, those who died or dropped out were excluded. Participants in the analysed sample were slightly wealthier and had slightly better health behaviours than the total ELSA sample. This is consistent with the “healthy participant effect”, where participants are generally better off than non-participants and this tends to attenuate over time (Mendes de Leon, 2007). However, this could mean that these findings provide a conservative estimate of lifestyle change, and things could be worse than these figures suggest.

As the analyses for this study required participants to have three consecutive waves of data, the sample size was substantially smaller than the total ELSA sample. Unfortunately this meant that I was unable to run my analyses separately for breast, prostate and colorectal cancers as with the small sample size there would not have been sufficient power to detect an effect. It is therefore possible that health behaviours improved for some types of cancers but got worse for others, so the current results may show an average of little or no change to lifestyle.

Even in the analysed sample, there may not have been sufficient power to detect a significant effect. It is possible that with a larger sample size, the higher rates of quitting smoking from pre to peri-diagnosis might have been significant, in line with previous
studies (Newsom, Huguet, McCarthy, et al., 2012; Newsom, Huguet, Ramage-Morin, et al., 2012). However, the proportion of smokers was still higher than the general population.

4.5.2 Conclusions

Overall, the results of this study provide little evidence that a cancer diagnosis is associated with spontaneous positive lifestyle changes, with only modest reductions in smoking rates and a decrease in physical activity similar to population level age-related changes. This conflicts with studies that have found cancer survivors report making positive lifestyle changes following their diagnosis, in line with the ‘teachable moment’ hypothesis (McBride & Ostroff, 2003). Given this discrepancy, it is important to understand cancer survivors’ beliefs about the role of lifestyle post-cancer diagnosis, and whether they are receiving appropriate information and advice about lifestyle.
CHAPTER 5: STUDY 2: CANCER SURVIVORS’ BELIEFS ABOUT LIFESTYLE AND THEIR SOURCES OF INFORMATION

5.1 Introduction

Study 1 found little evidence that a cancer diagnosis leads to sustained positive changes in health behaviours, but it did not explore why this might be the case. Understanding the factors that influence whether cancer survivors make lifestyle changes following their diagnosis may help highlight potential opportunities for interventions to help them have a healthier lifestyle.

One explanation for why cancer survivors do not appear to make sustained positive changes to their lifestyle is that they are unsure about what they should be doing. The lack of strong trial evidence for some health behaviours and absence of guidelines for specific cancer groups may cause confusion for some survivors, who may benefit from professional advice. However, a recent survey of 3,300 colorectal cancer survivors found that over 20% would like more advice on diet and lifestyle, suggesting that many do not feel sufficiently informed in this area (Department of Health & NHS, 2012). This has been echoed by qualitative studies which have found cancer survivors report a lack of information about physical activity, diet and weight (James-Martin, Koczwar, Smith, & Miller, 2014). Another qualitative study of colorectal cancer survivors in the UK found that several people reported actively trying to seek out further information about lifestyle, and their preferred source of information was expert patients (Anderson, Steele, & Coyle, 2013).

Although important, information alone is unlikely to be sufficient to ensure cancer survivors make positive changes to their lifestyle (Ryan, 2009). Perceived benefits and barriers are key components of several psychological models which aim to explain and predict health behaviours (Ajzen, 1985; Janz & Becker, 1984; Leventhal et al., 1997). Consistent with these theories, there is evidence that positive beliefs are associated with an increased likelihood of performing a behaviour, for example, breast cancer survivors

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4 A version of this chapter is currently under review at the European Journal of Cancer Care
have been found to be more likely to implement healthy lifestyle changes if they think it will help prevent cancer recurrence (Rabin & Pinto, 2006). Similarly, colorectal cancer patients who report barriers to physical activity have been found to be less likely to engage in physical activity (Fisher, Wardle, et al., 2015). Therefore, understanding cancer survivors’ beliefs about the potential benefits of a healthy lifestyle and their barriers to making lifestyle changes is crucial to understanding why their health behaviours are suboptimal and why they do not appear to make lifestyle changes following their diagnosis.

Several studies have examined barriers to lifestyle changes among cancer survivors, the majority of which have focused on physical activity in breast cancer survivors. Qualitative studies of women with breast cancer have found that they report cancer-related symptoms and side effects (e.g. fatigue) as the main barrier to exercise participation (Brunet, Taran, Burke, & Sabiston, 2013; Husebø, Karlsen, Allan, Søreide, & Bru, 2015). In contrast, a survey of 452 breast and prostate cancer survivors enrolled in the FRESH START trial, found that practical barriers such as being too busy (breast 52%, prostate 45%) and lack of willpower (breast 51%, prostate 44%) were most commonly reported (Ottenbacher et al., 2011). In a survey of a mixed group of 975 cancer survivors, the most commonly endorsed barriers to exercise participation were illness or other health problems (37%), joint stiffness (37%) and fatigue (36%), although practical barriers, such as lack of motivation (27%), weather (26%) and lack of facilities (26%), were also mentioned (Blaney, Lowe-Strong, Rankin-Watt, Campbell, & Gracey, 2013). Another qualitative study of men diagnosed with prostate cancer found that unreliable information was reported as a barrier to dietary change (Avery et al., 2014).

Several studies have examined cancer survivors’ beliefs about the causes of cancer and these have found that most do not attribute their cancer to lifestyle factors. In a recent systematic review of 24 studies examining causal attributions among breast cancer survivors, the proportion of those who believed their cancer was caused by lifestyle ranged from 10.1% to 38.4% for physical activity, 1.0% to 67.9% for diet, 6.7% to 25.0% for alcohol, 1.3% to 16.4% for smoking, and around 16.0% for body size (Dumalaon-Canaria, Hutchinson, Prichard, & Wilson, 2014). Similar results were found in a study
examining causal attributions among the survivors of 10 common cancers, with lifestyle being attributed as a cause by only 18.8% of prostate, 37.7% colorectal, 10.5% lung, 21.2% Non-Hodgkin lymphoma and 46.8% other cancer survivors (Ferrucci et al., 2011). Smoking was listed separately, with fewer than 10.0% attributing it as a cause of all cancers except lung, where it was attributed by 76.3% survivors.

Less is known about cancer survivors’ beliefs about the role of lifestyle in cancer recurrence and long-term health. A recent study of 200 breast cancer survivors found that the most frequently endorsed factors for preventing recurrence were avoiding tobacco use (84%), exercising at least three times per week (74%), eating five portions of fruit and vegetables per day (72%), and limiting food intake to maintain or lose weight (70%) (Burris, Jacobsen, Loftus, & Andrykowski, 2012). These findings would suggest that cancer survivors consider lifestyle factors to play a more important role in reducing recurrence than they do reducing risk, which may be an attempt to minimise feelings of blame for their cancer onset while taking control of their future health. However, another study of 355 breast cancer survivors found many were unsure or did not agree that eating five portions of fruit and vegetables (46.5%) or engaging in regular physical activity (32.9%) would help reduce the risk of breast cancer recurrence (Weiner, Jordan, Thompson, & Fink, 2010), suggesting that a substantial proportion of survivors remain uncertain of the role of lifestyle following a cancer diagnosis. This uncertainty was echoed in a qualitative study with 36 cancer survivors (86% breast cancer), which found they were unsure about the relationship between diet and body weight, and cancer recurrence (Maley, Warren, & Devine, 2013).

Although quantitative research gives an indication of cancer survivors’ beliefs about lifestyle and cancer, it does not provide a detailed understanding of these beliefs or the reasons behind them. In addition, although existing research suggests that cancer survivors report making lifestyle changes following their diagnosis, it does not explain their motivations behind these changes. Gaining a more detailed understanding of cancer survivors’ beliefs about lifestyle and their attempted lifestyle changes, may help explain why changes do not appear to be sustained at a population level. In addition, determining cancer survivors’ sources of information about lifestyle may help explain
any gaps in knowledge or misconceptions about the role of lifestyle in cancer survivorship.

5.2 Aim

The aim of this study was therefore to use qualitative methodology to explore cancer survivors’ beliefs about the role of lifestyle in their long-term health and survival, and their attempted lifestyle changes since their diagnosis. It also aimed to examine their sources of information about lifestyle in order to understand what drives their beliefs and lifestyle choices.

5.3 Methods

This study is reported in accordance with the consolidated criteria for reporting qualitative research (COREQ) checklist (Tong, Sainsbury, & Craig, 2007).

5.3.1 Ethical approval

This study was approved by the University College London Research Ethics Committee, reference 0793/004 (Appendix 5.1).

5.3.2 Design

A qualitative methodology was chosen in order to explore cancer survivors’ thoughts and feelings about the role of lifestyle in their long-term health. Although there are many benefits of quantitative methodologies, such as questionnaires, they do not typically capture this level of detail. This deeper exploration enables a different understanding of the factors that influence cancer survivors’ beliefs about lifestyle and what drives these beliefs, as well as an understanding of why and where they seek out information.

Semi-structured interviews were selected as they are an appropriate method for exploring the beliefs, experiences and motivations of individuals on specific matters (Gill, Stewart, Treasure, & Chadwick, 2008). The interviews were carried out by myself (n=7), Dr Rebecca Beeken (RB; n=6); a Senior Research Psychologist, and Dr Helen Croker
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(HC; n=6); a Clinical Research Dietitian, both in the Health Behaviour Research Centre (HBRC) at UCL. All researchers had previous experience of conducting qualitative interviews and had a general interest in health behaviours and cancer survivorship. Interviews were carried out between March and July 2013 and were either face-to-face or by telephone depending on the participant’s preference. All interviews were conducted privately with only the researcher and the participant present.

5.3.3 Participants

Participants were eligible if they were adult cancer survivors (age ≥18 years), lived in the UK, had been diagnosed with any cancer during adulthood, and were not currently receiving treatment for cancer. Survivors of paediatric cancers were excluded because the focus of this thesis is on adult cancers. Although the evidence for the role of health behaviours in cancer outcomes is limited to certain groups of survivors, existing lifestyle recommendations do not discriminate (WCRF & AICR, 2007). Therefore, all adult diagnoses were included in order to get an overview of the beliefs held by cancer survivors generally, and to find out where they obtain their information. Participants were also only included if they had completed treatment for cancer, to ensure that all had gone through the cancer care pathway and had the opportunity to be given information about lifestyle at various stages.

5.3.4 Recruitment

The study was advertised on Cancer Research UK’s ‘Cancer Chat’ online forum5 and by posters and flyers displayed in the University College Hospital Macmillan Cancer Centre in London (Appendix 5.2). Potential participants were asked to contact the study team by telephone or email to check eligibility, and a follow-up telephone call was arranged for those making contact by email. During this telephone call, potential participants were given further information about the study and the researchers, and had the opportunity to ask questions. Those who were still interested in taking part were then invited for an interview. They were given the choice of having this face-to-face at the HBRC in Central London, or over the telephone.

5 https://www.cancerresearchuk.org/about-cancer/cancer-chat/
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Before their interview, all participants were mailed a study information sheet (Appendix 5.3), consent form (Appendix 5.4), and brief socio-demographic questionnaire (Appendix 5.5). For those interviews being conducted by telephone, participants were asked to return their signed consent form and socio-demographic questionnaire in the freepost envelope provided. Those who attended in person either brought their consent form and questionnaire along to their interview, or completed them on arrival. Interviews did not take place until a signed consent form had been received by the researchers. Figure 5.1 shows the flow of participants through the study.

![Figure 5.1 Flow of participants through the study](image)

5.3.5 Measures

5.3.5.1 Socio-demographic questionnaire

Socio-demographic questions included sex, age, marital status (‘What is your marital status’ with response options: single or never married/married or living with partner/married separated from spouse/divorced/widowed/civil partnered/prefer not to say), ethnicity (‘Which of these best describes your ethnic group’ with response options: White British/White Irish/Any other White background/White and Black Caribbean/White and Black African/White and Asian/Any other mixed background/Indian/Pakistani/Bangladeshi/Any other Asian background/Black...
Caribbean/Black African/Any other Black background/Chinese/Other/Prefer not to say),
education (‘What is the highest level of educational qualification you have obtained’
with response options: Degree of higher degree/higher education qualification below
degree level/A-levels or Higher/ONC or BTEC/Still studying/O level or GCSE equivalent
(Grades A-C)/O level or GCSE equivalent (Grades D-G)/No formal
qualifications/Other/Prefer not to say) and employment (‘Are you currently...’ with
response options: Employed full-time/Employed part-time/Unemployed/Self-
employed/Full-time homemaker/Retired/Still studying/Disabled or too ill to work/Prefer
not to say).

Participants were also asked questions about their cancer diagnosis including ‘Have you
ever been diagnosed with cancer’ (with response options: Yes/No/Not sure), the primary
cancer site (‘If yes, which type (please print site)’), and the date of diagnosis (‘When
were you diagnosed (please print year)’).

Some brief measures of health behaviours were also included, including smoking (‘Do
you smoke’ with response options: current smoker/former smoker/never smoker),
alcohol (‘How often do you have a drink containing alcohol’ with response options:
never/monthly or less/2-4 times per month/2-3 times per week/4+ times per week).
Physical activity was assessed with the same three questions described in Study 1, one
about each of mild, moderate and vigorous activity (‘Do you take part in any sports that
are [vigorous/moderately energetic/mildly energetic]’ with response options: more than
once a week/once a week/one to three times a month/hardly ever or never) (Marmot et
al., 1991). Participants were also asked to report their height and weight.

5.3.5.2 Interview topic guide

A semi-structured topic guide was developed that allowed participants to deviate from
the structure and discuss their experiences freely (Appendix 5.6). The guide consisted of
a series of open-ended questions covering beliefs about the relationship between
lifestyle and cancer, lifestyle changes following their cancer diagnosis, and sources of
information about lifestyle. Participants were given the opportunity to talk freely, but
prompts were included in order to keep the discussion within the broad topic area.
Once the guide had been drafted, it was reviewed by the other researchers involved (HC & RB), and amended according to their feedback. The topic guide was piloted with two participants, but as no substantial changes were required these data were included in the main analysis.

5.3.6 Analyses

5.3.6.1 Socio-demographic questionnaire

Descriptive statistics were produced to show the socio-demographic, health and anthropometric characteristics of the sample, along with their health behaviours. Specifically, the mean age of the sample was calculated, and percentages were produced to show the proportion of participants in each category. As with Study 1, only the proportion of those who reported doing moderate physical activity more than once per week are reported. BMI (weight (kg)/height (m)²) was calculated using participants’ self-reported height and weight. The proportions of those falling into each BMI category are reported. This was classified according to the NHS BMI cut-offs for underweight (<18.5kg/m²), normal weight (18.5-24.9kg/m²), overweight (25-29.9kg/m²), or obese (≥30kg/m²) (NHS Choices, 2014a).

5.3.6.2 Thematic analysis of interviews

All interviews were recorded using an electronic recorder and transcribed verbatim by an external company (Devon Transcription⁶). Data were analysed using Thematic Analysis, a qualitative method for identifying, analysing and reporting themes (Braun & Clarke, 2006). Thematic analysis is independent of theory, and can therefore be used to analyse data from a range of qualitative approaches. This method was chosen due to its flexibility and potential to provide a rich and detailed, yet complex account of the data. It is also a useful method for summarising key features of a large body of data and comparing similarities and differences.

The analysis followed the six phase guide to thematic analysis outlined by Braun and Clarke in their paper on using thematic analysis in psychology: familiarisation,

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⁶ http://www.devontranscription.co.uk/
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generation of codes, searching for themes, reviewing themes, defining the themes and then writing the report (Braun & Clarke, 2006). As part of the familiarisation phase, I listened to the recordings of the interviews conducted by HC and RB, and read all of the transcripts several times to ensure I was fully immersed in the data.

5.3.6.3 Coding

Once I had familiarised myself with the transcripts, I generated an initial list of codes. This was also done independently by the other two researchers on the study (HC & RB). I then amended and refined these lists through discussion with the other researchers until a single list was agreed.

The subsequent stages of the analysis were conducted in NVivo version 10, a software package designed to aid qualitative data analysis (QSR International Pty Ltd, 2012). I uploaded all of the transcripts to NVivo in preparation for coding, entered the list of codes and coded all of the transcripts. This involved selecting parts of the text within the transcripts and assigning codes to them, taking care to ensure the context of the quote was also captured. Where relevant, more than one code was assigned to the same piece of text. This initial coding was very detailed in order to identify all of the relevant passages of text. If new codes emerged during the coding of later interviews, these were added to the list and earlier interviews were recoded to ensure that no passages were missed. A selection of transcripts (n=5) were then coded by HC to check for consistency. Agreement on the coding was high and minor discrepancies were resolved in discussion with the other researchers.

5.3.6.4 Themes

Once the coding was completed, I reviewed the coded transcripts to search for common themes. This process was also conducted independently by RB. The lists of themes were then compared and discussed in detail by all three researchers (myself, HC & RB) in order to refine the list. Some themes, although interesting, were not relevant to the specific area of interest and did not add to the understanding of cancer survivors’ beliefs about lifestyle, changes to their lifestyle or their sources of information. For example, some participants talked about the role of stress in the development of their cancer. As
these themes were not useful within the context of this research study, they were not included in this chapter. Once the final list of themes was decided they were each named and given a written description. The themes were then checked against all the transcripts to ensure that they were applicable to the majority of the sample.

5.3.6.5 Data saturation

Participants were recruited until data saturation was reached. As thematic analysis was used, data saturation was defined as the point at which no new insights are obtained or no new themes are identified in the data (Bowen, 2008). After each researcher (HC, RB & I) had conducted a few interviews, the emerging themes were discussed to see if saturation had been reached. More interviews were then conducted as required.

5.4 Results

5.4.1 Participants

Twenty four cancer survivors made contact having seen an advert for the study. Of these, two were not eligible because they lived abroad, two had contacted us about issues unrelated to the study (these two were referred to the Cancer Research UK nurse helplines), and one did not respond to our attempts to contact them back. Nineteen interviews were conducted in total; five in person and 14 by telephone. Duration of interviews ranged from 35 to 77 minutes. After 15 interviews had been conducted, the researchers (HC, RB and I) discussed the emerging themes and whether saturation had been reached. Although it appeared that saturation was reached at this point, a further four interviews were conducted to confirm this, after which recruitment ceased.

The socio-demographic and health characteristics of the participants are shown in Table 5.1. The mean age of the sample was 59 years (standard deviation: 13 years) and 58% were female. All participants described their ethnicity as White British, the majority were married (68%), and just over half were employed in some capacity (53%). Educational attainment varied, although the majority (58%) had a higher education qualification. Breast cancer was the most common diagnosis (37%) and the majority of participants had been diagnosed in the past five years (63%).
There were no current smokers in the sample but 37% were former smokers (Table 5.1). The majority (63%) reported never drinking alcohol or only drinking monthly or less. Only 53% were doing some moderate physical activity at least once a week. The average BMI of the sample was 25.5 (overweight) with 47% participants falling into the overweight or obese categories.
<table>
<thead>
<tr>
<th><strong>Socio-demographic characteristics</strong></th>
<th><strong>Mean ± SD (range)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>59 ± 13.11 (24-77)</td>
</tr>
<tr>
<td>Gender</td>
<td>% (N)</td>
</tr>
<tr>
<td>Male</td>
<td>41 (8)</td>
</tr>
<tr>
<td>Female</td>
<td>58 (11)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>100 (19)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Single/never married</td>
<td>11 (2)</td>
</tr>
<tr>
<td>Married/living with partner</td>
<td>68 (13)</td>
</tr>
<tr>
<td>Married separated from partner</td>
<td>5 (1)</td>
</tr>
<tr>
<td>Divorced</td>
<td>16 (3)</td>
</tr>
<tr>
<td>Highest educational status</td>
<td></td>
</tr>
<tr>
<td>Degree of higher degree</td>
<td>47 (9)</td>
</tr>
<tr>
<td>Higher education below degree</td>
<td>11 (2)</td>
</tr>
<tr>
<td>A levels or Highers</td>
<td>11 (2)</td>
</tr>
<tr>
<td>O level or GCSE equivalent (Grade A – C)</td>
<td>16 (3)</td>
</tr>
<tr>
<td>No formal qualifications</td>
<td>5 (1)</td>
</tr>
<tr>
<td>Other</td>
<td>11 (2)</td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
</tr>
<tr>
<td>Employed full-time</td>
<td>26 (5)</td>
</tr>
<tr>
<td>Employed part-time</td>
<td>11 (2)</td>
</tr>
<tr>
<td>Self-employed</td>
<td>16 (3)</td>
</tr>
<tr>
<td>Retired</td>
<td>42 (8)</td>
</tr>
<tr>
<td>Disabled or too ill to work</td>
<td>5 (1)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Health characteristics</strong></th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer diagnosis*</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>37 (7)</td>
</tr>
<tr>
<td>Colorectal</td>
<td>5 (1)</td>
</tr>
<tr>
<td>Prostate</td>
<td>5 (1)</td>
</tr>
<tr>
<td>Lung</td>
<td>5 (1)</td>
</tr>
<tr>
<td>Thyroid</td>
<td>11 (2)</td>
</tr>
<tr>
<td>Non Hodgkin lymphoma (NHL)</td>
<td>16 (3)</td>
</tr>
<tr>
<td>Hodgkin lymphoma (Hodgkin disease)</td>
<td>5 (1)</td>
</tr>
<tr>
<td>Testicular</td>
<td>5 (1)</td>
</tr>
<tr>
<td>Bladder</td>
<td>5 (1)</td>
</tr>
<tr>
<td>Melanoma</td>
<td>11 (2)</td>
</tr>
<tr>
<td>Neuroendocrine tumour (NET)</td>
<td>5 (1)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date of diagnosis</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 5 years ago</td>
<td>63 (12)</td>
</tr>
<tr>
<td>5-10 years ago</td>
<td>21 (4)</td>
</tr>
<tr>
<td>11-20 years ago</td>
<td>11 (2)</td>
</tr>
<tr>
<td>&gt;20 years ago</td>
<td>5 (1)</td>
</tr>
</tbody>
</table>
### Table 5.1 Socio-demographic, health, and anthropometric characteristics, and health behaviours of the sample (N=19)

<table>
<thead>
<tr>
<th>Health behaviours</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Smoking</strong></td>
<td></td>
</tr>
<tr>
<td>Current smoker</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Former smoker</td>
<td>36.8 (7)</td>
</tr>
<tr>
<td>Never smoker</td>
<td>63.2 (12)</td>
</tr>
<tr>
<td><strong>Alcohol</strong></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>15.8 (3)</td>
</tr>
<tr>
<td>Monthly or less</td>
<td>47.4 (9)</td>
</tr>
<tr>
<td>2-4 times per month</td>
<td>21.1 (4)</td>
</tr>
<tr>
<td>2-3 times per week</td>
<td>0 (0)</td>
</tr>
<tr>
<td>4+ times per week</td>
<td>15.8 (3)</td>
</tr>
<tr>
<td>Invalid</td>
<td>5.3 (1)</td>
</tr>
<tr>
<td>Moderate physical activity &gt; once a week</td>
<td>52.6 (10)</td>
</tr>
<tr>
<td>Missing</td>
<td>5.3 (1)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Anthropometric characteristics</th>
<th>Mean ± SD (range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>BMI</td>
<td>25.5 ± 4.8 (18.7-39.2)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Weight status:</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Underweight</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Healthy weight</td>
<td>52.6 (10)</td>
</tr>
<tr>
<td>Overweight</td>
<td>36.8 (7)</td>
</tr>
<tr>
<td>Obese</td>
<td>10.5 (2)</td>
</tr>
</tbody>
</table>

*Total >100% as two people had been diagnosed with more than one type of cancer
5.4.2 Themes

Participants all felt that lifestyle was an important factor in their health. There were five main themes: 1) Uncertainty about lifestyle as a cause of cancer, 2) The importance of lifestyle for long-term health, 3) Increased awareness of lifestyle following diagnosis, 4) Difficulty maintaining a healthy lifestyle, and 5) Desire for further information about lifestyle and cancer. Unsurprisingly, the themes were strongly influenced by the interview topic guide and pre-set objectives of the study because the discussion was facilitated in this way. There were no obvious differences in responses by socio-demographic or health characteristics, so results are presented from the whole sample.

5.4.2.1 Uncertainty about lifestyle as a cause of cancer

Many participants were unsure about what had caused their cancer and some described how they had tried to understand it:

“for me it was like, well where did this come from, what’s caused it?”
(101, Male, 60 years, NHL)

“Once I got the cancer it was like, “Ok, you have to find a reason for this.”
(105, Female, 51 years, breast cancer)

A wide range of internal and external factors were proposed as possible causes of cancer, from power stations to stress to lack of vitamin D. However, they did not seem to think that lifestyle was the most important factor in the development of their own cancer:

“the healthy lifestyle I didn’t actually connect with breast cancer at all. I’ve always thought it was more either hereditary”
(106, Female, 50 years, breast cancer)

Part of the reason for this was that they felt like they already had a healthy lifestyle before they were diagnosed with cancer:

“I don’t seem to fit the criteria. I do have the odd glass of wine but never very much”
(103, Female, 62 years, breast cancer and NHL)
“I don’t know if it’s hereditary or if it’s anything in my lifestyle but I would consider my lifestyle, apart from the occasional alcohol over the past few years, is quite healthy”

(108, Male, 24 years, NET)

However, they did acknowledge the role of lifestyle in the development of other cancers:

“For some cancers, obviously, there is a more direct link”

(101, Male, 60 years, NHL)

“cancer generally, not the thyroid cancer...there was never any link between what I had and lifestyle”

(113, Female, 47 years, thyroid cancer)

Although many participants did not appear to believe that lifestyle was the main cause of their cancer, many had considered that it may have played a role. Diet was commonly mentioned in this context:

“I’ve thought of food – is there food I am eating what’s causing this?”

(110, Female, 51 years, breast and bladder cancer)

“I honestly don't think I could have been doing anything wrong, apart from possibly something to do with my diet”

(105, Female, 51 years, breast cancer)

Several participants mentioned specific foods that they thought may contribute to the development of cancer. Occasionally this was mentioned in relation to their own cancer:

“It could be the result of eating too many crisps...I’m a bit of a crispholic”

(101, Male, 60 years, NHL)

However, generally they talked about the role of diet in the onset of other cancers, or cancer in other people, rather than relating it to themselves:

“If you eat lots of fatty foods you’re going to get, I don’t know, some sort of cancer, diabetes, maybe, but, erm, that wasn’t the case when it came to mine.”

(108, Male, 24 years, NET)
When participants did mention specific foods in relation to causing cancer, these beliefs were generally in line with recommendations. For example, red meat was described as a potential causal factor, whereas fibre was described as beneficial in reducing risk:

“I sometimes think that red meat causes possibly bowel cancer”
(102, Male, 38 years, Hodgkin disease)

“Certain nuts, apparently the high fibre in it’s supposed to help stop you getting the cancer”
(104, Male, 69 years, prostate cancer)

Smoking was also commonly mentioned in relation to the cause of cancer. Many participants were aware that smoking was a risk factor for cancer but as the majority had never smoked, they did not relate this to their own diagnosis. Instead, it was usually mentioned as a cause of lung cancer:

“lung cancer is caused by smoking”
(102, Male, 38 years, Hodgkin disease)

“If you smoke too much you’re going to get lung cancer”
(108, Male, 24 years, NET)

Two former smokers discussed the role of smoking in the development of their own cancers, but they were uncertain about how important its influence was:

“I don’t think breast cancer has ever been linked to smoking”
(110, Female, 51 years, breast and bladder cancer)

“I used to smoke moderately. And I think because the cancer was on the outside of the lung, maybe it wasn’t…I don’t suppose it helped, but I don’t think it was the main cause. It was just unfortunate”
(116, Male, 68 years, lung cancer)

When discussing the possible cause of their cancer, a few participants mentioned overweight and obesity. Generally they were aware that this was a possible risk factor for cancer, but again they did not think it applied to them or related to their cancer:
“I’ve never been obese or overweight”
(101, Male, 60 years, NHL)

“You are thinking about obesity, you are thinking of diabetes or other cancers”
(106, Female, 50 years, breast cancer)

Participants seemed aware that physical activity may play a role in the prevention of cancer:

“I think it’s absolutely fascinating to know whether it is partly our diet or exercise, or lack of exercise, lifestyle”
(103, Female, 62 years, breast cancer and NHL)

However, several participants discussed physical activity in relation to long-term health (discussed in the next section) rather than as an important factor in the prevention of cancer. Similarly, alcohol was rarely discussed as a possible cause of cancer, although some participants implied that they believed it was a risk factor by saying it was something they did not do very often:

“I don’t know enough about it, to be honest with you, whether I could have done anything differently? I eat healthily, I am not a big drinker”
(102, Male, 38 years, Hodgkin disease)

“I don’t seem to fit the criteria. I do have the odd glass of wine but never very much”
(103, Female, 62 years, breast cancer and NHL)

5.4.2.2 The importance of lifestyle for long-term health

All participants agreed that a healthy lifestyle was important for health in general and some also mentioned specific benefits that they thought may apply following a cancer diagnosis:

“If my body can stay as fit and healthy as possible it may keep it still at a slow-growing stage so that there’s longer between having to have treatment”
(103, Female, 62 years, breast cancer and NHL)
“there's now reasonably strong evidence that it aids recovery from that to make lifestyle changes”
(107, Male, 50 years, melanoma)

Again, diet was the most frequently discussed lifestyle factor and several participants mentioned dietary factors they thought might influence their long term health. Overall, they did not have strong beliefs about specific dietary components that could prevent recurrence, but they sometimes mentioned foods in relation to cancer:

“I read that if you have a carcinoid tumour in your body, still, you need to avoid...spicy food such as curries”
(108, Male, 24 years, NET)

“Like bowel cancer, there are certain foods you are recommended to try and avoid. I think red meat is one”
(104, Male, 69 years, prostate cancer).

More frequently, participants talked about foods that are healthy or unhealthy in general, regardless of whether one has been diagnosed with cancer:

“eating tomatoes, apparently, is supposed to be good for you, and nuts, tomatoes, anything, apparently, red-coloured is supposed to help”
(104, Male, 69 years, prostate cancer)

“Plenty of green veggies, i.e. broccoli and greens and things like that”
(114, Female, 74 years, breast cancer)

“my understanding is that white flour and sugar are kind of poison to your body”
(105, Female, 51 years, breast cancer).

Some participants also mentioned methods of cooking that they believed were bad for them:

“Just the fact that the way they’re manufactured, the stuff’s not fresh, it’s not getting to you until it’s been through all these processes...and it’s kept in these polystyrene-type dishes and stuff which you stick in the microwave or stick in the oven”
(105, Female, 51 years, breast cancer)
CHAPTER 5: CANCER SURVIVORS’ BELIEFS ABOUT LIFESTYLE

Others did not mention specific foods but thought it more important to eat a balanced diet:

“I believe you should have a little bit of everything. I am not one of these who think fruits and vegetables are going to change my life”

(110, Female, 51 years, breast and bladder cancer)

“I think everything in moderation is the way”

(116, Male, 68 years, lung cancer)

Several participants also mentioned dietary supplements and views were polarised. Some believed that they were good for their health, although they did not specifically mention them in relation to cancer cure or prevention of recurrence:

“Selenium is very good for you”

(114, Female, 74 years, breast cancer)

“manuka honey...it’s meant to have antibacterial”

(112, Female, 69 years, NHL)

“magnesium...that’s good for the bones”

(114, Female, 74 years, breast cancer)

In contrast, others believed dietary supplements could be harmful to health and potentially even cause cancer:

“there are some supplements that will give you cancer”

(107, Male, 50 years, melanoma)

“I fundamentally disagree with them [supplements]. I am a pharmacist’s daughter and just think it’s all rubbish”

(113, Female, 47 years, thyroid cancer)

Those who expressed negative attitudes toward supplements were from academic backgrounds or had family members who worked in healthcare.

Many participants agreed that physical activity was beneficial for general health and in some cases this view appeared to have been reinforced following a cancer diagnosis:
“I think that makes a lot of difference, keeping happy and keeping reasonably active”
(104, Male, 69 years, prostate cancer)

“It [cancer] just reinforced my view that being active was an important thing, actually”
(113, Female, 47 years, thyroid cancer)

One participant also talked about the appropriate intensity of the physical activity and the importance of becoming out of breath:

“If you are going to have a walk I think you need to brisk walk and, you know, make yourself puff a bit”
(109, Male, 77 years, colon cancer)

Some participants talked about the specific benefits that physical activity may offer to someone who has been diagnosed with cancer. For example, a few participants thought it may help improve cancer recovery and others talked about the potential of physical activity to help reduce the risk of cancer recurrence:

“There’s now reasonably strong evidence that it aids recovery from [breast cancer] to make lifestyle changes, lower-fat diet, do more exercise. There’s really good evidence now that [physical activity’s] certainly a good idea”
(107, Male, 50 years, melanoma)

“It seems that today’s thinking is exercise is good for you. I don’t think there’s any doubt about that anyway and it’s particularly good in recovery from cancer, I gather”
(116, Male, 68 years, lung cancer)

“One of the things my oncologist said to me at the end of my treatment was, ‘Exercise has been proven to be a factor in reducing the risk of it coming back, that’s proven’”
(106, Female, 50 years, breast cancer)

In contrast, other participants discussed the benefits of physical activity in relation to other factors, such as to help reduce the risk of heart disease or to help with weight management:
“I’ve just recently bought a bike and I really enjoy the cycling, ........ it is more to do with blood pressure and heart stuff than cancer, in a way”

(115, Female, 63 years, breast cancer)

“And the weight management, I assumed that once I was eating healthily, I might... but I think I am aware now that I actually need to take more exercise”

(103, Female, 62 years, breast cancer and NHL)

In relation to this, participants generally agreed that overweight and obesity are detrimental to health, but rather than relating this to cancer specifically, they generally referred to other health conditions:

“your heart, and diabetes I know can become a problem if you are overweight”

(103, Female, 62 years, breast cancer and NHL)

Participants were in agreement that smoking is detrimental to health, regardless of diagnosis: “nobody thinks that smoking’s good for you anymore” (107, Male, 50 years, melanoma). However, one participant mentioned that they had become more alert to the harms of smoking as a result of their cancer diagnosis:

“this applies I think to anyone who has cancer, you become acutely sensitised to anything cancer-related. So anything carcinogenic, I mean, you become really tuned into...what you breathe, keep away from smoke or, particularly, cigarette smokers”

(101, Male, 60 years, NHL)

Participants did not talk about alcohol in relation to long-term health. However, one mentioned that he thought he should avoid it following his cancer diagnosis:

“I read that if you have a carcinoid tumour in your body, still, you need to avoid... alcohol”

(108, Male, 24 years, NET)

5.4.2.3 Increased awareness of lifestyle following diagnosis

Although participants were generally aware of the benefits of a healthy lifestyle, it was not something that they had necessarily paid attention to until they were diagnosed with cancer:
“I never really read up on [lifestyle] before...maybe I did and I just ignored it because we were all fine...then once I got the cancer...all the things that you used to do that they’re saying are bad for you, you’re trying to cut out”

(105, Female, 51 years, breast cancer)

Several participants had similar stories about how their cancer diagnosis had prompted them to make changes to their lifestyle:

“I have really, really looked at my diet since I was diagnosed with a lymphoma”

(103, Female, 62 years, breast cancer and NHL),

“Within one week of having breast cancer I’d stopped smoking. I have never smoked since”

(110, Female, 51 years, breast and bladder cancer)

The majority of reported changes were to diet and several participants talked about the importance of having a healthy balanced diet:

“Just an ordinary, really healthy, sensible diet”

(119, Female, 67 years, melanoma)

Many described this as eating more specific healthy foods, such as fruit and vegetables, or avoiding particular unhealthy foods such as fatty, sugary foods, processed meat and alcohol:

“I eat a lot more fruit than I ever did”

(102, Male, 38 years, Hodgkin disease)

“Cutting down on fatty food, I’ve reduced my intake of crisps”

(101, Male, 60 years, NHL)

“Red meat, definitely, was reduced”

(103, Female, 62 years, breast cancer and NHL)

“I used to eat biscuits and cakes, cakes for breakfast, loved it, always loved cake for breakfast but I haven’t had cake for ages, haven’t had cake for ages. I might have an occasional biscuit but very rarely. So my diet has changed radically, as has my life”

(111, Female, 63 years, thyroid cancer)
“I barely touch alcohol now”  
(106, Female, 50 years, breast cancer)

However, some also reported taking dietary supplements. One participant mentioned supplement use in the context of cancer:

“Selenium is supposed to be prevention from cancer”  
(114, Female, 74 years, breast cancer)

Others did not provide any specific reasons for taking supplements, but it seemed to be something they had been doing for a while for general health:

“I have been taking supplements for years – magnesium, because that’s good for the bones, selenium, as I said, vitamin C, I take that, and also I take a vitamin B which is very good”  
(114, Female, 74 years, breast cancer)

“I take multivitamins and minerals every day”  
(108, Male, 24 years, NET)

Several participants spoke of their desire to be more active and of their efforts to achieve this following their cancer diagnosis. One participant had gone to great lengths to increase her fitness in order to cope better with the second round of her cancer treatment:

“I thought if I could bolster myself as much as possible, when I came off my thyroxine I might have reserves of energy that would help…I hired a personal trainer…I said, “This is what I am about to do. I am going to go in three months’ time through this appalling process. Here’s how it works. I need you to get me into a really peak fitness so, when I start this, I am going to be feeling absolutely fantastic and, when I finish it, I may feel bad but not as bad as I did last time. And I want my recovery to be much quicker. And I think if I get myself into peak fitness, my recovery after this will probably be quicker””  
(113, Female, 47 years, thyroid cancer)

Others reported making some changes to their physical activity levels but acknowledged that these changes were modest:

“I slightly increased the amount of exercise”  
(107, Male, 50 years, melanoma),
“I did think I should be taking more exercise and I did start various things”
(103, Female, 62 years, breast cancer and NHL)

Although a cancer diagnosis was often reported as a prompt for making lifestyle changes, it was not necessarily the reason behind the changes. Some participants specifically mentioned that they had made lifestyle changes to avoid cancer recurrence:

“I read that this has more chance of coming back, then I have to cut out the only things that I can cut out now. I can’t stop smoking because I never did, and I can’t stop alcohol because I don’t. So the only thing I’ve got to work on is my diet”
(105, Female, 51 years, breast cancer)

However, others seemed to be more concerned about their long-term health in general and wanted to give themselves the best chance at living a healthy life having survived cancer:

“I think I’m probably more worried about [high blood pressure] than I am about getting cancer again”
(115, Female, 63 years, breast cancer)

“I just felt that [lifestyle changes] would be better for my health”
(114, Female, 74 years, breast cancer)

One participant mentioned that weight management was a factor in their dietary choices:

“If I am being honest, we did it [eat more healthily] more as part of the weight-loss plan”
(106, Female, 50 years, breast cancer)

Others talked about how they had been forced to make changes to their lifestyle as a result of being ill with cancer, but had continued with these even now they were better. This particularly applied to alcohol consumption:

“We’d drink quite a lot, we’ve cut down on that. That’s virtually just, well, while I was sick it was down to zero, and now occasional”
(101, Male, 60 years, NHL)
“that’s changed, that’s definitely changed, mainly because of, you know, health but I did find certainly... that would be October time, I was away, October I had three glasses, I think, and felt so uncomfortable, horrible indigestion and everything”

(103, Female, 62 years, breast cancer and NHL)

5.4.2.4 Difficulty maintaining a healthy lifestyle

As it was not the focus of the study, participants were not asked specifically about barriers to lifestyle change; however, some reported them when discussing the changes they had made. The most commonly reported difficulty was with physical activity, and this was generally due to the side effects of cancer treatment:

“The peripheral neuropathy I’ve got is a permanent legacy of one of the therapy drugs, so walking is difficult”

(101, Male, 60 years, NHL)

“I couldn’t walk very well because I have got arthritis, which is caused by the chemotherapy”

(110, Female, 51 years, breast and bladder cancer)

“I used to walk all day Sunday and then, because of the radiotherapy, on this side, then my right foot, sort of, collapsed. So I can’t walk as I used to be able to do and I’ve had quite a lot of trouble”

(112, Female, 69 years, NHL)

Some also mentioned symptoms, such as fatigue, which had stopped them from being as physically active as they used to be:

“the tiredness is the biggest...it’s the biggest problem, it’s the biggest factor of the whole thing...I can’t play 18 holes of golf, well because I just can’t physically do it anymore, after 9 holes I am just knackered”

(102, Male, 38 years, Hodgkin disease)

“I am not as active...when I had bladder cancer you can’t stop going to the toilet, you will urinate, oh God, every five minutes sometimes so you can’t actually go very far because you will want to go to the toilet”

(110, Female, 51 years, breast and bladder cancer)
Other participants mentioned that they had been unable to follow a healthy diet due to symptoms and side effects of their treatment. However, these issues were generally short-term while they were receiving treatment rather than at the present time:

“It was a question of what I could tolerate in terms of physically swallowing without being sick rather than what was the best thing to eat or good for me at the time”

(101, Male, 60 years, NHL)

“I guess I didn’t want to eat... for the first four or five days I didn’t eat at all, purely because you just don’t want to eat”

(102, Male, 38 years, Hodgkin disease)

“The only foods I could eat for about three days was chocolate, bacon, chips, which I never used to eat before”

(110, Female, 51 years, breast and bladder cancer)

“So my diet in that time did change, just for a short time, for between two and four weeks it changed while my throat was sore. Then after about four weeks it stopped being sore and I ate my usual solid foods again”

(113, Female, 47 years, thyroid cancer)

“Because it [the cancer] was near the oesophagus, the oesophagus got inflamed and I was unable to eat for about two weeks”

(116, Male, 68 years, lung cancer)

5.4.2.5 Desire for further information about lifestyle and cancer

Participants were positive about the idea of receiving information about lifestyle, but the majority reported receiving very little or no advice from a health professional:

“Well, shamefully, I wasn’t given much information”

(111, Female, 63 years, thyroid cancer)

“I didn’t really get any advice about that... if anything, it was just try and eat a well-balanced diet”

(110, Female, 51 years, breast and bladder cancer)

“I thought it was a bit of a joke, actually. I did pay to go and see a local physiotherapist who gave me some very good exercises... but I paid for that, you know, there was nothing available from my GP or from the oncologist group”

(101, Male, 60 years, NHL)
When participants did not receive much information, they often reported asking their healthcare team about lifestyle:

“I sort of said to my consultant, “What about diet?”

(103, Female, 62 years, breast cancer and NHL)

“One thing that I did say was, “should I be doing anything about my diet or anything while I’m doing this?””

(105, Female, 51 years, breast cancer)

Even when participants did receive advice, this was not always consistent and sometimes added to their confusion about what they should be doing:

“It was suggested by my breast care nurse that selenium might be a suitable supplement to take and to take it with vitamin A, C and E, as a combo...my current consultant doesn’t seem to favour supplements”

(103, Female, 62 years, breast cancer and NHL)

As professional advice was often lacking, several participants mentioned that they had researched information about lifestyle themselves. Some had sought advice from cancer charities, and reported that this had been helpful:

“There were lots of [Macmillan] booklets on all sorts of things – living with cancer, the emotional aspects, the travel insurance, diet, all sorts of things”

(112, Female, 69 years, NHL)

“I went to Breast Cancer Care for most of my literature”

(106, Female, 50 years, breast cancer)

“I phoned, once, Macmillan, and they were fairly helpful”

(111, Female, 63 years, thyroid cancer)

However, more frequently, participants had used the internet to search for information about lifestyle:

“I went onto the internet and found a few things. I just put in ‘anti-cancer foods’ and got what came up”

(105, Female, 51 years, breast cancer)
“The internet for hours and hours and hours, and printing off and printing off”
(111, Female, 63 years, thyroid cancer)

Some mentioned Cancer Research UK’s Cancer Chat forum as a source of information about lifestyle:

“On the Cancer Research you get a lot of people with lots of ideas and suggestions”
(101, Male, 60 years, NHL)

However, participants said that they had experienced difficulty sifting the reliable information from the wealth of nonsense online:

“There is so much information and so many claims and counter-claims, some good-hearted or good-willed, some just out to make money and some just plain scams that it’s just impossible to tell one from another”
(101, Male, 60 years, NHL)

“When I was first diagnosed I went on a heck of a lot of different sites...I found some of them are downright misleading”
(104, Male, 69 years, prostate cancer)

“The worst place of all is online...there are a lot of deliberately misinforming websites”
(107, Male, 50 years, melanoma)

“I think I was afraid that [my cancer] was linked to [smoking]. But since then, I think I have heard people say breast cancer and cigarette smoking are not linked. I do a lot of googling. I mean, how true it is I don’t know”
(110, Female, 51 years, breast and bladder cancer)

In addition to doing their own research, participants mentioned obtaining information about lifestyle incidentally from the media:

“I keep an eye on reports and media”
(116, Male, 68 years, lung cancer)

“I get [lifestyle information] by reading the paper”
(117, Male, 65 years, testicular cancer)
“If there’s an article in the newspaper, I’ll read that, on cancer prevention”  
(118, Female, 64 years, breast cancer)

“You pick things up in the press”  
(115, Female, 63 years, breast cancer)

5.5 Discussion

5.5.1 Overview of the findings

Building on the findings of Study 1, this study aimed to understand some of the reasons why cancer survivors do not appear to make sustained positive changes to their lifestyle following a cancer diagnosis. Specifically, the aim was to explore cancer survivors’ beliefs about the role of lifestyle in their long-term health and survival, the changes made to their lifestyle since their diagnosis, and their sources of information about lifestyle.

Participants in this study were aware of the importance of a healthy lifestyle for long-term health. When asked about the possible causes of cancer, several mentioned aspects of lifestyle that could be linked to cancer, and these were generally in line with recommendations, such as smoking, red meat and being overweight. However, very few participants believed that lifestyle was a contributor to their own cancer. This belief seemed to be due to the fact that they did not think they fit the criteria because they thought they already had a healthy lifestyle and were not doing anything wrong. This was the case regardless of current or former lifestyle, for example, one former smoker did not think that smoking was the main cause of his lung cancer, even though smoking is an established cause of lung cancer (Peto, 1994). Other participants did not think lifestyle was important in the development of their particular type of cancer or they thought other factors were more important. These beliefs are in line with previous studies which have found cancer survivors are more likely to attribute lifestyle factors as a cause of cancer in people other than themselves (Wold, Byers, Crane, & Ahnen, 2005).

In contrast to their beliefs about the causes of cancer, participants were much more likely to acknowledge the role of lifestyle in their long-term health or the prevention of
cancer recurrence. Several participants held specific beliefs about aspects of lifestyle that may be particularly healthy or unhealthy. Generally these beliefs were in line with recommendations, such as it is beneficial to be physically active, eat plenty of vegetables and avoid red meat. However, some participants believed that dietary supplements were beneficial, even though these are not recommended for cancer prevention (WCRF & AICR, 2007). Some participants discussed their beliefs about lifestyle in relation to cancer specifically, for example, they mentioned that physical activity may help with cancer recovery or prevent recurrence. However, the majority seemed to think lifestyle was more important for general health or for the prevention of other chronic conditions.

In line with previous qualitative studies and surveys (Blanchard et al., 2003; Maunsell et al., 2002; Patterson et al., 2003; Salminen et al., 2002), several participants mentioned that their cancer diagnosis had prompted them to make lifestyle changes or at least think more about their lifestyle. However, although a cancer diagnosis was often a trigger, it was not usually the main reason participants continued with any healthy changes. Instead, their motivations were usually a desire to be healthy in general or because of other concerns such as blood pressure or weight management. One woman had quit smoking as soon as she was diagnosed with cancer, but apart from this, the majority of reported changes were to diet. Most of these changes were in line with recommendations, such as reducing their intake of fatty foods or eating more fruit and vegetables. However, several participants reported taking dietary supplements, which is against current recommendations for cancer survivors (WCRF & AICR, 2007). Although some participants mentioned that they had tried to increase their physical activity levels, they admitted that such changes were modest. This may explain why Study 1 and other prospective studies have failed to show improvements in physical activity levels following a cancer diagnosis (Newsom, Huguet, McCarthy, et al., 2012; Newsom, Huguet, Ramage-Morin, et al., 2012).

Although it was not the focus of this study, some participants reported barriers to maintaining a healthy lifestyle following their diagnosis. In line with previous research, participants commonly reported difficulties with physical activity and this was generally due to symptoms and side effects of cancer treatment (Brunet et al., 2013; Husebø et
al., 2015). Some previous studies had found that participants reported practical barriers to exercise participation (Blaney et al., 2013; Ottenbacher et al., 2011), however, these were not reported in this study, although participants were not asked specifically about them. Some participants talked about problems maintaining a healthy diet, but this was while they were undergoing treatment rather than at the present time.

Similar to reports in previous studies (Avery et al., 2014; James-Martin et al., 2014), the majority of participants had not received any professional advice about lifestyle, which had led many of them to seek out further information (Anderson, Steele, et al., 2013). Some participants reported obtaining information about lifestyle from cancer charities, such as Macmillan Cancer Support or Breast Cancer Care, where they are likely to encounter reliable information. However, several participants had not been particularly focused in their searching and reported searching the internet more generally rather than going to specific websites. Those who did not actively seek out information often obtained it from the media incidentally.

5.5.2 Interpretation of the findings

Interestingly, although several participants in this study believed that a healthy lifestyle was important and had attempted to make some lifestyle changes, cancer was not always the motivator for these changes. A possible reason for this is that they were unaware of the potential added benefits of a healthy lifestyle following a cancer diagnosis. As discussed earlier in this thesis, there are many adverse consequences of a cancer diagnosis (Chapter 1), and a healthy lifestyle may help counteract some of these effects (Chapter 2). However, public awareness of the link between lifestyle and cancer prevention is known to be low, so the same may be true for cancer survivors (Redeker, Wardle, Wilder, Hiom, & Miles, 2009). They may also not have been aware of specific lifestyle recommendations for cancer survivors. None of the participants in this study mentioned an awareness of any guidelines such as those by the WCRF; although they were not specifically asked about this in the interviews. This is consistent with other studies which have shown that cancer survivors are uncertain about lifestyle changes they should make post-diagnosis (Maley et al., 2013).
Although a cancer diagnosis was not necessarily the reason participants tried to maintain a healthy lifestyle, several mentioned that it had prompted them to make changes. This is consistent with other studies (Blanchard et al., 2003; Maunsell et al., 2002; Patterson et al., 2003; Salminen et al., 2002) and supports the ‘teachable moment’ hypothesis (McBride & Ostroff, 2003). These findings are also consistent with psychological models, which propose that those with positive beliefs about a particular health behaviour are more likely to engage in that behaviour (Ajzen, 1985; Janz & Becker, 1984; Leventhal et al., 1997). However, although some participants reported making changes to their physical activity levels, the majority acknowledged that these changes were modest. This is likely due to the fact that many experienced barriers to physical activity, such as fatigue or other side effects of treatment.

Although the reported lifestyle changes in this study are encouraging, they are conflicting with the findings of Study 1, which showed little evidence of sustained positive lifestyle changes on a population level. A possible explanation is that in surveys, cancer survivors may overestimate the extent to which they have made lifestyle changes following their cancer diagnosis. As participants acknowledged that changes to physical activity were modest, this may explain why they may not be captured by large-scale prospective studies which often use quite crude measurement tools. Alternatively, this discrepancy could be explained by the particular health behaviours being studied. In this study, the most commonly reported changes were to participants’ diets. However, the majority of prospective studies have not included diet so it is not possible to know if such changes would be seen on a population level. The majority of former smokers included in this study reported that they had quit before they were diagnosed with cancer.

The majority of participants’ beliefs and attempted lifestyle changes were in line with recommendations for cancer survivors; such as not smoking, eating plenty of fruit and vegetables, limiting consumption of red meat and being physically active (WCRF & AICR, 2007). While it is possible that participants were aware of lifestyle guidelines for cancer survivors, these changes are also reflective of government guidelines for the general population (Department of Health, 2011; NHS Choices, 2014b, 2014c, 2014a; Public
Health England, 2013). However, several participants also reported taking dietary supplements and one of these specifically said she thought they were beneficial for cancer prevention. This finding is concerning as there is no scientific evidence that they are beneficial for cancer survivors and as such they are not recommended (WCRF & AICR, 2007).

Most participants in this study had not received any advice about lifestyle following their cancer diagnosis and had therefore sought out information from other sources. Insufficient information and advice about lifestyle may partly explain the discordance between these beliefs and scientific evidence. A large number of participants in this study reported that they had searched for information about lifestyle online. Although some reported looking at reputable websites, others had searched more generally and would therefore have come across a huge amount of information, much of which may not be reliable. This may add to confusion about appropriate lifestyle changes and could result in cancer survivors absorbing incorrect information. Information obtained from the media may be similarly unreliable, as studies have shown that over two thirds of dietary health claims are not supported by sufficient evidence (Cooper, Lee, Goldacre, & Sanders, 2011). These findings further highlight a need for cancer survivors to be directed to appropriate information about lifestyle.

5.5.3 Limitations

This study had a number of limitations. The sample was heterogeneous and included individuals with various types of cancers, who had undergone different treatments, and were at varying points from diagnosis. This meant it was not possible to make generalisations about the beliefs, behaviours or information sources of any particular groups of cancer survivors. Although this was a qualitative study and was not designed to be representative, all participants were White British, relatively young, and well educated. Also, due to self-selection bias it is possible that those who opted to take part in a study about lifestyle were more motivated and better informed than the general population.
Due to the subjective nature of qualitative research, it is likely that the results of this study would have been influenced by my own personal biases as a researcher. However, input from other researchers was obtained at each stage of the analysis in order to remain as objective as possible and minimise this bias.

Recruitment took place partly through an internet forum which meant that some participants may be particularly motivated to find out information about their cancer. This may also partly explain why a high proportion of participants in this sample reported obtaining information about lifestyle from the internet. However, not all participants were recruited in this way as the study was also advertised using posters displayed in a cancer centre where participants were attending routine appointments.

As described in Study 1, the physical activity question in the socio-demographic questionnaire only asked about sport so would not have captured other aspects of physical activity. However, this was not part of the main analysis so did not impact the results.

5.5.4 Conclusions

Overall, the results of this study indicate that although cancer survivors may not think lifestyle played a role in the development of their cancer, they believe it is important for long-term health. In general, participants were informed about what constitutes a healthy lifestyle, although some also believed that dietary supplements could be beneficial. Several participants reported that they had tried to make changes to their lifestyle following their diagnosis, but these were mainly to diet rather than physical activity. A cancer diagnosis appeared to have been a prompt for making lifestyle changes, but it was not the main motivator as participants seemed more concerned about health in general. This may be because they are unaware of the added benefits of a healthy lifestyle following a cancer diagnosis. These findings highlight an area for improved education to ensure that cancer survivors are fully informed about the potential benefits of a healthy lifestyle following a cancer diagnosis, and to ensure they are aware of recommendations regarding dietary supplements.
The majority of participants in this study had not received any professional advice about lifestyle, which may in part explain why they were not fully informed about the benefits of a healthy lifestyle following a cancer diagnosis, or the recommendations regarding dietary supplements. This had led several participants to seek out information about lifestyle themselves and a large proportion had obtained this from the internet or the media. In order to ensure that cancer survivors are properly informed about the role of lifestyle post-diagnosis, it is important that they receive sufficient advice from health professionals and are directed to appropriate sources of information. In addition, health and cancer organisations should provide appropriate information about lifestyle on their websites as this may be the first point of call for survivors searching for information.
CHAPTER 6: STUDY 3: A REVIEW OF ONLINE INFORMATION ABOUT LIFESTYLE FOR CANCER SURVIVORS

6.1 Introduction

Several participants in Study 2 reported that they had used the internet to find information about lifestyle, but were cautious about doing so. A recent analysis of the Health Information National Trends Survey found that the internet was the preferred source of information for 51% of cancer survivors, highlighting a shift from more traditional sources (Hartoonian, Ormseth, Hanson, Bantum, & Owen, 2014). Similarly, a study of breast cancer survivors found that they used the internet for information, even after their treatment has ended, and this was the most frequently cited source of information at 16 months post-diagnosis (Satterlund, McCaul, & Sandgren, 2003). This suggests that cancer survivors may desire and continue to search for information long after regular contact with their healthcare team has ended. A more recent study found that cancer survivors were more likely to use the internet to search for health-related purposes than the general population (Chou, Liu, Post, & Hesse, 2011).

Qualitative research with breast and prostate cancer survivors in the UK suggests that those who use the internet for information prefer non-commercial websites, and trust websites supported by the NHS or other recognised ‘Centres of Excellence’ such as charities and cancer centres (Rozmovits & Ziebland, 2004). Given the rising number of cancer survivors and the shift from health professional care to supported self-management (Department of Health, 2010); it is likely that such websites will increasingly be used to obtain information about a range of topics including lifestyle. As described previously, supporting self-management involves educating people about their condition and equipping them with the tools to help them choose healthy behaviours (de Silva, 2011). This is consistent with psychological models that emphasise the importance of self-efficacy; an individual’s belief in their ability to meet a particular goal, in determining whether an individual performs a particular behaviour (Bandura, 1977).

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7 A version of this chapter has been published in *JMIR Cancer* (Appendix 6.1)
1986). Having access to appropriate lifestyle information may help boost self-efficacy for making lifestyle changes.

It is therefore crucial to examine the lifestyle information provided by the NHS, charities and cancer centres, in order to highlight any gaps and ensure that cancer survivors not only have access to reliable information, but are provided with the tools to help them overcome barriers and make the lifestyle changes which could ultimately improve their long-term outcomes. If cancer survivors are unable to find the information they are looking for on these websites, they may turn to less reliable websites putting them at risk of misinformation.

6.2 Aim

The purpose of this review was therefore to identify the lifestyle information and resources provided for cancer survivors by the statutory and charity sectors, and cancer centres in the UK. Specifically, it aimed to identify information on smoking, alcohol, physical activity, diet, and weight designed for people who have been diagnosed with cancer. In addition to examining organisations that provide information to all groups of cancer survivors, this search also focused specifically on information for patients diagnosed with breast, prostate or colorectal cancer. These cancer sites were chosen as recent figures indicate that they constitute approximately 41% of new cancer diagnoses each year in the UK (Cancer Research UK, 2014a), and, as described in Chapter 2, there is evidence for the role of lifestyle in these cancers.

6.3 Methods

6.3.1 Identification of statutory sector organisations

The first search sought to identify any lifestyle information for cancer survivors provided by the DoH or NHS. The focus of this search was centred on the NHS Choices website (NHS Choices, 2014d), a DoH funded website which aims to provide objective and trustworthy information and guidance to the public on all aspects of health and healthcare. It is the UK’s largest health website and is certified by the Information
Standard as a producer of reliable health and social care information (NHS Choices, 2013).

6.3.2 Identification of cancer centres

‘Comprehensive cancer centres’ accredited by the Organisation of European Cancer Institutes (OECI) were also included in the search. This comprised cancer centres based in the NHS or in universities. As only a limited number of cancer centres were accredited by the OECI, this search was supplemented with a Google search for ‘cancer centre’, where cancer centres based in the NHS, charity sector or universities from the first page of results were added to the list of accredited centres. Cancer centres in the private sector were excluded as these are not among those preferred by patients (Rozmovits & Ziebland, 2004).

6.3.3 Identification of charity sector organisations

The Charity Commission is the official register of charities in England and Wales.\textsuperscript{8} Searches for generic, breast, prostate and colorectal cancer charities were done separately using the advanced search function. To identify generic cancer charities, I searched for the keyword ‘cancer’ in ‘charity name’, ‘charity objects’ and ‘charity activities’. The search was refined by selecting only charities operating throughout England and Wales, and those who described their operations as providing ‘advocacy/advice/information’. This was to ensure that the included charity sector organisations could reasonably be expected to provide advice on lifestyle.

The three largest generic cancer organisations were selected from the list, provided they met the inclusion criteria outlined below. After discussion with my supervisors and other colleagues in the HBRC, it was agreed that the largest charities on this list were also the most publically well known, and the same charities also appeared at the top of internet search results. Organisation size was defined by income in 2012; as this was the only information about size available from the Charity Commission. The keywords ‘breast cancer’, ‘prostate cancer’ and ‘colorectal cancer’ were then used to identify the

\textsuperscript{8} http://www.charitycommission.gov.uk/
three largest charities for each of these cancers. The colorectal cancer search was repeated using the terms ‘bowel cancer’, ‘colon cancer’ and ‘rectal cancer’. It was a pragmatic decision to include three of each based on the time and resources available.

6.3.4 Charity inclusion criteria

1. Registered in the Charity Commission database.
2. Within the top three breast, prostate, colorectal or generic (all cancer types) cancer charities in England (defined by income in 2012).
3. Listed in the Charity Commission database as providing advocacy, advice or information.
4. Operating in England or Wales (there was no single category for England).
5. Aimed at adults.
6. Colorectal and generic cancer charities must be for both men and women.

6.3.5 Search for lifestyle information

The NHS Choices website was searched using the terms ‘cancer survivor’, ‘cancer AND smoking’, ‘cancer AND alcohol’, ‘cancer AND physical activity’, ‘cancer AND exercise’, ‘cancer AND diet’, and ‘cancer AND weight’ in the website’s search function and manually searching the results and following relevant links. The same search was repeated in the websites of the cancer centres and charities but without the word ‘cancer’ as these sites were already specific to cancer information. If filters were available, they were used to refine the results to pages aimed at cancer patients or survivors. If the website did not have a search function, I conducted a manual search using the drop-down menus. The searches were conducted between November 2014 and January 2015.

6.3.6 Lifestyle information inclusion criteria

Information was included on smoking, alcohol, physical activity, diet, or weight management, aimed at improving the general or long-term health of cancer survivors. Lifestyle information designed to improve acute outcomes of cancer and its treatment (e.g. to help manage a short-term diet problem or acute symptom management) was
excluded as the focus was on longer-term survivorship. Information on cancer prevention was also excluded unless cancer survivors were specifically directed to it.

6.3.7 Data synthesis

I conducted the initial searching of the 20 websites to identify lifestyle information for cancer survivors, then a selection (n=4) was checked by a student volunteer in the HBRC at UCL. Any uncertainties or discrepancies were discussed and resolved through discussion with my supervisors, Dr Rebecca Beeken and Dr Abigail Fisher. Once all the relevant lifestyle information had been agreed, I extracted the content. This included identifying any specific recommendations made by the organisation, and the basis of these recommendations. Other details about the information were also recorded including the format (e.g. print, video, and podcasts), and resources or advice for helping patients change their lifestyle behaviours.

6.4 Results

Figure 6.1 summarises the identification of organisations for review.
Figure 6.1 Identification of organisations

Statutory organisations
N=1
(NHS Choices)

Charity Commission search
N=216
(183 generic cancer charities, 13 breast cancer charities, 15 prostate cancer charities, 5 colorectal cancer charities)

3 largest charities selected from each category
N=12

OECI search
N=3
(King’s Health Partners Integrated Cancer Centre, the Cancer Research UK Cambridge Institute, Christie NHS Foundation Trust)

Google search
N=4
(Maggie’s, University College Hospital Macmillan Cancer Centre, The Royal Marsden Hospital, The Clatterbridge Cancer Centre)

Organisations included in this review
N=20
6.4.1 Statutory sector organisations

As outlined in the methods section 6.3.1, the NHS Choices website was used to identify lifestyle information for cancer survivors provided by the UK government (NHS Choices, 2014d).

6.4.2 Cancer centres

Three ‘comprehensive cancer centres’ in England were accredited by the OECI. These were the King’s Health Partners Integrated Cancer Centre (King’s Health Partners Integrated Cancer Centre, 2015), the Cancer Research UK Cambridge Institute (Cancer Research UK Cambridge Institute, 2015) and the Christie NHS Foundation Trust (The Christie NHS Foundation Trust, 2015). The top Google search results for cancer centres also found Maggie’s (Maggie’s, 2015), University College Hospital Macmillan Cancer Centre (University College Hospital Macmillan Cancer Centre, 2015), The Royal Marsden Hospital (The Royal Marsden, 2015) and The Clatterbridge Cancer Centre (The Clatterbridge Cancer Centre, 2015).

6.4.3 Charity sector organisations

The search for generic cancer charities found 183 results. Once these had been narrowed down using the inclusion and exclusion criteria, the three largest charities were Cancer Research UK (CR-UK) (Cancer Research UK, 2014c), Macmillan Cancer Support (Macmillan Cancer Support, 2014) and the WCRF (World Cancer Research Fund International, 2014). The search for breast cancer, prostate cancer and colorectal cancer charities found 13, 15 and 5 results respectively. The three largest for each cancer site were Breakthrough Breast Cancer (Breakthrough Breast Cancer, 2014), Breast Cancer Care (Breast Cancer Care, 2014), Breast Cancer Campaign (Breast Cancer Campaign, 2014), Prostate Cancer UK (Prostate Cancer UK, 2014), Movember Europe (Movember, 2014), the Orchid Cancer Appeal (Orchid Cancer Appeal, 2014), Bowel Cancer UK (Bowel Cancer UK, 2014), Beating Bowel Cancer (Beating Bowel Cancer, 2014), and Bowel Cancer Information (Bowel Cancer Information, 2014).
6.4.4 Availability of lifestyle information

All of the website searches yielded a large number of results, but the majority were not relevant. The NHS Choices website did not contain any lifestyle information for cancer survivors, but it did provide a link to a CR-UK page on diet. It also included a page on lifestyle changes after chronic illness; however, this was not included as it did not specifically mention cancer. Ten organisations (3/7 cancer centres and 7/12 charities) had lifestyle information for cancer survivors available on their websites. Of these, The Christie NHS Foundation Trust (The Christie NHS Foundation Trust, 2015), Macmillan Cancer Support (Macmillan Cancer Support, 2014) and Prostate Cancer UK (Prostate Cancer UK, 2014) had the most comprehensive guides, covering smoking, alcohol, physical activity, diet and weight management. Table 6.1 shows a summary of the online lifestyle information provided by the different sources.

6.4.5 Summary of lifestyle information

All ten organisations with lifestyle information for cancer survivors had information on diet and physical activity, but only seven had information on alcohol (Beating Bowel Cancer, 2014; Breast Cancer Care, 2014; Macmillan Cancer Support, 2014; Prostate Cancer UK, 2014; The Christie NHS Foundation Trust, 2015; The Royal Marsden, 2015; World Cancer Research Fund International, 2014), six on weight management (Breast Cancer Care, 2014; Macmillan Cancer Support, 2014; Prostate Cancer UK, 2014; The Christie NHS Foundation Trust, 2015; The Royal Marsden, 2015; World Cancer Research Fund International, 2014), and four on smoking (Beating Bowel Cancer, 2014; Macmillan Cancer Support, 2014; Prostate Cancer UK, 2014; The Christie NHS Foundation Trust, 2015) (Table 6.1). The information from six organisations made reference to other guidelines; most often those produced by the WCRF (Beating Bowel Cancer, 2014; Cancer Research UK, 2014c; Macmillan Cancer Support, 2014; The Christie NHS Foundation Trust, 2015; The Royal Marsden, 2015; World Cancer Research Fund International, 2014). Eight organisations suggested discussing lifestyle with a health professional (including the GP, cancer doctor, cancer nurse specialist, physiotherapist or dietitian) before making any changes (Beating Bowel Cancer, 2014; Bowel Cancer UK, 2014; Breast Cancer Care, 2014; Cancer Research UK, 2014c; Macmillan Cancer Support,
2014; Prostate Cancer UK, 2014; The Christie NHS Foundation Trust, 2015; The Royal Marsden, 2015).
<table>
<thead>
<tr>
<th>Organisation</th>
<th>Smoking</th>
<th>Alcohol</th>
<th>Physical activity</th>
<th>Diet</th>
<th>Weight management</th>
<th>Which guidelines is the information based on?</th>
<th>Which sources does the information direct to?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. NHS</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>N/A</td>
<td>Provides link to CR-UK page on diet</td>
</tr>
<tr>
<td>2. King’s Health Partners Integrated Cancer Centre</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>3. Cancer Research UK Cambridge Institute</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>N/A</td>
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<tr>
<td>4. The Christie NHS Foundation Trust</td>
<td>Recommendation: Go smoke free. Becoming smoke-free is the most important step you can take to reduce ill health and early death from many cancers and other lung and heart diseases. We strongly advise you not to smoke.</td>
<td>Recommendation: Drink less alcohol. Drinking less alcohol can help improve mood and sleep, and reduce nausea and a sore mouth during chemotherapy and radiotherapy.</td>
<td>Recommendation: Exercise and stay active. Try to accumulate at least 30 minutes of physical activity throughout the day. During the 30 minutes you must work at moderate intensity, meaning you are very slightly breathless.</td>
<td>Recommendation: Eat a balanced diet. Reduce your intake of high energy foods and sugary drinks, eat 5 portions of different coloured fruit and vegetables a day, eat less red and processed meats, eat less salty foods and processed foods and increase your fibre foods.</td>
<td>Recommendation: The aim following treatment is to be as near to a normal healthy weight as possible. If you have experienced weight gain, aim to reduce it gradually by following a healthy eating plan.</td>
<td>DoH alcohol guidelines</td>
<td>Doctor, physiotherapist, dietitian, nurse, Macmillan, WCRF, Netfit, CR-UK, National Association of Cancer Exercise Rehabilitation, NHS Choices, Drink Aware, British Dietetic Association, Manchester Community Alcohol Team, ‘Quit’ – smokers quitline</td>
</tr>
<tr>
<td>Organisation</td>
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<td>Weight management</td>
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<td>-</td>
<td>Research has shown across a range of cancers that Going Smoke Free will help improve fatigue levels, sleep, pain, nausea, help with treatment recovery and reduce the risk of developing new cancers.</td>
<td>Includes information on why hospital staff will assess alcohol levels and some common facts and myths about alcohol.</td>
<td>Exercise is not contraindicated for people living with or recovering from cancer. Research suggests daily exercise can help with reducing nausea, help with fatigue, insomnia and low mood. It can boost confidence and self-esteem, reduce anxiety and depression, help with lymphoedema and ease pain</td>
<td>Having a healthy eating approach to your diet can reduce the risk of cancer reoccurring or development of a new one and reduce risk of other diseases such as heart disease.</td>
<td>Can download ‘Eating well following treatment and recovery from cancer’ booklet which contains information (not for people who are underweight) on foods associated with weight gain/loss.</td>
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</table>
### Table 6.1 Summary of online lifestyle information for cancer survivors

<table>
<thead>
<tr>
<th>Organisation</th>
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<tbody>
<tr>
<td>-</td>
<td>Can download 'Smoking Cessation and Alcohol Advice Services' leaflet which contains information on the harms of smoking, advice on e-cigarettes and directs to smoking cessation and support services.</td>
<td>Can download 'Smoking Cessation and Alcohol Advice Services' leaflet which contains information and directs patients to alcohol advice and support services.</td>
<td>Can download 'Be Active, Stay Active' booklet which contains information on the importance of exercise, how much to do, examples of exercises, as well as directing to further sources of information and support.</td>
<td>Can download 'Eating well following treatment and recovery from cancer' booklet which contains information on what foods to eat and why, sample menus and tips, and directs patients to further sources of information.</td>
<td>Can download 'Be Active, Stay Active' booklet which contains information on the risks of being overweight and how exercise can help maintain weight.</td>
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<td>-</td>
<td>Has a podcast on exercise.</td>
<td>Has a podcast called 'Let's move forward with your eating' by a specialist dietitian.</td>
<td>Has a podcast called 'Worried about losing weight' by a specialist dietitian.</td>
<td>Has a podcast called 'Worried about losing weight' by a specialist dietitian.</td>
<td>Has a podcast called 'Worried about losing weight' by a specialist dietitian.</td>
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<tr>
<td>5. Maggie’s</td>
<td>None</td>
<td>None</td>
<td>- No specific recommendation but says that exercise offers many benefits, from reducing fatigue and improving your wellness and physical fitness, to building your confidence during and after cancer treatment.</td>
<td>- No specific recommendation but says that eating well during and after cancer treatment can make a real difference to the way you feel.</td>
<td>None</td>
<td>N/A</td>
<td>Maggie’s exercise classes and nutrition workshops, Maggie’s Online Centre</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Maggie’s offers exercise classes for people with cancer so there is information on how to book these on their website.</td>
<td>- Maggie’s offers nutrition workshops for people with cancer so there is information on how to book these on their website.</td>
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### Table 6.1 Summary of online lifestyle information for cancer survivors

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<tr>
<td>6. University College Hospital Macmillan Cancer Centre</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>N/A</td>
<td>N/A</td>
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Table 6.1 Summary of online lifestyle information for cancer survivors

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<tr>
<td>7. The Royal Marsden Hospital</td>
<td>None</td>
<td>Recommendation: - Limit your alcohol intake to two drinks a day for men or one drink a day for women.</td>
<td>Recommendation: - 30 minutes of physical activity five times a week.</td>
<td>Recommendation: - Reduce your intake of high-calorie foods and avoid sugary drinks, eat at least five portions of fruit/vegetables every day, eat a portion of pulses or wholegrain foods with every meal, reduce your intake of red meat to no more than 500g (18oz) a week and eat minimal amounts of processed meats, lower your salt intake, do not use dietary supplements for the prevention of cancer.</td>
<td>Recommendation: - Maintain your weight within the normal BMI range. If overweight, it is not good to lose weight during treatment as it may make you more susceptible to infections and poor wound healing.</td>
<td>DoH exercise and diet guidelines, WCRF diet guidelines</td>
<td>Doctor, nurse, physiotherapist, dietitian, Macmillan Cancer Support, DoH, Cancer Equality</td>
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<tr>
<td>Organisation</td>
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<td>- Provides information - about the number of units in different alcoholic drinks.</td>
<td></td>
<td>Provides examples of different types of activities (e.g. walking) and emphasises starting slowly and building up gradually.</td>
<td>Provides examples of different foods to eat and foods to avoid.</td>
<td></td>
<td>Provides information on how to calculate BMI</td>
<td>Can download ‘Eating well when you have cancer’ booklet which contains information on different foods, meal ideas, recipes, advice on overcoming problems with eating, frequently asked questions and directs patients to other sources of information.</td>
<td>Can download ‘Eating well when you have cancer’ booklet which includes advice on what to eat if you are losing/have lost weight and what to do if you are overweight.</td>
</tr>
<tr>
<td>Organisation</td>
<td>Smoking</td>
<td>Alcohol</td>
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<tr>
<td>8. The Clatterbridge Cancer Centre</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>N/A</td>
<td>N/A</td>
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<tr>
<td>9. CR-UK</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>ACSM</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Recommendation:</td>
<td>Recommendation:</td>
<td>Macmillan Cancer Support, Cancer</td>
<td>Cancer doctor/nurse</td>
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<tr>
<td></td>
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<td></td>
<td></td>
<td>- No general UK guidelines about exercising after cancer but generally doctors advise 30 minutes a day, 5 days a week.</td>
<td>- Important to include everything you need in your diet including protein, carbohydrates, fat, vitamins and minerals, water and fibre.</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>- Exercise should be tailored to the individual patient.</td>
<td>- No advice on how to eat a healthy diet or make dietary changes for long-term health.</td>
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</table>
### Table 6.1 Summary of online lifestyle information for cancer survivors

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<th>Which sources does the information direct to?</th>
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</thead>
<tbody>
<tr>
<td>10. Macmillan Cancer Support</td>
<td>Recommendation: If you’re a smoker, choosing to stop is a decision that will benefit your health.</td>
<td>Recommendation: Limit alcohol intake and include one or two alcohol-free days per week.</td>
<td>Recommendation: UK adults advised to do 2.5 hours moderate intensity activity per week.</td>
<td>Recommendation: There still isn’t enough clear information to make exact recommendations about what someone with cancer should eat. In general, cancer experts recommend following a healthy, balanced diet.</td>
<td>Recommendation: Try to keep your weight within the normal range.</td>
<td>ACSM, WCRF, British Heart Foundation, Drinkaware, National Comprehensive Cancer Network, NHS Choices, The Organic Center, ACSM, National Cancer Survivorship Initiative, DoH: healthy lives healthy people, Food Standards</td>
<td>GP, nurse specialist, NHS Smokefree/smoking cessation services, DoH, World Health Organisation</td>
</tr>
<tr>
<td>Organisation</td>
<td>Smoking</td>
<td>Alcohol</td>
<td>Physical activity</td>
<td>Diet</td>
<td>Weight management</td>
<td>Agency, NICE, academic papers</td>
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<tr>
<td>- Refers to smoking cessation services, NRT and medications for help with quitting.</td>
<td>- Men should avoid drinking more than 3-4 and women 2-3 units per day.</td>
<td>- A 'Move More' pack is available to order and includes a booklet with tips for becoming active, case studies and an activity planner (goal setting and diary).</td>
<td>- A balanced diet includes lots of fruit and vegetables, plenty of starchy foods, some protein-rich foods, some milk and dairy foods, small amounts of foods high in fat, salt and sugar, and sugar-free drinks.</td>
<td>- Aim for a maximum weight loss of 0.5-1kg per week.</td>
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<tr>
<td>- Also have a DVD called 'Get Active, Feel Good' which includes exercise demonstrations and case studies.</td>
<td>- If you’re thinking of taking dietary supplements, it’s important to talk to your cancer doctor first</td>
<td>- Advises speaking to GP before trying to lose weight.</td>
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<tr>
<td>Organisation</td>
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<tr>
<td>11. WCRF</td>
<td>None</td>
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</tbody>
</table>

- Evidence is not clear enough to make detailed recommendations for cancer survivors. Until further research is done, the best advice to reduce the risk of cancer returning is to follow recommendations for prevention.

- Evidence is not clear enough to make detailed recommendations for cancer survivors. Until further research is done, the best advice to reduce the risk of cancer returning is to follow recommendations for prevention.

- Evidence is not clear enough to make detailed recommendations for cancer survivors. Until further research is done, the best advice to reduce the risk of cancer returning is to follow recommendations for prevention.

- Includes advice on healthy eating and activity and has a ‘food and activity planner’ available to download.

- Can download ‘Healthy eating and cancer’ leaflet which contains these recommendations, advice on making changes, and frequently asked questions.
### Table 6.1 Summary of online lifestyle information for cancer survivors

<table>
<thead>
<tr>
<th>Organisation</th>
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<th>Which sources does the information direct to?</th>
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<tbody>
<tr>
<td><strong>Recommendation for prevention:</strong></td>
<td><strong>Recommendation for prevention:</strong></td>
<td><strong>Recommendations for prevention:</strong></td>
<td><strong>Recommendation for prevention:</strong></td>
<td><strong>Recommendation for prevention:</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>- Drink less alcohol. Aim for no more than two drinks a day if you’re a man and no more than one drink a day if you’re a woman.</td>
<td>- Move More. Aim for 30 minutes or more of moderate (or vigorous) activity a day. Reduce the time you spend doing sedentary activities</td>
<td>1) Avoid high calorie foods and drinks, 2) Put plant foods first, 3) Eat less red meat and cut down on processed meats, 4) Eat less salt, 5) For most people, eating a healthy, balanced diet is a better way of reducing your cancer risk than taking supplements. For more advice about taking supplements, it is best to talk to your GP</td>
<td>- Stay in shape. If you’re overweight, losing even a few pounds will make a positive difference to your health.</td>
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<tr>
<td>12. Breakthrough Breast Cancer</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Organisation</td>
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<tr>
<td>13. Breast Cancer Care</td>
<td>None</td>
<td>Recommendation: 2-3 units of alcohol a day or women and 3-4 for men.</td>
<td>Recommendation: 150 minutes of moderate activity per week.</td>
<td>Recommendation: Try to enjoy a balanced, nutritious diet with plenty of fruit and vegetables, plenty of wholegrain starchy foods, some milk and dairy foods and some lean protein.</td>
<td>Recommendation: If you decide to lose weight after treatment, aim to lose 0.5-1kg per week.</td>
<td>N/A</td>
<td>Specialist team, GP, Dietitian, NHS Choices</td>
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<td></td>
<td></td>
<td>Before you start exercise it's important to discuss it with your specialist team and build up gradually.</td>
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<td></td>
<td></td>
<td>Includes tips on how to get active including joining their walking groups 'Best Foot Forward'.</td>
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<td></td>
<td>Recommendations talking to dietitian or GP.</td>
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<td></td>
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<td></td>
<td></td>
<td>Includes tips for losing and gaining weight depending on patient requirements.</td>
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<tr>
<td>Organisation</td>
<td>Smoking</td>
<td>Alcohol</td>
<td>Physical activity</td>
<td>Diet</td>
<td>Weight management</td>
<td>Which guidelines is the information based on?</td>
<td>Which sources does the information direct to?</td>
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<tr>
<td>14. Breast Cancer Campaign</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>N/A</td>
<td>N/A</td>
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<tr>
<td>15. Prostate Cancer UK</td>
<td>Recommendation: Stop smoking</td>
<td>Recommendation: Men should not regularly drink more than three to four units of alcohol a day.</td>
<td>Recommendation: Aim to be physically active at least 2-3 times per week. Start gently and build up to 30 minutes of moderate exercise 3-5 days per week.</td>
<td>Recommendations: Eat at least 5 portions of fruit and vegetables a day, about 1/3 of diet should be starchy foods, include some protein, include some dairy foods, eat foods that are</td>
<td>Recommendation: If overweight, eating a balanced diet, cutting down on fatty and sugary foods and being active will help to lose weight gradually and healthily.</td>
<td>None reported</td>
<td>Dietitian, NHS Choices, British Dietetic Association, British Nutrition Foundations</td>
</tr>
<tr>
<td>Organisation</td>
<td>Smoking</td>
<td>Alcohol</td>
<td>Physical activity</td>
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<td>low in fat or saturated fat, cut down on foods high in sugar, cut down on salt, drink 6-8 glasses of water per day.</td>
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- Stopping smoking can reduce the side effects of treatment.

- Suggests looking at NHS Choices website for advice on managing alcohol consumption.

- Gives some simple exercise ideas but recommends speaking to GP or hospital doctor before starting an exercise plan.

- Foods that may be beneficial are: soy and pulses, green tea, tomatoes, selenium (not supplements), cruciferous vegetables, pomegranate juice, fish.

- Recommends asking GP to refer to a dietitian or weight loss programme.

- Suggests looking at NHS Choices website for advice on how to stop smoking.

- Can download a ‘diet, physical activity and prostate cancer’ factsheet which includes information on all 5 lifestyle factors.

- Can download a ‘diet, physical activity and prostate cancer’ factsheet which includes information on all 5 lifestyle factors.

- Foods to limit: dairy, red and processed meat, well done meat and fat.

- Can download a ‘diet, physical activity and prostate cancer’ factsheet which includes information on all 5 lifestyle factors.
### Table 6.1 Summary of online lifestyle information for cancer survivors

<table>
<thead>
<tr>
<th>Organisation</th>
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<th>Which sources does the information direct to?</th>
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</thead>
<tbody>
<tr>
<td>16. Movember Europe</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>N/A</td>
<td>N/A</td>
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</tbody>
</table>

- Can download a ‘diet, physical activity and prostate cancer’ factsheet which includes information on all 5 lifestyle factors.
- Gives some tips on healthy eating but recommends asking GP to refer to dietitian. Also suggests looking at NHS Choices website.
- Can download a ‘diet, physical activity and prostate cancer’ factsheet which includes information on all 5 lifestyle factors.
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</thead>
<tbody>
<tr>
<td>17. Orchid Cancer Appeal</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>18. Bowel Cancer UK</td>
<td>None</td>
<td>None</td>
<td>Recommendation:</td>
<td>Recommendation:</td>
<td>Does not include a specific recommendation but there are two leaflets available to download, one on ‘gaining weight safely’ and another on ‘losing weight safely’.</td>
<td>N/A</td>
<td>Macmillan Cancer Support, Penny Brohn Cancer Care, GP</td>
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<tr>
<td></td>
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<td></td>
<td>- People living with and beyond cancer are now encouraged to remain active and resume daily activities as soon as possible during and after their treatment. Suggests building up to 30 minutes per day.</td>
<td>- After bowel surgery, aim to eat a balanced diet.</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>- There are two leaflets available to download including a ‘staying healthy after bowel cancer’</td>
<td>- There are several leaflets available to download including a ‘staying healthy after bowel cancer’</td>
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<th>Which guidelines is the information based on?</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>factsheet, and a leaflet on ‘physical activity after bowel cancer’, which includes information on the benefits of physical activity, tips on building up and a case study.</td>
<td>factsheet and a leaflet on ‘what is a balanced diet’, among other leaflets aimed at specific diet issues.</td>
<td>healthy weight or the amount of weight gain/loss to aim for.</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>- Recommends speaking to doctor or nurse before starting an exercise regime.</td>
<td>- These leaflets cover information the different food groups, advice on eating fibre, and information about vegetarian and vegan diets. They also have advice on what to eat at different stages of disease and treatment.</td>
<td></td>
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<table>
<thead>
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<th>Weight management</th>
<th>Which guidelines is the information based on?</th>
<th>Which sources does the information direct to?</th>
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</thead>
<tbody>
<tr>
<td>19. Beating Bowel Cancer</td>
<td>- Giving up smoking will have many health benefits, including reducing your risk of cancer.</td>
<td>- If consumed at all, alcohol should be limited to 2 small drinks for men and 1 for women per day.</td>
<td>- Take 30 minutes of moderate exercise every day and avoid sitting for long periods.</td>
<td>- Recommendations: 1) Reduce the amount of processed foods, especially those high in fat and sugar, 2) Increase the amount of fresh fruit and vegetables, 3) Eat less than 500g red meat per week and avoid processed meat, 4) Eat small portions of high quality protein.</td>
<td>N/A</td>
<td>WCRF GP, specialist nurse, NHS Choices, British Dietetic Association</td>
<td></td>
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</tbody>
</table>

- This information is included in the downloadable 'Living well after bowel cancer' leaflet.
- This information is included in the downloadable 'Living well after bowel cancer' leaflet.
- This information is included in the downloadable 'Living well after bowel cancer' leaflet.

- Refers to Macmillan Cancer Support and other charities for more specific information.

- This information is included in the downloadable 'Living well' and 'Eating Well' leaflets which
## Table 6.1 Summary of online lifestyle information for cancer survivors

<table>
<thead>
<tr>
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<th>Weight management</th>
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<th>Which sources does the information direct to?</th>
</tr>
</thead>
<tbody>
<tr>
<td>20. Bowel Cancer Information</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

- Suggests speaking to GP, specialist nurse or local sports centre for information on local exercise classes.
- Also suggests a website with information on ‘health walks’ and the NHS Choices website.

Include tips from bowel cancer patients.
6.4.6 Smoking

Four organisations provided information on smoking (Beating Bowel Cancer, 2014; Macmillan Cancer Support, 2014; Prostate Cancer UK, 2014; The Christie NHS Foundation Trust, 2015); recommending that smokers should quit. These organisations did not provide their own advice on how to stop smoking, but referred smokers to smoking cessation services and the NHS Choices website for further support.

6.4.7 Alcohol

Seven organisations provided information on alcohol (Beating Bowel Cancer, 2014; Breast Cancer Care, 2014; Macmillan Cancer Support, 2014; Prostate Cancer UK, 2014; The Christie NHS Foundation Trust, 2015; The Royal Marsden, 2015; World Cancer Research Fund International, 2014). These were almost identical and recommended 2-3 units per day for women and 3-4 units for men (three organisations stated this as the number of drinks: 1 for women and 2 for men (Beating Bowel Cancer, 2014; The Royal Marsden, 2015; World Cancer Research Fund International, 2014). The Christie NHS Foundation Trust did not provide a specific recommendation regarding a number of units or drinks, but recommended drinking less alcohol (The Christie NHS Foundation Trust, 2015). The organisations did not provide much advice on how to limit alcohol consumption, but one charity (Prostate Cancer UK, 2014) referred to the NHS Choices website.

6.4.8 Physical activity

Ten organisations had information on physical activity on their websites and eight of these provided specific recommendations on the duration and intensity of physical activity that cancer survivors should aim for (Beating Bowel Cancer, 2014; Breast Cancer Care, 2014; Cancer Research UK, 2014c; Macmillan Cancer Support, 2014; Prostate Cancer UK, 2014; The Christie NHS Foundation Trust, 2015; The Royal Marsden, 2015; World Cancer Research Fund International, 2014), of which five recommended 150 minutes of moderate physical activity per week, in varying forms (e.g. 30 minutes, 5 times per week) (Breast Cancer Care, 2014; Cancer Research UK, 2014c; Macmillan Cancer Support, 2014; Prostate Cancer UK, 2014; The Royal Marsden, 2015) and the other three recommended 30 minutes every day (Beating Bowel Cancer, 2014; The
One also highlighted the importance of reducing sedentary behaviour (Beating Bowel Cancer, 2014). Bowel Cancer UK and Maggie’s did not specify duration or intensity, but emphasised the importance of being active (Bowel Cancer UK, 2014; Maggie’s, 2015).

Information about physical activity was provided in a variety of formats. Two had DVDs (Breast Cancer Care, 2014; Macmillan Cancer Support, 2014), one had a podcast (The Christie NHS Foundation Trust, 2015) and others had booklets, leaflets or factsheets available to download or order in paper formats (Beating Bowel Cancer, 2014; Bowel Cancer UK, 2014; Macmillan Cancer Support, 2014; The Christie NHS Foundation Trust, 2015). Others had brief advice about becoming active on their websites (Cancer Research UK, 2014c; Prostate Cancer UK, 2014; The Royal Marsden, 2015). Some organisations offered exercise classes that patients could join to help them get active.

The majority of organisations gave suggestions on the types of physical activity cancer survivors could do, for example, walking, swimming or housework (Bowel Cancer UK, 2014; Breast Cancer Care, 2014; Macmillan Cancer Support, 2014; Prostate Cancer UK, 2014; The Christie NHS Foundation Trust, 2015; The Royal Marsden, 2015; World Cancer Research Fund International, 2014), and some provided specific exercises for cancer survivors to try at home (The Christie NHS Foundation Trust, 2015). These often included information about the benefits of being physically active following a cancer diagnosis, for example, ‘exercise for cancer patients can reduce the risk of cancer coming back’ (Breast Cancer Care, 2014; Macmillan Cancer Support, 2014; The Christie NHS Foundation Trust, 2015). Patients were encouraged to start exercise gently and build up slowly and some organisations gave examples of how to do this, for example, ‘5 minutes of housework in the morning followed by a 5 minute walk to the shop, followed by a 10 minute dog walk’ (The Christie NHS Foundation Trust, 2015). Several organisations provided information about safety during exercise and when to be careful, for example, ‘people with low immunity should avoid public gyms’ or ‘stop exercising if you feel sick or are sick during exercise’ (Bowel Cancer UK, 2014; Cancer Research UK, 2014c; Macmillan Cancer Support, 2014; The Christie NHS Foundation Trust, 2015).
CHAPTER 6: REVIEW OF ONLINE LIFESTYLE INFORMATION FOR CANCER SURVIVORS

A range of resources were provided to help cancer survivors be physically active. The leaflets included case studies of patients with tips on exercising with cancer, and advice on finding local exercise programmes. The DVDs had information on how to become more active, including advice from experts, case studies from other cancer survivors, and exercise demonstrations (Breast Cancer Care, 2014; Macmillan Cancer Support, 2014).

6.4.9 Diet

All organisations recommended that cancer survivors eat a balanced diet, and the majority provided further detail. They highlighted the importance of eating plenty of fruit, vegetables and starchy foods, and limiting intake of energy dense foods (high in sugar or saturated fat) and red or processed meat. Prostate Cancer UK also provided a list of more specific and unusual foods which may be beneficial (e.g. green tea and tomatoes), although they acknowledged that the evidence is limited.

The websites provided information about diet in a range of formats. Five organisations had leaflets available for patients to download and print at home. Others had videos for patients to watch (Breast Cancer Care, 2014; The Christie NHS Foundation Trust, 2015) and podcasts for them to listen to (The Christie NHS Foundation Trust, 2015). In some cases, the website itself did not provide much information but had details about free courses patients could sign up to in order to learn more about diet (Maggie’s, 2015).

All of the organisations with information about diet gave guidelines for what cancer survivors should be eating. Most provided a diagram of the ‘Eatwell plate’ (Public Health England, 2013) to help cancer survivors understand the different food groups on which they should be basing their diet (Beating Bowel Cancer, 2014; Bowel Cancer UK, 2014; Breast Cancer Care, 2014; Prostate Cancer UK, 2014; The Christie NHS Foundation Trust, 2015; The Royal Marsden, 2015). Some then gave examples of the types of foods that come under each food group, for example, ‘meat, fish, eggs, tofu, soya products, pulses and Quorn are a good source of protein’ (Bowel Cancer UK, 2014; The Christie NHS Foundation Trust, 2015; The Royal Marsden, 2015) and reasons why these foods are beneficial or harmful, for example, ‘fibre keeps bowels working regularly’ or ‘red and
processed meat are associated with an increased risk of some cancers’. In order to help cancer survivors eat appropriate amounts of different types of foods, several organisations gave examples of portion sizes, for example, a serving would be ‘three heaped tablespoons of cooked vegetables’ (Breast Cancer Care, 2014; Macmillan Cancer Support, 2014; The Christie NHS Foundation Trust, 2015; World Cancer Research Fund International, 2014). To inspire patients, many organisations also provided recipe ideas for meals and snacks, for example, breakfast could be ‘wholegrain cereal topped with sliced banana and semi-skimmed milk’ (Inoue-Choi, Lazovich, Prizment, & Robien, 2013; Macmillan Cancer Support, 2014; The Christie NHS Foundation Trust, 2015; The Royal Marsden, 2015).

As well as this fairly general information on what to eat, several organisations provided information about what to eat following specific cancers or treatments, or when experiencing particular symptoms. For example, Beating Bowel Cancer provided an explanation of how bowel cancer treatment and surgery affects the bowel, and how this may impact on diet (Beating Bowel Cancer, 2014). They also included tips for eating and avoiding bowel symptoms, for example, ‘eat at regular intervals, and don’t eat on the move’. Other organisations gave information on what to eat when losing or gaining weight. For example, The Royal Marsden suggested that when losing weight it is best to ‘eat when your appetite is best and have small regular meals’ (The Royal Marsden, 2015).

Some organisations provided tools to help cancer survivors with their diet. For example, the Royal Marsden gave some tips for overcoming problems with eating, such as ‘if you are too tired get friends to help with shopping or have snacks that don’t require much preparation’ (The Royal Marsden, 2015). The Beating Bowel Cancer leaflet contained quotes from other patients with tips on what they found useful, for example, ‘Ginger beer really helped with nausea when undergoing chemotherapy’, as well as tips for family members (Beating Bowel Cancer, 2014). Similarly, the Breast Cancer Care DVD was largely narrated by patients who told their stories about how they changed their diet following their cancer diagnosis (Breast Cancer Care, 2014).
6.4.10 Weight management

Seven organisations provided information on weight management for cancer survivors (Befort et al., 2011; Bowel Cancer UK, 2014; Breast Cancer Care, 2014; Macmillan Cancer Support, 2014; Prostate Cancer UK, 2014; The Royal Marsden, 2015; World Cancer Research Fund International, 2014). They all recommended maintaining a healthy weight (within the normal BMI range) and the WCRF recommended being as lean as possible without becoming underweight. Several organisations recommended that people who are overweight try to lose their excess weight, but emphasised that this should be done gradually (at around 0.5-1kgs a week) and should be done in consultation with a health professional (Bowel Cancer UK, 2014; Breast Cancer Care, 2014; Macmillan Cancer Support, 2014; Prostate Cancer UK, 2014). In contrast, the Royal Marsden recommended that those who are overweight should not try to lose weight during treatment as this would make them more susceptible to infections and poor wound healing (The Royal Marsden, 2015).

Several organisations provided advice on how to lose weight with a focus on healthy eating and physical activity. Four had advice on their websites to help get people started, including tips on weight loss (and weight gain for those who had lost weight during treatment) (Breast Cancer Care, 2014; Macmillan Cancer Support, 2014; Prostate Cancer UK, 2014; The Royal Marsden, 2015). Two included information about weight in their booklets about diet (The Christie NHS Foundation Trust, 2015; The Royal Marsden, 2015).

6.5 Discussion

This review aimed to identify lifestyle information specifically for cancer survivors provided by the statutory and charity sectors, and cancer centres in the UK. Ten organisations had lifestyle information for cancer survivors on their websites. The Christie NHS Foundation Trust (The Christie NHS Foundation Trust, 2015), Macmillan Cancer Support (Macmillan Cancer Support, 2014) and Prostate Cancer UK (Prostate Cancer UK, 2014) had the most comprehensive guides, covering physical activity, diet, weight management, smoking and alcohol. The NHS website did not provide any
lifestyle information for cancer survivors but had a link to CR-UK’s information about diet.

The absence of lifestyle information for cancer survivors on the NHS website is a matter of concern, given that the NHS is the preferred source of information for many patients (Rozmovits & Ziebland, 2004). It is encouraging that the NHS Choices website provides links to CR-UK’s webpage on diet, but it would be helpful if they also directed cancer survivors to advice on physical activity and other health behaviours. Although there was no information on the main NHS website, The Christie NHS Foundation Trust (The Christie NHS Foundation Trust, 2015) had very comprehensive information on its website, suggesting that lifestyle information from statutory organisations is provided to cancer patients at a local level. However, not all cancer centres provided lifestyle information, which may lead to a geographical disparity in access to lifestyle information. Even if some cancer centres have lifestyle information on their websites, patients from other centres may not know it exists or where to find it.

In the charity sector, Macmillan Cancer Support (Macmillan Cancer Support, 2014) and Prostate Cancer UK (Prostate Cancer UK, 2014) had the most comprehensive information on their websites; consistent with them being leading cancer charities. Macmillan Cancer Support in particular had dedicated sections on its website, making it easy for cancer survivors to navigate and find the lifestyle information they need. Several of the other charities (e.g., CR-UK (Cancer Research UK, 2014c) and Breast Cancer Care (Breast Cancer Care, 2014)) had information on each health behaviour in a different section, making it more difficult to assemble the relevant information. This highlights a challenge that cancer survivors may face when searching for information about lifestyle.

Where lifestyle recommendations were given, they were similar to UK government guidelines for the general population (Department of Health, 2011; NHS Choices, 2014b, 2014c, 2014a; Public Health England, 2013). These included not smoking, limiting alcohol intake, maintaining a healthy weight, being moderately physically active for at least 150 minutes per week, and eating a diet high in fruit and vegetables and low in fat,
sugar and red and processed meat. As discussed in Chapter 2, this is likely to be due to the lack of evidence to inform the development of specific recommendations for cancer survivors, although studies have consistently demonstrated associations between cancer survival and physical activity (Fong et al., 2012; Ibrahim & Al-Homaidh, 2011), and some studies have suggested benefits of a low fat diet (Chlebowski et al., 2006), smoking abstinence (Parsons et al., 2010), and limited alcohol consumption (Mayne et al., 2009).

Five organisations suggested that cancer survivors who are overweight or obese should attempt to lose weight (Breast Cancer Care, 2014; Department of Health, 2010; Prostate Cancer UK, 2014; The Christie NHS Foundation Trust, 2015; World Cancer Research Fund International, 2014). This is somewhat surprising given that, as described in Chapter 2, this recommendation is less well supported by the literature, and weight loss has been associated with poorer disease outcomes for cancer survivors, even among those who are overweight or obese (Caan et al., 2005, 2012b). In the absence of good trial evidence, organisations should perhaps be more cautious about recommending weight loss for cancer survivors. The Royal Marsden’s recommendation was more in line with the evidence, saying that it is not a good idea to lose weight during treatment, even if overweight (The Royal Marsden, 2015). Such inconsistencies in recommendations may be confusing for cancer survivors, particularly those who lose or gain weight during treatment.

The findings of this study have considerable implications for the organisations included in this review. On the whole, the level of information provided was suboptimal, as only half of the organisations provided any information about lifestyle and only three provided information on all health behaviours. This was the case even though it included the website of the NHS and charities that all described their operations as providing ‘advocacy, advice or information’. These findings are concerning given that statutory and charity sector organisations and cancer centres have been found to be a favoured source of information for cancer survivors and are likely to be the first point of call for those seeking information (Rozmovits & Ziebland, 2004). With the rise of internet use among older adults (Zickuhr & Madden, 2012), the websites of these organisations are likely to experience increasing traffic (Department of Health, 2010).
addition, with increasing focus on supported self-management, access to appropriate lifestyle information may help build cancer survivors’ self-efficacy for making lifestyle changes, which in turn could make them more likely to change their behaviour (Bandura, 1986).

If cancer survivors are unable to find the information they are looking for on these websites, they may turn to less reliable sources. Given the abundance of misreporting about lifestyle and cancer in the media and online (Goldacre, 2009), this could put cancer survivors at risk of misinformation and potentially hinder their chances of giving themselves the best long-term outcomes. As a result it is crucial that the information on the majority of these websites is improved. Specifically, the main NHS website would benefit from including information about lifestyle specifically for cancer survivors, or alternatively add clear links to hospitals which already provide good quality information and advice, such as The Christie NHS Foundation Trust or The Royal Marsden. Other organisations would benefit from reorganising their websites so that recommendations are easy to identify and all lifestyle information can be found in one section rather than having to search for behaviours separately (Breast Cancer Care, 2014; Cancer Research UK, 2014c).

Several of the organisations referred patients to other sources of information and emphasised the importance of talking to a health professional before making any lifestyle changes. The latter may be problematic for longer term survivors as they may no longer have regular contact with their healthcare team. If patients are required to make an appointment with their GP before making lifestyle changes then they may be less likely to make those changes, whether through loss of motivation or other barriers. Those who do have contact with their health care team may find that their doctor or nurse is unable to advise them about lifestyle. Examining health professionals’ awareness of lifestyle guidelines for cancer survivors, and current practices with regard to giving lifestyle advice would help highlight any barriers to such advice.
6.5.1 Limitations

This study has a number of limitations. First, for practical reasons it was only possible to include 20 UK-based statutory and charities and cancer centres. Although this provides a useful overview of the information provided by such organisations, it is likely that users in the UK would also encounter a range of other websites when searching for information about lifestyle. My search excluded websites based in North America and other English speaking nations, yet it is likely that cancer survivors would encounter such websites, particularly as the US is a leader in the cancer survivorship field. Therefore, a wider search, incorporating all English-language websites, could be useful. I also excluded the websites of commercial organisations (e.g. private healthcare companies) which cancer survivors may also encounter, even if these are not their preferred sources of information.

All searches were conducted between November 2014 and January 2015 and as is the case with all internet research, the findings may quickly become outdated as organisations update the information on their websites. Although this review provides a snapshot of the availability of lifestyle information for cancer survivors at present, it would benefit from being continually updated to ensure knowledge is up-to-date and to track how provision changes over time.

It is possible that some websites did not provide lifestyle information for cancer survivors on their websites because they did not intend this to be the primary function of the site. Although all of the included charities described their operations as providing ‘advocacy/advice/information’, this may not be the primary function of the website. Historically, charities may have used websites in order to fundraise rather than provide information which may explain the limited information available.

6.5.2 Conclusions

Overall, the results of this study show that the statutory and charity sectors, and cancer centres in the UK provide limited online information about lifestyle for cancer survivors. There was no advice on the NHS website and only three organisations had comprehensive guides, encompassing smoking, alcohol, physical activity, diet and
weight. These organisations should consider adding or updating their websites to include adequate information and advice about lifestyle for cancer survivors, or risk cancer survivors turning to less reliable sources of information. The majority of recommendations emphasised that cancer survivors should talk to a health professional before making any lifestyle changes. However, the findings from Study 2 suggest that many cancer survivors do not receive professional advice about lifestyle. It is therefore important to ensure that health professionals are aware of lifestyle guidelines for cancer survivors, and are appropriately trained to advise cancer survivors about lifestyle changes following their diagnosis.
CHAPTER 7: STUDY 4: PREDICTORS OF HEALTH PROFESSIONALS’ PROVISION OF LIFESTYLE ADVICE

7.1 Introduction

Several of the organisations identified in the review in Study 3 emphasised the importance of talking to a health professional before attempting any lifestyle changes. This is in line with previous studies that have recommended that cancer patients should receive counselling about lifestyle (Murphy & Girot, 2013).

Health professionals potentially play a role in promoting favourable lifestyle behaviours among cancer patients. An oncologist initiated discussion about exercise has been associated with more frequent and longer duration of exercise among a mixed group of survivors undergoing treatment (Jones & Courneya, 2002). Among newly diagnosed breast cancer patients, a recommendation from an oncologist has been shown to increase self-reported exercise by a mean of 3.4 metabolic equivalent hours per week compared with those who received no such recommendation (Jones, Courneya, Fairey, & Mackey, 2004). In addition, colorectal cancer survivors who recall receiving information or advice about exercise have been found to have higher levels of physical activity than those who do not recall such advice (Fisher, Williams, Beeken, & Wardle, 2015).

A survey of oncologists in Canada found that 62% believed exercise was beneficial, and 56% thought it was important for cancer patients during treatment (Jones, Courneya, Peddle, & Mackey, 2005). However, despite having positive attitudes towards a healthy lifestyle, studies to date suggest that provision of advice is lacking. Fewer than half of cancer specialists in the UK routinely discuss physical activity with their patients (Daley, Bowden, Rea, Billingham, & Carmicheal, 2008; Macmillan Cancer Support/ICM, 2011), and similar results have been reported in the US and Australia (Demark-Wahnefried, Peterson, McBride, Lipkus, & Clipp, 2000; Spellman, Craike, & Livingston, 2013).

9 A version of this chapter has been published in the European Journal of Cancer Care (Appendix 7.1)
CHAPTER 7: PREDICTORS OF HEALTH PROFESSIONALS’ PROVISION OF LIFESTYLE ADVICE

Research on other aspects of lifestyle is lacking; although one study of cancer survivors in the US found that fewer than 30% received advice on diet (Demark-Wahnefried et al., 2000). These findings are consistent with the results of Study 2, where the majority of participants reported that they had not received advice about lifestyle. In contrast, a qualitative study with a mixed group of oncology professionals found that the majority reported discussing weight management with their patients (A. M. Baker et al., 2015).

A few studies have investigated health professionals’ reported barriers to providing lifestyle advice for cancer survivors. Among physiotherapists and oncology nurses in Ireland, lack of guidelines and lack of knowledge have been cited as barriers to providing physical activity advice to cancer survivors (O’Hanlon & Kennedy, 2014). In the US, clinicians have reported insufficient time (Karvinen, DuBose, Carney, & Allison, 2010), and believing that giving advice is not part of their role (Spellman et al., 2013), as barriers to providing such advice. In the UK, awareness of the importance of diet and lifestyle issues in relation to cancer survivorship among nurses has been found to be limited (Rodman & Murphy, 2011). A qualitative study among consultants, nurses and a variety of other cancer specialists, also implicated lack of time and knowledge, but in addition, the desire to minimise guilt and blame (Miles, Simon, & Wardle, 2010). Studies have also found that lack of evidence, patient sensitivities, lack of relevance to their clinical role, time constraints, inappropriate timing, insufficient weight management skills, and lack of training, have all been cited as barriers to providing weight management advice (Anderson, Caswell, Wells, & Steele, 2013; A. M. Baker et al., 2015).

Little is known about health professionals’ views and current practices with regard to giving advice on lifestyle topics other than physical activity. As described in Chapter 2, a number of organisations including the WCRF, ACS and ACSM have produced lifestyle guidelines for cancer survivors, but it is not known if health professionals are aware of these guidelines or are following them. Similarly, it is not known if health professionals working with prostate cancer patients are aware of the NICE guidance on physical activity for fatigue in this population (NICE, 2014). In addition, although a number of potential barriers to providing lifestyle advice in general have been identified, their
prevalence within specific lifestyle topics is unknown. There have also been no studies investigating relationships between barriers and provision of advice.

7.2 Aim

The aim of the present study was therefore to determine the proportion of health professionals who were familiar with lifestyle guidelines for cancer patients, the proportion of those who reported giving lifestyle advice to their patients, and the prevalence of barriers to giving such advice. It also aimed to determine the factors associated with the provision of lifestyle advice for cancer patients among health professionals working in the cancer area in the UK.

7.3 Methods

7.3.1 Ethical approval

This study was approved by the UCL Research Ethics Committee, reference 4456/001 (Appendix 7.2).

7.3.2 Design and participants

This was an online survey developed using the Survey Monkey website.\textsuperscript{10} Participants were health professionals in roles working directly with cancer patients in the UK. This included physicians, surgeons, nurses and allied health professionals (defined as all other health professionals including physiotherapists, dietitians and occupational therapists).

7.3.3 Recruitment

In order to reach eligible participants, a number of professional organisations were contacted to ask if they would be willing to distribute the survey to their mailing lists. Four organisations agreed, including the British Association for Surgical Oncology, the UK Oncology Nursing Society, the British Uro-Oncology Group, and the Association of Breast Surgery. The survey was also circulated by existing contacts within London

\textsuperscript{10} https://www.surveymonkey.net/
CHAPTER 7: PREDICTORS OF HEALTH PROFESSIONALS’ PROVISION OF LIFESTYLE ADVICE

Cancer and the London Cancer Alliance. An email was drafted containing a link to the online survey and this was sent directly from the organisations to their members (I was not given access to the mailing lists). The flow of participant recruitment is shown in Figure 7.1.

Figure 7.1 Flow of participants through the study

Survey sent to mailing lists of:
British Association for Surgical Oncology,
UK Oncology Nursing Society,
British Uro-Oncology Group,
Association of Breast Surgery

Survey sent to existing contacts within London Cancer and the London Cancer Alliance

Participants start survey and complete at least one question
N=460

Participants complete full survey
N=231

7.3.4 Questionnaire development and piloting

The initial questionnaire was designed and questions developed to best answer the research questions of the study. Where possible, measures used in similar studies with health professionals were obtained and adapted if appropriate (Anderson, Caswell, et al., 2013; Daley et al., 2008; Jones et al., 2005; Karvinen et al., 2010). If existing measures were unavailable, I developed new questions and obtained feedback on these from my supervisors, Professor Jane Wardle, Dr Rebecca Beeken and Dr Abigail Fisher, and from other colleagues in the HBRC.
Once the initial questionnaire had been developed, a paper version was piloted with a small sample of health professionals including oncologists (n=4) haematologists (n=2), nurses (n=2) and surgeons (n=1). These participants were recruited at the National Cancer Research Institute conference in Liverpool, UK in November 2013. Each participant completed the questionnaire in my presence and was asked to ‘think aloud’ by voicing any comments or suggestions as they went through.

Overall, the participants found the questionnaire quick and easy to complete and did not have any problems with the questions. One individual questioned what was meant by ‘weight’ so this was amended to ‘weight management’ (e.g. ‘are you familiar with any guidelines specifically for cancer patients for any of the following lifestyle topics’ with weight management as one of the response options) . Others also suggested additional barriers to providing advice (e.g. disease severity or the patient being in palliative care). The questionnaire was amended based on this feedback.

7.3.5 Measures

The questionnaire contained many questions, not all of which were used for this chapter. Only questions analysed in this chapter are reported here, but the full survey can be found in Appendix 7.3.

7.3.5.1 Socio-demographics

Socio-demographic questions included age (≤25 years/26-35/36-45/46-55/56-65/≥66 years), sex, professional group (physician/surgeon/nurse/allied health professional) and patient groups (all cancer sites/breast/lung/prostate/colorectal/malignant melanoma/Non-Hodgkin lymphoma/bladder/kidney/Brain, Other CNS & intracranial tumours/pancreatic/leukaemia/uterine/oesophageal/ovarian/stomach/oral/myeloma/liver/cervical/thyroid/other).

7.3.5.2 Familiarity with guidelines

Familiarity with guidelines was assessed with the question ‘Are you familiar with any guidelines specifically for cancer patients for any of the following lifestyle topics (please select all that apply)’. Response options were diet/physical activity/weight
management/drinking alcohol/I am not familiar with any guidelines. This was followed by the open question ‘Do you remember the name of the guidelines or who produced them (please give any details if you can)’.

7.3.5.3 Provision of lifestyle advice
Provision of lifestyle advice was assessed with the question ‘Do you give your patients advice on any of the following lifestyle topics’. Response options were diet/physical activity/weight management/smoking/drinking alcohol. They were also asked ‘How many of your patients do you give advice about the following lifestyle topics’, with response options: none/1-25%/26-50%/51-75%/>75% for each topic.

7.3.5.4 Barriers to providing lifestyle advice
Barriers to providing lifestyle advice were assessed with the question: ‘Would any of the following factors put you off giving your patients advice (if the topic was relevant to the patient) (please select all that apply)’. Response options were lack of time/lack of patient interest/not being the right person to give advice/patient too frail or unwell/seeming to blame the patient/lack of clear guidelines/cultural differences or beliefs/not convinced it would affect cancer outcomes/thinking the advice would not change behaviour/none of the above/other. These response options were based on barriers previously reported in the literature (Anderson, Caswell, et al., 2013; Karvinen et al., 2010; Miles et al., 2010; O’Hanlon & Kennedy, 2014; Spellman et al., 2013).

7.3.6 Analyses
7.3.6.1 Descriptive data
Descriptive statistics (frequencies and percentages) were generated to show the proportion of respondents who were familiar with lifestyle guidelines for cancer patients, the guidelines with which they were familiar, whether they gave lifestyle advice, and the approximate proportion of patients to whom they gave such advice.
7.3.6.2 Main analyses

Multivariable logistic regression models were conducted to examine demographic predictors of familiarity with lifestyle guidelines, and demographic predictors of providing lifestyle advice. Separate models were run for each outcome (familiarity or advice) and for each lifestyle topic (smoking, alcohol, physical activity, diet and weight). Age (dichotomised into ≤45 years and > 45 years), sex and profession (physician and surgeon were combined into ‘doctor’) were added as covariates to each of these models.

Separate univariate logistic regression models (one for each barrier) were conducted to examine which barriers were associated with the provision of lifestyle advice.

For the multivariable models, checks were made for the presence of multicollinearity between the predictor variables. This was done by examining the variance inflation factor (VIF) and tolerance statistic. A VIF of greater than 10 and a tolerance value of less than 0.2 were used as established indicators of multicollinearity. Where multicollinearity was present it is indicated in the text. I also created a crosstabulation of the predictor variables to check the frequencies in each group. As a rule of thumb, these should all be greater than one and no more than 20% should be less than five (Field, 2009). If this rule was breached it is indicated in the text.

7.4 Results

7.4.1 Response rate

The exact response rate is unknown as the email containing the link to the survey was cascaded independently within the organisations. However, as a guide, the survey was sent out by four organisations whose number of members ranged from 500-2500, in addition to existing contacts. The survey was started by 460 health professionals who answered at least one question.
7.4.2 Sample characteristics

Sample characteristics are shown in Table 7.1. Among those who answered the relevant questions, the majority were female (81%, n=272), nurses (55%, n=126), and aged between 36 and 55 years (75%, n=251). The most common patient group they worked with was breast cancer patients (25%, n=54), but 19% (n=42) worked with patients across all cancer sites.
### Table 7.1 Demographic characteristics of the sample

<table>
<thead>
<tr>
<th></th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (N=336)</strong></td>
<td></td>
</tr>
<tr>
<td>≤25 years</td>
<td>0.3 (1)</td>
</tr>
<tr>
<td>26-35 years</td>
<td>12 (41)</td>
</tr>
<tr>
<td>36-45 years</td>
<td>33 (110)</td>
</tr>
<tr>
<td>46-55 years</td>
<td>42 (141)</td>
</tr>
<tr>
<td>56-65 years</td>
<td>13 (42)</td>
</tr>
<tr>
<td>≥66 years</td>
<td>0.3 (1)</td>
</tr>
<tr>
<td><strong>Sex (N=336)</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>19 (64)</td>
</tr>
<tr>
<td>Female</td>
<td>81 (272)</td>
</tr>
<tr>
<td><strong>Profession (N=231)</strong></td>
<td></td>
</tr>
<tr>
<td>Physician</td>
<td>21 (48)</td>
</tr>
<tr>
<td>Surgeon</td>
<td>13 (31)</td>
</tr>
<tr>
<td>Nurse</td>
<td>55 (126)</td>
</tr>
<tr>
<td>Allied health professional</td>
<td>11 (26)</td>
</tr>
<tr>
<td><strong>Patient groups (N=217)</strong></td>
<td></td>
</tr>
<tr>
<td>All cancer sites</td>
<td>19 (42)</td>
</tr>
<tr>
<td>Breast</td>
<td>25 (54)</td>
</tr>
<tr>
<td>Prostate</td>
<td>10 (21)</td>
</tr>
<tr>
<td>Colorectal</td>
<td>15 (32)</td>
</tr>
<tr>
<td>Other</td>
<td>31 (68)</td>
</tr>
</tbody>
</table>
7.4.3 Familiarity with lifestyle guidelines

Almost two thirds of respondents (64%) were familiar with some lifestyle guidelines for cancer patients. Familiarity was highest for diet guidelines (50%) and lowest for weight management guidelines (33%) (Table 7.2).

Table 7.2 Reported familiarity with lifestyle guidelines for cancer patients among health professionals (N=460)

<table>
<thead>
<tr>
<th>Familiarity with lifestyle guidelines</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any guidelines</td>
<td>64 (293)</td>
</tr>
<tr>
<td>Smoking</td>
<td>45 (208)</td>
</tr>
<tr>
<td>Alcohol</td>
<td>38 (175)</td>
</tr>
<tr>
<td>Physical activity</td>
<td>49 (227)</td>
</tr>
<tr>
<td>Diet</td>
<td>50 (230)</td>
</tr>
<tr>
<td>Weight management</td>
<td>33 (153)</td>
</tr>
</tbody>
</table>

Among those who were familiar with lifestyle guidelines, Macmillan Cancer Support was the most commonly mentioned (30%), followed by national guidelines such as those by the DoH or NICE (23%). A smaller proportion recalled local (e.g. hospital specific) (7%) or international guidelines (e.g. National Cancer Institute) (5%), or guidelines from other charities (5%), the WCRF (4%), Cancer Research UK (4%) and academic organisations (4%). Over a third of respondents (39%) were unable to recall the source of the guidelines.

In the multivariable analysis, familiarity with any lifestyle guidelines for cancer patients was higher in the older groups (Odds Ratio (OR) 1.93 [95% Confidence Interval (CI) 1.08-3.46], p<.05) (Table 7.3). The same trend was seen for individual behaviours, although it did not always reach statistical significance. Compared with nurses, doctors were significantly less familiar with lifestyle guidelines in general (OR 0.42 [95% CI 0.21-0.85], p<.05), and a trend in this direction was seen for individual health behaviours. Allied health professionals were more familiar than nurses with lifestyle guidelines generally.
(OR 4.03 [95% CI 1.11-14.57], p<.05), although this increased familiarity appeared to be specific to physical activity and diet guidelines. This may reflect the inclusion of dietitians and exercise specialists in this group. There were no gender differences in familiarity with guidelines.

Examination of the frequencies in the crosstabulation revealed that although all cells were greater than or equal to one, 33% were less than five. Specifically, there were only a very small number of male allied health professionals and male nurses in each age group (Appendix 7.4).
Table 7.3  Health professional demographic predictors of familiarity with lifestyle guidelines for cancer patients (N=231)

<table>
<thead>
<tr>
<th>Age in years</th>
<th>Any topic</th>
<th>Smoking</th>
<th>Adjusted OR [95% CI]</th>
<th>Alcohol</th>
<th>Physical activity</th>
<th>Diet</th>
<th>Weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤45 years</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>&gt;45 years</td>
<td>1.93 [1.08-3.46]*</td>
<td>1.71 [0.99-2.96]</td>
<td>1.97 [1.12-3.46]*</td>
<td>1.72 [1.00-2.99]</td>
<td>1.72 [0.99-2.98]</td>
<td>1.66 [0.93-2.97]</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th>Any topic</th>
<th>Smoking</th>
<th>Adjusted OR [95% CI]</th>
<th>Alcohol</th>
<th>Physical activity</th>
<th>Diet</th>
<th>Weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Female</td>
<td>1.26 [0.56-2.84]</td>
<td>1.04 [0.46-2.34]</td>
<td>1.15 [0.49-2.68]</td>
<td>1.27 [0.75-2.83]</td>
<td>1.59 [0.70-3.60]</td>
<td>1.38 [0.58-3.30]</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Profession</th>
<th>Any topic</th>
<th>Smoking</th>
<th>Adjusted OR [95% CI]</th>
<th>Alcohol</th>
<th>Physical activity</th>
<th>Diet</th>
<th>Weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Doctor</td>
<td>0.42 [0.21-0.85]*</td>
<td>0.53 [0.26-1.06]</td>
<td>0.61 [0.30-1.26]</td>
<td>0.57 [2.87-1.12]</td>
<td>0.54 [0.27-1.08]</td>
<td>0.86 [0.42-1.79]</td>
<td></td>
</tr>
<tr>
<td>Allied HP</td>
<td>4.03 [1.11-14.57]*</td>
<td>0.93 [0.39-2.21]</td>
<td>0.82 [0.33-2.04]</td>
<td>1.85 [0.73-4.71]</td>
<td>1.51 [0.62-3.69]</td>
<td>0.76 [0.29-2.00]</td>
<td></td>
</tr>
</tbody>
</table>

OR=odds ratio, CI=confidence interval, HP=health professional
Adjusted ORs are adjusted for age, sex and profession
*p<.05
7.4.4 Provision of lifestyle advice

The majority (87%) of health professionals reported giving some lifestyle advice. Provision of lifestyle advice was highest for diet (72%), although only 57% reported giving diet advice to the majority of their patients (Table 7.4). Provision of advice was lowest for alcohol, with only 39% reporting giving some advice, and only 33% giving advice to the majority of their patients.
### Table 7.4 Proportion of health professionals who give advice and health professional demographic predictors of giving lifestyle advice (N=231)

<table>
<thead>
<tr>
<th></th>
<th>Smoking</th>
<th>Alcohol</th>
<th>Physical activity</th>
<th>Diet</th>
<th>Weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>% (N)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proportion who give some advice (N=361)</td>
<td>62 (222)</td>
<td>39 (139)</td>
<td>67 (240)</td>
<td>72 (260)</td>
<td>58 (208)</td>
</tr>
<tr>
<td>Proportion who give advice to &gt;50% patients (N=361)</td>
<td>42 (97)</td>
<td>33 (60)</td>
<td>51 (130)</td>
<td>57 (149)</td>
<td>46 (108)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Adjusted OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age in years</strong></td>
<td></td>
</tr>
<tr>
<td>≤45 years</td>
<td>1.00</td>
</tr>
<tr>
<td>&gt;45 years</td>
<td>1.31 [0.74-2.33]</td>
</tr>
</tbody>
</table>

| **Sex**              |                      |
| Male                 | 1.00                 | 1.00                 | 1.00 | 1.00 | 1.00 |
| Female               | 0.85 [0.36-2.03]     | 0.67 [0.31-1.48]     | 2.18 [0.93-5.10] | 1.64 [0.70-3.85] | 1.23 [0.55-2.76] |

| **Profession**       |                      |
| Nurse                | 1.00                 | 1.00                 | 1.00 | 1.00 | 1.00 |
| Doctor               | 1.07 [0.51-2.24]     | 1.03 [0.52-2.04]     | 1.03 [0.48-2.21] | 0.66 [0.31-1.45] | 1.01 [0.50-2.04] |
| Allied HP            | 0.54 [0.23-1.31]     | 1.15 [0.48-2.76]     | 1.42 [0.51-3.97] | 0.74 [0.27-2.00] | 1.32 [0.52-3.34] |

OR=odds ratio, CI=confidence interval, HP=health professional, Adjusted odds ratios are adjusted for age, sex and profession, *p<.05
7.4.5 Barriers to providing lifestyle advice

The most commonly endorsed barrier was the patient being too frail or unwell (70%), followed by perceived lack of patient interest (48%) and lack of time (36%). Other reported barriers included not being the right person to give advice (25%), lack of clear guidelines (25%), not being convinced that change would affect cancer outcomes (17%), thinking the advice would not change their behaviour (17%), cultural differences or beliefs (16%), and concern about putting blame on the patient (16%). Only 7% of respondents did not endorse any barrier to giving lifestyle advice.

7.4.6 Predictors of provision of lifestyle advice

Familiarity with guidelines was associated with increased likelihood of providing lifestyle advice for physical activity (OR 2.17 [95% CI 1.39-3.39], p<.01), diet (OR 2.00 [95% CI 1.25-3.20], p<.01), weight (OR 3.13 [95% CI 1.93-5.08], p<.001), smoking (OR 1.76 [95% CI 1.14-2.71], p<.05) and alcohol (OR 3.45 [95% CI 2.21-5.40], p<.001).

Those who reported a lack of clear guidelines or did not believe lifestyle advice would affect cancer outcomes had lower odds of providing advice on all lifestyle topics (Table 7.5). Lack of time, believing they were not the right person to give advice, and believing that advice would be blaming the patient, were generally associated with lower odds of providing lifestyle advice, although this was not significant for all behaviours (Table 7.5). Cultural differences appeared to be associated with lower odds of providing advice about weight (OR 0.54 [95% CI 0.30-0.96], p<.05).
### Table 7.5 Barrier endorsement in relation to provision of lifestyle advice in each domain (N=341)

<table>
<thead>
<tr>
<th></th>
<th>Smoking</th>
<th>Alcohol</th>
<th>Physical activity</th>
<th>Diet</th>
<th>Weight</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Lack of time</strong></td>
<td>1.19 [0.75-1.88]</td>
<td>0.73 [0.46-1.15]</td>
<td>0.60 [0.38-0.96]</td>
<td>0.72 [0.45-1.17]</td>
<td>0.62 [0.39-0.96]</td>
</tr>
<tr>
<td><strong>Lack of patient interest</strong></td>
<td>1.72 [1.11-2.68]</td>
<td>1.08 [0.70-1.68]</td>
<td>0.66 [0.42-1.04]</td>
<td>1.19 [0.74-1.90]</td>
<td>0.92 [0.60-1.42]</td>
</tr>
<tr>
<td><strong>Not right person</strong></td>
<td>0.54 [0.33-0.88]</td>
<td>0.50 [0.29-0.85]</td>
<td>0.63 [0.38-1.05]</td>
<td>0.54 [0.32-0.90]</td>
<td>0.57 [0.35-0.93]</td>
</tr>
<tr>
<td><strong>Blaming patient</strong></td>
<td>0.46 [0.26-0.83]</td>
<td>0.32 [0.16-0.66]</td>
<td>0.64 [0.35-1.17]</td>
<td>0.67 [0.36-1.23]</td>
<td>0.43 [0.24-0.77]</td>
</tr>
<tr>
<td><strong>Lack of guidelines</strong></td>
<td>0.54 [0.33-0.89]</td>
<td>0.48 [0.28-0.83]</td>
<td>0.31 [0.18-0.51]</td>
<td>0.39 [0.23-0.65]</td>
<td>0.41 [0.25-0.68]</td>
</tr>
<tr>
<td><strong>Cultural differences</strong></td>
<td>1.32 [0.71-2.43]</td>
<td>0.70 [0.38-1.30]</td>
<td>0.55 [0.31-1.00]</td>
<td>1.67 [0.82-3.40]</td>
<td>0.54 [0.30-0.96]</td>
</tr>
<tr>
<td><strong>Wouldn’t affect cancer outcomes</strong></td>
<td>0.48 [0.27-0.86]</td>
<td>0.36 [0.18-0.71]</td>
<td>0.42 [0.23-0.74]</td>
<td>0.41 [0.23-0.74]</td>
<td>0.38 [0.21-0.68]</td>
</tr>
<tr>
<td><strong>Wouldn’t change behaviour</strong></td>
<td>1.04 [0.58-1.86]</td>
<td>0.56 [0.30-1.04]</td>
<td>0.64 [0.36-1.14]</td>
<td>0.65 [0.36-1.18]</td>
<td>0.64 [0.36-1.12]</td>
</tr>
</tbody>
</table>

OR=odds ratio, CI=confidence interval, Reference category 1.00 is ‘no’, they did not endorse barrier, *p<.05, **p<.01, ***p<.001
Surprisingly, perceived lack of patient interest was associated with higher odds of providing advice on smoking (Table 7.5). Those who reported their patient being too unwell as a potential barrier to providing lifestyle advice were also more likely to give advice on physical activity (OR 1.86 [95% CI 1.15-3.02], \( p < .05 \)), diet (OR 1.77 [95% CI 1.08-2.92], \( p < .05 \)), weight (OR 1.87 [95% CI 1.17-2.99], \( p < .01 \)) and smoking (OR 1.70 [95% CI 1.06-2.71], \( p < .05 \)).

Respondents who were over the age of 45 years had higher odds of providing advice on physical activity but there were no other demographic differences (Table 7.4).

### 7.5 Discussion

#### 7.5.1 Overview of the findings

This study aimed to examine health professionals’ familiarity with lifestyle guidelines for cancer patients, current practices with regard to giving lifestyle advice, and perceived barriers to providing such advice. It also aimed to identify the determinants of health professionals’ provision of lifestyle advice for cancer patients. Familiarity with guidelines was suboptimal, with almost a third of respondents unfamiliar with any lifestyle guidelines for cancer patients, although the majority reported providing some lifestyle advice to their patients. Those who were unfamiliar with guidelines were less likely to provide advice on any of the lifestyle topics.

The most commonly endorsed barriers to providing lifestyle advice were the patient being too unwell, lack of patient interest and lack of time. Endorsing the barriers perceived lack of guidelines and lifestyle change would not affect cancer outcomes, was associated with lower odds of giving advice across all lifestyle topics. Those who reported their patient being too unwell as a potential barrier had higher odds of providing lifestyle advice on all topics except alcohol. Age was the only health professional demographic predictor, with older age associated with higher odds of providing advice on physical activity.
7.5.2 Interpretation of the findings

Two thirds of respondents in this study reported being familiar with some lifestyle guidelines for cancer patients; higher than has been reported in previous studies (Anderson, Caswell, et al., 2013). This may be because compared with previous studies, this sample had a higher proportion of nurses and allied health professionals, who were more likely to be familiar with guidelines than doctors. However, fewer than half of health professionals were familiar with guidelines for any individual health behaviour. This is surprising given that a number of organisations have produced lifestyle recommendations for people diagnosed with cancer (Rock et al., 2012; Schmitz et al., 2010; WCRF & AICR, 2007). A large proportion of health professionals could not recall the source of the guidelines, suggesting that they may not be very familiar with the guidelines, and may therefore be unlikely to discuss them with their patients. Of those who could recall where the guidelines were from, Macmillan Cancer Support was most commonly mentioned, which is probably due to them being one of the key players in the National Cancer Survivorship Initiative in the UK (Department of Health, 2010).

The majority (87%) of health professionals reported giving some lifestyle advice to their cancer patients. The finding that more health professionals reported giving lifestyle advice than were aware of guidelines raises the question of what they are advising. One explanation is that some health professionals may give very general advice based on their existing knowledge, for example ‘do not smoke’, rather than following specific guidelines. While this may be appropriate, it may not provide sufficient detail for cancer survivors to feel fully informed. Alternatively, they may give their patients advice based on guidelines for the general population. Such guidelines have many overlaps with guidelines for cancer survivors, but some recommendations may not be appropriate for cancer survivors, for example, the recommendation to lose weight if overweight. Therefore, further exploration of the details of the lifestyle advice that health professionals are providing is warranted.

Although the proportion of health professionals who reported giving lifestyle advice was lower for individual health behaviours (39-72%), it is still greater than has been reported in previous studies, which have indicated that fewer than half discuss physical activity or
diet with their cancer patients, and such discussions are not necessarily based on guidelines (Daley et al., 2008; Demark-Wahnefried et al., 2000; Macmillan Cancer Support/ICM, 2011; Spellman et al., 2013). No significant effect of professional group was found, so the greater proportion providing advice in this study cannot be attributed to the large proportion of nurses. Instead it may be due to the raised prominence of cancer survivorship in the UK since the Cancer Reform Strategy in 2007 (Department of Health, 2007). However, fewer health professionals reported giving advice to the majority of their patients, suggesting that it is not something that is done routinely.

One of the commonly endorsed barriers to giving lifestyle advice was perceived lack of patient interest. This is inconsistent with studies which have found that cancer patients would welcome advice on health promotion and lifestyle and often try to seek it out (Anderson, Steele, et al., 2013; Demark-Wahnefried et al., 2000); suggesting a need for improved communication to ensure that patients’ needs are met. In line with previous research (O’Hanlon & Kennedy, 2014), lack of clear guidelines was endorsed as a barrier to giving lifestyle advice by a quarter of respondents, demonstrating that a significant number of health professionals are not familiar with existing lifestyle recommendations for cancer patients. Also consistent with previous studies, lack of time (Karvinen et al., 2010) and not being the right person to give lifestyle advice (Spellman et al., 2013) were cited as potential barriers.

Familiarity with guidelines was strongly associated with provision of lifestyle advice for all health behaviours. Given that fewer than half of respondents were familiar with guidelines for individual health behaviours, and lack of clear guidelines was endorsed as a barrier by a quarter of respondents, this finding highlights a need for improved education for health professionals in this area, particularly among doctors. Around a sixth of respondents thought that lifestyle change may not affect cancer outcomes and this group were less likely to give advice on any lifestyle topic. It is possible that these particular health professionals may work only with palliative patients or cancer sites with poorer survival. However, given the increasing evidence linking aspects of lifestyle with health outcomes post-diagnosis (Ibrahim & Al-Homaidh, 2011; Je et al., 2013;
Kroenke, Fung, Hu, & Holmes, 2005; McCleary et al., 2010), this again suggests a need for more health professional training in this area.

Respondents who did not believe they were the right person to give advice were less likely to give it overall. This might be resolved by integrating a discussion about lifestyle into the cancer care pathway so that responsibilities can be assigned. Concern about blaming the patient was associated with lower odds of giving advice about some lifestyle topics but this barrier was endorsed by the least number of professionals. Encouragingly, although lack of patient interest was endorsed as a barrier by nearly half of respondents, this was associated with higher odds of providing advice on smoking. This suggests that some health professionals may try to motivate less interested patients and encourage lifestyle change.

These findings highlight gaps in knowledge about lifestyle among all groups of health professionals. However, in order to ensure that as many patients as possible are given lifestyle advice; it may be beneficial to assign the responsibility to a specific role. There is some evidence that cancer survivors may seek lifestyle advice from primary care practitioners, suggesting that education should be focused on this group (Murphy & Girot, 2013). This may be particularly appropriate as cancer survivors should meet with their GP as part of the cancer care review. Alternatively, the cancer care team may be better placed to provide tailored lifestyle advice to cancer patients. Clinical nurse specialists interact with patients on a regular basis, and part of their role is to help personalise the cancer care pathway to meet the individual information and support needs of patients (National Cancer Action Team, 2010). However, lifestyle is not currently listed under their remit, highlighting a potential opportunity for additional training and expansion of their role.

Even with appropriate training, health professionals face a number of challenges when providing lifestyle advice. With the exception of the NICE guidance on physical activity for fatigue in prostate cancer survivors, there are currently no clinical guidelines for health professionals on what they should be recommending to cancer survivors. Given the evidence for the benefits of physical activity for breast and colorectal cancer
survivors, there is a need for clinical guidance in these populations as well. As described earlier, several organisations have produced general lifestyle recommendations for cancer survivors (Rock et al., 2012; Schmitz et al., 2010; WCRF & AICR, 2007), but cancer specific guidelines are lacking. This could make it difficult for health professionals to know what to recommend, particularly those who work with patient groups where the evidence linking lifestyle with cancer survival is more limited. However, even without this evidence, survivors may benefit from information about reducing their risk of the long-term and late effects of cancer. Even for cancers where the evidence is clearer, as the guidelines are very general, health professionals may struggle to provide specific advice to their patients.

The absence of specific lifestyle guidelines for cancer survivors raises the question of what health professionals should be recommending to their patients. There is clear evidence that smoking is associated with adverse outcomes among cancer survivors (Bérubé et al., 2014; van Imhoff et al., 2015; Walter et al., 2014), so health professionals should advise and support smokers to quit. Given the success of the NHS stop smoking services (Bauld et al., 2010), referring patients to these services would be the best course of action. For most groups of cancer survivors, there is little evidence that moderate alcohol consumption is harmful, so it would be reasonable to suggest that health professionals encourage their patients to follow the WCRF guidelines (WCRF & AICR, 2007). However, as described in Chapter 2, alcohol consumption has been associated with poorer outcomes among head and neck cancer survivors, so health professionals may choose to recommend alcohol cessation for these patients, particularly if this may have been the cause of their cancer (Do et al., 2003; Mayne et al., 2009).

The WCRF guidelines recommend that cancer survivors are moderately physically active for at least 30 minutes every day (WCRF & AICR, 2007). Although there is insufficient evidence from the academic literature to determine the optimal mode, duration and intensity of physical activity, there is evidence of a dose-response relationship between physical activity and a range of outcomes (Schmid & Leitzmann, 2014). As such, health professionals may choose to advise their patients to be as active as possible. Where
available, health professionals should consider referring cancer survivors to an exercise programme to assist them with making changes. Several local schemes are available across the country, for example, Aquaterra work in partnership with Islington Public Health in London to offer a free 12 week programme to cancer survivors living in the borough. However, not all areas offer such programmes and there is no national scheme. NICE recommends structured exercise programmes for the management and rehabilitation of a number of health conditions, including myocardial infarction, but cancer is not currently included (NICE, 2015).

Diet is a complex issue for health professionals to advise on, as cancer symptoms and treatment side effects may impact a patient’s ability to eat and drink. The majority of patients with specific issues around eating and drinking are usually referred to a hospital dietitian for assessment. For those without specific issues, health professionals may give dietary advice to cancer survivors in order to promote their long-term health. Although there is insufficient evidence for the role of specific dietary factors in outcomes among cancer survivors, the literature suggests that an overall healthy diet may be beneficial. Therefore, it would be reasonable for health professionals to give advice based on the WCRF lifestyle guidelines (WCRF & AICR, 2007). As described previously, given the lack of trial evidence for a benefit of weight loss among cancer survivors, health professionals should be cautious about making such recommendations. Instead, it would be preferable to focus their efforts on encouraging their patients to have a healthy diet and to be physically active.

7.5.3 Limitations

This study had a number of limitations. The sample was limited to members of organisations who were willing to email the survey to their members. Although it was possible to obtain a rough estimate of the number of members within each organisation, the exact response rate is unknown. It is therefore likely that the sample is not representative of all health professionals, but reflects a particularly interested subset. In particular, although the survey was sent to a range of organisations, it was

http://www.aquaterra.org/activities/cancer-survivorhip-programme
dominated by nursing organisations resulting in a large proportion of nurses in this sample. However, health professionals in the current sample were of a range of ages and worked with patients across a range of cancer sites across the UK, which should help increase the generalisability of the results.

It is anticipated that respondents were likely to be more motivated and interested in lifestyle than non-responders. This may mean that cancer health professionals generally are even less knowledgeable and less likely to give lifestyle advice, than those who completed the survey; highlighting a need for education.

The survey did not ask about relevance of lifestyle advice and in the case of smoking and alcohol, the proportions to whom they gave advice may be lower if the patient did not smoke or drink. However, this was a deliberate decision as I did not want respondents to avoid a question about physical activity or diet because they did not think it was relevant, when in these aspects of lifestyle would be relevant to everyone.

Logistic regression was used to examine factors associated with familiarity with lifestyle guidelines and the provision of lifestyle advice. With an alpha of 0.05, the probability of a type I error in any given analysis is one in twenty. However, when examining multiple comparisons the chances of a type I error is increased, so these results should be interpreted with caution. In addition, although logistic regression examines associations between variables, it is not possible to determine causation.

Examination of the data revealed that there were only a very small number of male allied health professionals and male nurses in each age group in the sample. The impact of these groups on the regression analyses may therefore be limited by these small numbers of participants, as these subjects may not accurately reflect the group as a whole.

7.5.4 Conclusions

Overall, the results of this study show that familiarity with lifestyle guidelines for cancer patients remains low among cancer health professionals in the UK, with some clinicians
also unaware of, or sceptical about, links between lifestyle and cancer outcomes. Both of these were associated with lower likelihood of giving lifestyle advice. Given the wealth of evidence that health behaviours are related to longer-term cancer outcomes, and emerging evidence that clinician advice on lifestyle is both desired by patients, and influential, it is important to bridge this gap in awareness. Improved education, particularly among doctors, may lead to an increase in the number of patients receiving lifestyle advice, which could not only improve patient satisfaction but also their long-term health outcomes.
CHAPTER 8: STUDY 5: SOCIAL NETWORKS AND CANCER SURVIVORS’ VIEWS ON LIFESTYLE ADVICE TO CANCER SURVIVORS12

8.1 Introduction

In line with previous studies, Study 2 found that cancer survivors are interested in lifestyle advice and often try to seek it out themselves (Anderson, Steele, et al., 2013; James-Martin et al., 2014). Study 4 found that health professionals were generally positive about lifestyle advice for cancer patients, but a significant proportion (16%) expressed concerns that their advice would be perceived as blaming the patient for their cancer. Endorsing this barrier was associated with lower odds of providing advice on weight, smoking and alcohol, so should not be ignored. Previous qualitative studies have also indicated that health professionals have the desire to minimise guilt and avoid blame when talking to their cancer patients (Miles et al., 2010), and concern about lifestyle being a sensitive issue was raised in a survey of 400 health professionals (Macmillan Cancer Support/ICM, 2011).

Cancer survivors’ social networks may provide an important perspective on whether patients would perceive lifestyle advice as insensitive or implying blame. The term ‘social network’ has been referred to as “the web of social relationships that surround individuals”, and are a valuable source of support and information (Heaney & Israel, 2008). The potential impact of a social network was highlighted in a meta-analysis of 87 studies which found that high levels of perceived social support, a larger social network, and being married were associated with 25%, 20%, and 12% decreases in relative risk of cancer mortality respectively (Pinquart & Duberstein, 2010).

There are a number of possible explanations for why social networks may influence mortality among cancer survivors, but one such way is by influencing their health behaviours (Pinquart & Duberstein, 2010). Social support has been shown to be an important factor in health behaviour change; for example, it may help cancer survivors

12 A version of this chapter has been published in the British Journal of Cancer (Appendix 8.1)
to quit smoking. In a study of cancer survivors who were smokers at the time of diagnosis, high levels of social support were associated with higher odds of quitting (H.-K. Yang et al., 2013). In addition, a systematic review of 22 studies found that 50% showed a significant positive relationship between social support and physical activity engagement (Barber, 2012). Aside from providing social support, psychological models, such as the Theory of Planned Behaviour, acknowledge the importance of social normative pressures and the influence of significant others as factors influencing an individual’s behaviour (Ajzen, 1985). For example, a qualitative study found that family influences were a key factor in the food choices of breast cancer survivors (Beagan & Chapman, 2004).

Social networks are also an important source of information for cancer survivors. A survey of 84 cancer survivors found that they rated family members as the second most important source of health information (after doctors) and were most satisfied with information from family and friends (Pecchioni & Sparks, 2007). A qualitative study of African American cancer patients found that they reported family and friends to play the most important role in their health education (Matthews, Sellergren, Manfredi, & Williams, 2002). Information from interpersonal (non-medical) sources has also been associated with increased fruit and vegetable consumption among breast, prostate and colorectal cancer survivors, highlighting how influential social network members can be (Lewis et al., 2012).

As survivorship care shifts towards supported self-management, cancer survivors’ social networks are likely to play an increasingly important role in supporting them through their diagnosis and treatment. This was demonstrated in a recent study of 990 cancer patient-caregiver pairings, which found that 63.5% patients and 51.4% caregivers preferred that patients lead treatment decisions with input from their family (Shin et al., 2013). A qualitative study also found that both patients and health professionals acknowledged the importance of including family members in the care process, and patients found that they were helpful as an ‘extra set of ears’ (Speice et al., 2000).
Given that social networks are becoming increasingly involved in the care of cancer survivors, they may influence their reception of lifestyle advice and any subsequent lifestyle changes. Even if cancer survivors are themselves positive, if their social networks are not supportive of them making lifestyle changes, then they may be less likely to be receptive of lifestyle advice. Conversely, if social network members are positive about lifestyle advice for cancer patients, this may help counteract some of health professionals’ reported concerns about providing lifestyle advice. Determining the views of cancer survivors’ social networks may therefore be an important step in helping cancer survivors to make lifestyle changes.

8.2 Aim

The aim of this study was to investigate the views of cancer patients’ social networks on doctors giving advice to cancer patients on physical activity, diet and weight. For comparison, the same data were also collected from a small sample of cancer survivors.

8.3 Methods

8.3.1 Ethical approval

This study was exempt from ethical approval under the UCL Research Ethics Committee guidelines, as it only involved the use of anonymous survey data.

8.3.2 Design and Participants

Data were collected from a sample of 2,024 British adults (aged ≥50 years) as part of a home-based, computer-assisted, face-to-face Omnibus survey. Data collection was carried out by an independent social research agency (TNS) who asked the questions for this study alongside questions on other topics. TNS employs random-location, quota sampling to ensure the sample matches census data. Details of the TNS Omnibus sampling method are provided in Appendix 8.2. Briefly, quotas were set for sex and work status and, for women, the presence of children in the home. Interviewers were instructed to leave three doors between each successful interview. Interviews were

13 http://www.tnsglobal.com/
carried out on weekdays between 2pm and 8pm and at weekends in March/April 2012. The flow of participants is shown in Figure 8.1.

In order to identify an unbiased sample of individuals comprising the social networks of individuals diagnosed with cancer, respondents were asked ‘Has anyone close to you ever had cancer’ (yes/no/not sure). They were also asked ‘Have you ever been diagnosed with cancer yourself’ (yes/no/do not wish to answer). Respondents who had received a cancer diagnosis were classified as cancer survivors, and those who reported that someone close to them had been affected by cancer were classified as social network members.

**Figure 8.1** Flow of participants through the study

8.3.3 Questionnaire development and piloting

As this was the first study to examine attitudes towards doctors giving lifestyle advice to cancer survivors, there were no existing measures available to use. I therefore developed new questions to best answer the research questions. These questions were refined with input from my supervisors, Professor Jane Wardle and Dr Rebecca Beeken, and from other colleagues in the HBRC at UCL. The final list of questions was piloted with a small sample of the lay public and minor amendments were made based on their feedback.
8.3.4 Measures

8.3.4.1 Socio-demographic

Age (16-24/25-34/35-44/45-54/55-64/65+), sex, ethnicity (categorised as White or non-White), education (none/school only or university), marital status (married/separated/divorced/widowed/single) and UK region were recorded. Socioeconomic status (SES) information was based on the National Readership Survey classification (AB, C1, C2, D and E) (National Readership Survey (NRS), 2007). Group AB includes those with (or who have had) higher or intermediate managerial or professional occupations, group C1 have supervisory or junior managerial occupations, group C2 are skilled manual workers, group D are semi- and unskilled manual workers and group E are state pensioners or lowest grade workers.

8.3.4.2 Cancer status

As described above, respondents were asked ‘Has anyone close to you ever had cancer’, with response options: yes/no/not sure. They were also asked ‘Have you ever been diagnosed with cancer yourself’ with response options: yes/no/do not wish to answer.

8.3.4.3 Attitudes towards lifestyle advice

Attitudes towards advice on physical activity and healthy eating were each assessed with eight items: ‘Doctors giving advice on [physical activity/healthy eating] to cancer patients at the end of treatment would be [beneficial/helpful/encouraging/the doctor’s duty/insensitive/interfering/unnecessary/placing the blame on patients]’. Responses were scored on a 4-point scale as follows: strongly disagree=3, disagree=1, agree=1, strongly agree=3. The same items were also completed for advice on weight loss, but in this case the stem of the questions specified cancer patients who were overweight (e.g. ‘Doctors giving overweight cancer patients advice on weight-loss would be beneficial’ with response options: strongly disagree to strongly agree). This resulted in 24 questions in total; the full list is shown in Appendix 8.3. The questions only asked about doctors and not other health due to space limitations in the questionnaire.
8.3.5 Analyses

8.3.5.1 Data treatment

Responses to the attitude questions were dichotomised (agree/strongly agree and disagree/strongly disagree) for the analyses to aid interpretation. As well as being analysed individually, responses to the eight questions were averaged to create an overall attitude score for each domain (physical activity, healthy eating and weight loss), with higher scores indicating more positive attitudes. A reliability analysis found that the internal consistency of all three scales was high (physical activity: Cronbach’s alpha = 0.86, healthy eating: alpha = 0.88, weight loss: alpha = 0.89).

The SES categories were also dichotomised (ABC1 and C2DE). ‘Don’t know’ responses were coded as missing for all analyses.

8.3.5.2 Descriptive data

Descriptive statistics (frequencies and percentages) were produced to determine the proportion of respondents who agreed or disagreed with each statement about physical activity, healthy eating and weight loss advice. Chi square analyses were used to examine demographic differences between social network members and cancer survivors.

8.3.5.3 Main analyses

Paired t-tests were used to compare the mean attitude scores for physical activity, healthy eating and weight loss. Three separate analyses of covariance (ANCOVAs) were conducted to examine differences in each of the three mean attitude scores by demographic factors (age, sex, ethnicity, education, marital status and SES) and cancer experience.

8.3.5.4 Parametric assumptions

There are no simple non-parametric tests that are equivalent to an ANCOVA (Field, 2009). Therefore, where the parametric assumptions were violated, a variety of transformations were used, including logarithmic and square root. Transforming the
data in these ways attempts to correct for distributional problems or unequal variances. These are reported where applicable.

8.4 Results

8.4.1 Sample characteristics

Of the 2,024 adults who completed the survey, 63% (n=1,273) knew someone close who had ever had cancer, and were termed social network members, and 11% (n=222) were cancer survivors; giving a total sample of 1,495 for analysis.

Demographic characteristics are shown in Table 8.1. Social network members were significantly younger than cancer survivors (p<.01), but the groups did not differ by sex, SES, ethnicity, education or marital status (all p’s>.05). The majority were women (56%), married (54%) and from White ethnic backgrounds (97%). Only 15% were university educated, and more were in the lower than the higher SES categories (57% vs. 43%).
### Table 8.1 Demographic characteristics of social network members and cancer survivors

<table>
<thead>
<tr>
<th></th>
<th>Social network members</th>
<th>Cancer survivors</th>
<th>$\chi^2$ (df)</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤64 years</td>
<td>52 (658)</td>
<td>40 (88)</td>
<td>10.98 (1)</td>
<td>.001</td>
</tr>
<tr>
<td>65+ years</td>
<td>48 (615)</td>
<td>60 (134)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>44 (557)</td>
<td>42 (94)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>56 (716)</td>
<td>58 (128)</td>
<td>0.15 (1)</td>
<td>.695</td>
</tr>
<tr>
<td><strong>Socioeconomic status (SES)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AB,C1 (higher)</td>
<td>43 (544)</td>
<td>46 (101)</td>
<td>0.59 (1)</td>
<td>.443</td>
</tr>
<tr>
<td>C2,D,E (lower)</td>
<td>57 (729)</td>
<td>55 (121)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>97 (1240)</td>
<td>99 (219)</td>
<td>0.89 (1)</td>
<td>.345</td>
</tr>
<tr>
<td>Non-White</td>
<td>2 (30)</td>
<td>1 (3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Educational qualifications</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>University</td>
<td>15 (185)</td>
<td>15 (33)</td>
<td>0.01 (1)</td>
<td>.929</td>
</tr>
<tr>
<td>None/school only</td>
<td>85 (1079)</td>
<td>85 (189)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>58 (741)</td>
<td>54 (119)</td>
<td>1.64 (1)</td>
<td>.200</td>
</tr>
<tr>
<td>Unmarried</td>
<td>42 (532)</td>
<td>46 (103)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
8.4.2 Attitudes towards lifestyle advice

Table 8.2 shows agreement with the individual items on physical activity, diet and weight loss. Social network members were broadly positive towards health behaviour advice. More than 80% believed it would be ‘beneficial’ and ‘encouraging’, and more than 90% believed it would be ‘helpful’. Interestingly, over 80% also thought it would be ‘the doctor’s duty’ to provide such advice. Fewer than 15% believed it would be ‘insensitive’, ‘interfering’, or ‘unnecessary’, with slightly more (14-18%) seeing it as ‘placing the blame’ on the patient.

Cancer survivors were also positive, with more than 80% believing that it would be ‘beneficial’, ‘helpful’, ‘encouraging’ and ‘the doctors duty’ to provide lifestyle advice, and fewer than 25% believing it would be ‘insensitive’, ‘interfering’ or ‘unnecessary’ or would imply ‘blame’.
Table 8.2 Respondent agreement with each statement about health behaviour advice

<table>
<thead>
<tr>
<th>Statement</th>
<th>Physical activity</th>
<th>Healthy eating</th>
<th>Weight loss (for overweight patients)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Agree/strongly agree % (N)</td>
<td>Disagree/strongly disagree % (N)</td>
<td>Agree/strongly agree % (N)</td>
</tr>
<tr>
<td><strong>Beneficial</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social network</td>
<td>88 (1116)</td>
<td>6 (71)</td>
<td>93 (1179)</td>
</tr>
<tr>
<td>Cancer survivor</td>
<td>87 (193)</td>
<td>7 (15)</td>
<td>93 (206)</td>
</tr>
<tr>
<td><strong>The doctor's duty</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social network</td>
<td>84 (1075)</td>
<td>9 (117)</td>
<td>85 (1086)</td>
</tr>
<tr>
<td>Cancer survivor</td>
<td>86 (191)</td>
<td>10 (23)</td>
<td>84 (187)</td>
</tr>
<tr>
<td><strong>Helpful</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social network</td>
<td>91 (1156)</td>
<td>4 (49)</td>
<td>93 (1184)</td>
</tr>
<tr>
<td>Cancer survivor</td>
<td>89 (198)</td>
<td>7 (16)</td>
<td>90 (200)</td>
</tr>
<tr>
<td><strong>Encouraging</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social network</td>
<td>89 (1129)</td>
<td>5 (66)</td>
<td>92 (1168)</td>
</tr>
<tr>
<td>Cancer survivor</td>
<td>86 (190)</td>
<td>11 (24)</td>
<td>89 (198)</td>
</tr>
<tr>
<td></td>
<td>Physical activity</td>
<td>Healthy eating</td>
<td>Weight loss (for overweight patients)</td>
</tr>
<tr>
<td>--------------------------</td>
<td>-------------------</td>
<td>----------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Agree/strongly agree % (N)</td>
<td>Disagree/strongly disagree % (N)</td>
<td>Agree/strongly agree % (N)</td>
</tr>
<tr>
<td>Insensitive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social network</td>
<td>14 (181)</td>
<td>79 (1002)</td>
<td>10 (128)</td>
</tr>
<tr>
<td>Cancer survivor</td>
<td>15 (34)</td>
<td>78 (172)</td>
<td>10 (23)</td>
</tr>
<tr>
<td>Placing the blame</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social network</td>
<td>17 (218)</td>
<td>73 (931)</td>
<td>14 (182)</td>
</tr>
<tr>
<td>Cancer survivor</td>
<td>20 (45)</td>
<td>72 (159)</td>
<td>18 (39)</td>
</tr>
<tr>
<td>Interfering</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social network</td>
<td>12 (148)</td>
<td>83 (1057)</td>
<td>10 (126)</td>
</tr>
<tr>
<td>Cancer survivor</td>
<td>15 (33)</td>
<td>81 (179)</td>
<td>10 (22)</td>
</tr>
<tr>
<td>Unnecessary</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social network</td>
<td>13 (165)</td>
<td>79 (1000)</td>
<td>10 (121)</td>
</tr>
<tr>
<td>Cancer survivor</td>
<td>17 (38)</td>
<td>78 (173)</td>
<td>11 (24)</td>
</tr>
</tbody>
</table>

Where scores do not total 100% this is due to ‘don’t know’ responses
The mean attitude scores for the whole sample were 1.18 (SD=0.84) for physical activity, 1.24 (SD=0.83) for healthy eating and 1.16 (SD=0.87) for weight loss (range -3 to 3). Attitudes were slightly more positive towards advice on healthy eating than physical activity (p<.001) or weight loss (p<.001). There were no differences between attitudes to physical activity or weight loss advice (p=.289).

8.4.3 Differences in attitudes

Differences in attitude scores by demographic characteristics and cancer experience are shown in Table 8.3. Younger respondents had slightly more positive attitudes to healthy eating advice (p<.01), and respondents with a university education had slightly more positive attitudes across all behaviours (p<.01). There were no differences between social network members and cancer survivors in the adjusted analyses.

The parametric assumptions for the variables in the ANCOVA were violated. However, the log and square root transformations were both unsuccessful in resolving the issues with normality or homogeneity of variance. Therefore, the results above are for the ANCOVA using the raw data.
| Table 8.3 | Comparison of mean attitude scores (range -3 to 3) by demographics and cancer experience in multivariable analysis |
|-----------|-------------------------------------------------|-------------------------------------------------|-------------------------------------------------|
| Physical activity | Healthy eating | Weight loss |
| M (SE) b | F (df) | p | M (SE) b | F (df) | p | M (SE) b | F (df) | p |
| **Age** | | | | | | | | | |
| ≤64 years | 1.21 (0.03) | 1.30 (0.03) | 1.18 (0.03) | | | | | |
| 65+ years | 1.15 (0.03) | 2.12 (1) | .146 | 1.18 (0.03) | 7.83 (1) | .005 | 1.14 (0.03) | 0.54 (1) | .462 |
| **Gender** | | | | | | | | | |
| Male | 1.18 (0.03) | 1.23 (0.03) | 1.18 (0.03) | | | | | |
| Female | 1.18 (0.03) | 0.00 (1) | .988 | 1.25 (0.03) | 0.17 (1) | .681 | 1.15 (0.03) | 0.48 (1) | .487 |
| **SES** | | | | | | | | | |
| Lower (C2,D,E) | 1.16 (0.03) | 1.23 (0.03) | 1.16 (0.03) | | | | | |
| Higher (AB,C1) | 1.20 (0.04) | 0.60 (1) | .441 | 1.25 (0.04) | 0.15 (1) | .702 | 1.15 (0.04) | 0.05 (1) | .828 |
| **Ethnicity** | | | | | | | | | |
| Non-White | 1.09 (0.16) | 1.01 (0.26) | 1.00 (0.16) | | | | | |
| White | 1.18 (0.02) | 0.35 (1) | .554 | 1.25 (0.02) | 2.35 (1) | .126 | 1.16 (0.02) | 0.99 (1) | .321 |
Table 8.3 Comparison of mean attitude scores (range -3 to 3) by demographics and cancer experience in multivariable analysis

<table>
<thead>
<tr>
<th></th>
<th>Physical activity</th>
<th></th>
<th>Healthy eating</th>
<th></th>
<th>Weight loss</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SE)^b</td>
<td>F (df)</td>
<td>p</td>
<td>M (SE)^b</td>
<td>F (df)</td>
<td>p</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None/school only</td>
<td>1.15 (0.03)</td>
<td></td>
<td>1.22 (0.02)</td>
<td></td>
<td>1.14 (0.03)</td>
<td></td>
</tr>
<tr>
<td>Degree or above</td>
<td>1.32 (0.06)</td>
<td>5.88 (1)</td>
<td>.015</td>
<td>1.36 (0.06)</td>
<td>4.08 (1)</td>
<td>.043</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unmarried</td>
<td>1.18 (0.04)</td>
<td></td>
<td>1.24 (0.03)</td>
<td></td>
<td>1.17 (0.04)</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>1.18 (0.03)</td>
<td>0.04 (1)</td>
<td>.850</td>
<td>1.24 (0.03)</td>
<td>0.03 (1)</td>
<td>.857</td>
</tr>
<tr>
<td><strong>Cancer experience</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social network</td>
<td>1.18 (0.02)</td>
<td></td>
<td>1.24 (0.02)</td>
<td></td>
<td>1.16 (0.03)</td>
<td></td>
</tr>
<tr>
<td>Cancer survivor</td>
<td>1.17 (0.06)</td>
<td>0.03 (1)</td>
<td>.868</td>
<td>1.27 (0.06)</td>
<td>0.40 (1)</td>
<td>.526</td>
</tr>
</tbody>
</table>

Adjusted for all demographic factors and cancer experience
8.5 Discussion

This was the first study to explore attitudes towards lifestyle advice in people who have someone close to them who has been diagnosed with cancer; their ‘social network members’. The results of this study showed that social network members recruited through a population-based survey have positive attitudes towards doctors giving lifestyle advice to patients who have recently completed cancer treatment. The majority of respondents (over 80%) saw lifestyle advice as helpful and believed that doctors had a duty to provide it. Fewer than 15% thought it would be insensitive and only 14-18% identified the possibility of appearing to blame the patient. Men and women were equally supportive of lifestyle advice, and the only demographic differences observed were slightly more positive attitudes towards advice among younger and more highly educated respondents. The findings were equally positive for the small sample of cancer survivors and there were no differences in attitudes towards advice between the two groups.

As survivorship care shifts towards supported self-management, the views of cancer survivors’ social networks are likely to be an increasingly important factor in how well lifestyle advice is received. Given that the findings of this study show that social networks are largely positive towards lifestyle advice, it is hoped that they will help cancer survivors to make lifestyle changes. This may be by providing social support to help them make lifestyle changes, as this has been found to be effective in previous studies (Barber, 2012; H.-K. Yang et al., 2013). This support could be emotional, such as providing encouragement, or it could be practical, such as becoming an exercise partner. The fact that social networks in this study were positive about lifestyle advice for cancer survivors, also suggests that they are informed about the potential benefits of a healthy lifestyle for this population. This is encouraging as not only are they an important source of information and advice for cancer survivors (Matthews et al., 2002; Pecchioni & Sparks, 2007), but, in line with psychological theory (Ajzen, 1985), their views have been shown to influence their behaviour (Beagan & Chapman, 2004).

As previous studies have indicated that health professionals may have some concerns about discussing lifestyle advice with their cancer patients (Macmillan Cancer
Support/ICM, 2011; Miles et al., 2010), it is encouraging that the findings of this study were so positive. This should help doctors feel more confident that not only do most cancer patients welcome advice on diet, physical activity and weight, but that their family and friends are also likely to be supportive. It is hoped that these results will help counter some of their concerns that giving lifestyle advice would be perceived as implying blame or make the patient feel guilty about their diagnosis. This may make them more receptive to the idea of discussing lifestyle with their patients.

Although the majority of participants in this study were positive about lifestyle advice for cancer survivors, it is important to acknowledge that some still had concerns. In particular, a considerable proportion of social network members (18%) and cancer survivors (24%) agreed that advice about weight loss may be perceived as blaming the patient. It is therefore important that health professionals are appropriately trained to discuss weight and deliver advice in a sensitive manner. Weight is a particularly difficult issue for health professionals to discuss because, as described previously, although the WCRF lifestyle guidelines recommend weight loss for cancer survivors who are overweight (WCRF & AICR, 2007), this is not well supported by the literature (Caan et al., 2005, 2012b). In the absence of good trial evidence, health professionals should be cautious about recommending weight loss and instead may want to focus on healthy eating and physical activity. Approaching the topic in this way may also help minimise any feelings of blame.

This study benefited from a novel approach of identifying members of the social networks of individuals with cancer through a population survey. This reduced the bias associated with patients nominating members of their social network and probably achieved a broader range of respondents. By recruiting through a survey that included a range of topics, it is less likely that agreement to participate was biased by attitudes to cancer.

8.5.1 Limitations

This study also had a number of limitations. Detailed response rate information was not available from TNS. The results only reflect the experience of individuals who agreed to
take part and may not be representative of the British population, as nothing is known about the people who declined to participate in the survey.

The attitude questions were hypothetical and very general. Participants were asked broad questions about advice on physical activity, diet and weight loss, rather than their views on specific recommendations. Although respondents may have positive attitudes about advice in general (for example, physical activity is beneficial), these attitudes may vary for specific recommendations (for example, be moderately physically active five times per week). Attitudes may also vary according to the format of the advice and who provides it. Social network members were also not asked to think about a specific individual with cancer, so it is possible that their responses may be different in the context of a particular individual.

The comparison of mean attitude scores was conducted using an ANCOVA even though the parametric assumptions were violated. This is because there are no simple non-parametric equivalent tests and transforming the data did not successfully correct for the distributional problems or unequal variances. Although these results do not affect the main finding that social networks are positive towards lifestyle advice for cancer survivors, these comparisons should be interpreted with caution.

The attitude questions asked specifically about advice from doctors and did not include other health professionals, such as nurses and allied health professionals, who may also be well placed to give cancer survivors advice about lifestyle. Participants’ views on advice may therefore also vary according to who provides the advice. It is possible that patients and those close to them would feel that the medical teams dealing with their cancer care are particularly well-placed to provide safe and appropriate advice. Study 6 will explore some of these issues in more detail.

There were no questions asking about advice on smoking or alcohol. The decision not to include these was based on the number of questions that there was space for within the whole questionnaire. Physical activity and diet were chosen as these have received the most research attention in the cancer survivorship literature, and are applicable to all groups of survivors and not just those who drink or smoke. Weight loss was included
because of the lack of clear evidence and controversy over its benefits for cancer survivors. Although it was interesting to examine views on weight loss advice, it would also be useful to know about views on weight management in general, particularly as the evidence suggests weight maintenance is preferable for cancer survivors.

The group identified as cancer survivors was small, as would be expected in a population sample of this size. This meant that it was not possible to make generalisations about the views of cancer survivors, although it allowed me to ascertain whether the patients and social network members had strikingly different attitudes. The study also lacked the clinical detail that would be available if recruitment had been through a clinical setting, such as how views vary according to cancer site. In the next chapter I report the results of a larger patient survey that attempts to overcome some of these limitations (Study 6).

8.5.2 Conclusions

Overall, the results of this study show that lifestyle advice in the cancer context is generally regarded as beneficial by the social network members of individuals with cancer, as well as by survivors themselves. These findings should help counter health professionals’ doubts about the acceptability of diet and physical activity advice, making them more receptive to the idea of discussing lifestyle with their patients. However, health professionals should receive training on how best to discuss lifestyle with their patients, to ensure that their advice has the maximum benefits.
CHAPTER 9: STUDY 6: CANCER SURVIVORS’ CURRENT LIFESTYLE, EXPERIENCE OF LIFESTYLE ADVICE, AND INTEREST IN LIFESTYLE INFORMATION

9.1 Introduction

Study 1 found little evidence that cancer survivors make positive changes to their lifestyle following a cancer diagnosis and, as described in Chapter 2, previous studies have also found that the health behaviours of cancer survivors are suboptimal (Bellizzi et al., 2005; Blanchard et al., 2008; Courneya, Katzmarzyk, et al., 2008; Eakin et al., 2007; Grimmett et al., 2009; Wang et al., 2015). In these studies, the proportion of cancer survivors meeting specific recommendations ranged from 30% to 64% for physical activity, 15% to 39% for fruit and vegetables, 48% to 54% for animal foods, 89% to 92% for alcohol consumption and 77% to 92% for smoking (Blanchard et al., 2008; Bruno et al., 2015; Wang et al., 2015). Few studies have examined the factors associated with meeting lifestyle guidelines, although there is some evidence that older cancer survivors (aged ≥ 65 years) are more likely to meet smoking recommendations but less likely to meet physical activity guidelines than their younger counterparts (Niu et al., 2015). Understanding more about these factors would help determine which groups of survivors are most in need of lifestyle change, and allow for interventions to be targeted accordingly.

Study 2 used qualitative methodology to examine cancer survivors’ beliefs about lifestyle and how these had influenced their lifestyle choices. This study found that many cancer survivors had been motivated to make lifestyle changes as a result of their diagnosis, but when probed, most acknowledged that changes had been modest. However, little is known about cancer survivors’ perceptions of their current lifestyle and whether they think they should be making changes. Examining whether cancer survivors think they should change their lifestyle would help understand how receptive they may be to receiving information about lifestyle change. Although cancer survivors may be positive about lifestyle advice in general (Studies 2 and 5), if they do not think it applies to them they may not take note of such advice. In addition, determining
whether those who are not meeting recommendations think they need to change would help target interventions to improve awareness of lifestyle recommendations.

Few participants in Study 2 had received any professional advice about lifestyle since they were diagnosed with cancer. This finding is similar to reports from previous qualitative studies which have found that cancer survivors report a lack of information about lifestyle (Anderson, Steele, et al., 2013; James-Martin et al., 2014). In a survey of cancer survivors in Canada, only 28% reported that their oncologist had initiated a discussion about exercise and 58% reported that exercise was not discussed at all (Jones & Courneya, 2002). Study 4 in this thesis found that although 87% health professionals reported giving some patients advice on lifestyle, few gave advice to more than 50% of their patients, suggesting that many patients still go without. Gaining a more detailed understanding of the type of advice cancer survivors receive about lifestyle, who they receive it from, and how satisfied they are with the information, would help determine where these gaps in information lie.

Studies 2 and 5 both found that cancer survivors were positive about receiving lifestyle advice. Previous studies have also found evidence that cancer survivors may be interested in lifestyle, although there is considerable variation in numbers across studies. A patient-reported outcome measures survey conducted as part of the National Cancer Survivorship Initiative found that only around 20% cancer survivors were interested in advice on diet and lifestyle and fewer were interested in advice on physical activity (Department of Health & NHS, 2012). However, this was part of a ‘tick all that apply’ question so participants did not explicitly say that they were not interested. In contrast, another study found that as many as 75% cancer survivors may be interested in exercise counselling at some point following their diagnosis (Gjerset et al., 2011). Qualitative studies have also suggested that cancer survivors would like information on lifestyle and health promotion (Anderson, Steele, et al., 2013; James-Martin et al., 2014). Quantitatively assessing cancer survivors’ interest in information on different lifestyle topics would provide clarification on some of these differences, and provide an indication of how receptive they may be to different types of information. Examining associations between meeting lifestyle recommendations and wanting lifestyle
information would help determine which groups of cancer survivors may be most receptive.

If cancer survivors are to routinely be given information or advice about lifestyle, it is important to determine their preferences with regard to such advice. An analysis of 458 cancer survivors in the Health Information National Trends Survey found that the internet was their preferred source of information (51%), followed by print materials (23%), their health care provider (19%) and other sources, including friends and family (7%) (Hartoonian et al., 2014). In contrast, a survey of 1,284 cancer survivors in Norway found that 95% preferred for exercise counselling to be face-to-face with an exercise specialist, although they were only asked about their first preference and not about their interest in other sources (Gjerset et al., 2011). In the UK, a qualitative study found that colorectal cancer patients found information from ‘expert patients’ to be most useful (Anderson, Steele, et al., 2013). Examining cancer survivors’ interest in a range of different sources of information would help determine not only their first choice, but also their interest in other options that may be more viable in routine care.

Determining cancer survivors’ preferred timing of lifestyle information is also crucial in order to capitalise on the ‘teachable moment’, when they may be most receptive of advice (McBride & Ostroff, 2003). The qualitative study of colorectal cancer survivors described above indicated that some participants were interested in receiving lifestyle advice at the end of treatment, although it was not clear if this view was shared by all participants (Anderson, Steele, et al., 2013). In the study of interest in exercise counselling, 47% preferred to receive it immediately after treatment, followed by 23% who preferred three to six months after treatment (Gjerset et al., 2011).

In summary, although several studies have indicated that the health behaviours of cancer survivors are suboptimal, little is known about the proportion of cancer survivors who are meeting specific guidelines for aspects of lifestyle other than fruit and vegetable intake, physical activity and smoking (WCRF & AICR, 2007). In addition, little is known about the factors determining whether cancer survivors are meeting these recommendations. Determining which groups of survivors are less likely to meet
recommendations would help allow for interventions to be targeted accordingly. It is also not known if cancer survivors’ current health behaviours are associated with thinking they need to change their lifestyle or wanting advice about lifestyle. It is possible that those who think they should change and want advice are those who are already motivated and meeting lifestyle guidelines. Alternatively, those who are not meeting lifestyle guidelines may be more interested in lifestyle advice, as they may be motivated to change. Finally, studies to date have found inconsistent results about cancer survivors’ preferred sources of information. Therefore, examining their interest in a variety of sources of lifestyle information should help determine which methods may be most effective.

9.2 Aim

The aim of this study was therefore to gain a more detailed understanding of the current lifestyle of cancer survivors, the advice they had received about lifestyle and their interest in lifestyle information or advice. Specifically, it aimed to answer the following questions: 1) What proportion of cancer survivors are meeting each of the WCRF lifestyle recommendations, what factors are associated with meeting these recommendations, and do cancer survivors report making changes to their lifestyle following their diagnosis? 2) What are cancer survivors’ perceptions of their current lifestyle and does whether they are meeting the WCRF recommendations influence these perceptions? 3) What proportion of cancer survivors have received a recommendation about lifestyle since their cancer diagnosis, and how satisfied were they with the information they were given? 4) What proportion of cancer survivors are interested in receiving lifestyle information, does whether they are meeting the WCRF recommendations influence their interest, and what are their preferences for this information?

9.3 Methods

9.3.1 Ethical approval

This study received favourable approval from the NHS National Research Ethics Committee South Central - Oxford B, reference 14/SC/1369 (Appendix 9.1). The study
was also adopted onto the North Thames Clinical Research Network (CRN) portfolio, reference 17783.\textsuperscript{14} Local R&D approval was obtained from each participating NHS Trust (Appendix 9.2).

### 9.3.2 Design and participants

This survey is part of a larger study, Advancing Survivorship after Cancer: Outcomes Trial (ASCOT), being conducted by a team of researchers, including myself, in the HBRC at UCL. The ASCOT study aims to send questionnaires to 5,000 patients diagnosed with primary breast, prostate or colorectal cancer in 2012 or 2013 at an NHS Trust in London or Essex. Patients have the option of completing the paper version of the questionnaire they are sent in the post or alternatively they can complete it online. The online version was created using the Survey Monkey website.\textsuperscript{15} The ASCOT study is ongoing until April 2017, so the full results are not yet available. The results presented in this chapter are from the questionnaires of patients diagnosed at one of three NHS trusts (Southend University Hospital NHS Foundation Trust, Mid Essex Hospital Services NHS Trust and Basildon and Thurrock University Hospitals NHS Trust). For practical reasons, I included questionnaires that had been returned and entered to the dataset by July 2015.

Due to patient confidentiality, I was not allowed access to the patients’ names and contact details in order to post the questionnaires directly. Instead, the research team within the NHS Trusts identified eligible patients and posted the questionnaires to them. I prepared the questionnaire packs and provided these to the research teams in advance.

### 9.3.3 Recruitment

Initial contact with the participating NHS trusts was made via a contact from a collaborator on the ASCOT study. I then met with the research teams at each trust to ensure they were willing to help with identifying patients and posting the questionnaires. Depending on the site, this work was carried out by research nurses, nurses,...

\textsuperscript{14} \url{http://public.ukcrn.org.uk/Search/StudyDetail.aspx?StudyID=17783}

\textsuperscript{15} \url{https://www.surveymonkey.net/}
data analysts or administrative staff. As the ASCOT study was adopted onto the CRN portfolio, the research teams were compensated for their role in recruiting patients.

The Somerset hospital database was used to identify eligible patients. The research teams at the NHS trusts were asked to identify all patients diagnosed with primary breast, prostate or colorectal cancer in 2012 or 2013. These years were chosen in order to ensure that the sample had been through the cancer care pathway relatively recently, but to minimise the chance that they were still undergoing primary treatment. Patients were only excluded if they were deceased or the staff deemed them inappropriate to be sent a questionnaire (e.g. they had previously stated that they did not want to take part in research studies). The inclusion criteria were kept deliberately broad as I was interested in characterising the health behaviours and experience of a cross-section of cancer survivors, rather than limiting the results to a specific group.

Once the research teams had identified their final lists of eligible patients, they provided me with the number of patients on these lists so I could prepare the appropriate number of questionnaire packs. These packs included the questionnaire and a self-addressed envelope so the patients could return the questionnaires directly to me. No consent forms were included as completing and returning the questionnaire was used as an indicator of consent. On receiving the questionnaire packs, the research teams added a letter of invitation addressed personally to the patient and signed by their consultant (Appendix 9.3). I provided the wording of this letter for the research teams to use. This letter also contained a link to the online version of the questionnaire in case the patient preferred this over the paper version. The research teams then added the patients’ names and addresses to the envelopes and posted the packs.

All questionnaires were identifiable by a unique ID number and these were used to keep a record of which questionnaires had been sent and returned. The research teams kept a record of which ID numbers corresponded to each patient (as I did not have access to the patient names). In order to maximise the response rate, participants who had not returned their questionnaire within a month received a reminder by telephone. The
research teams were notified when the questionnaires had not been returned and they dealt with the reminders accordingly. A flow of patients is shown in Figure 9.1.
Patients identified as eligible: 
N=3,519
(531 Basildon, 1,455 Mid Essex, 1,533 Southend)

Questionnaires sent by 6\textsuperscript{th} July 2015
N=2,460

Died since questionnaire sent n=6
Moved house n=1

Questionnaires returned by 6\textsuperscript{th} July 2015
N= 1,009
(154 Basildon, 458 Mid Essex, 388 Southend)

Returned blank n=9

Completed questionnaires as of 6\textsuperscript{th} July 2015
N= 1,000

Questionnaires added to dataset as of 6\textsuperscript{th} July 2015 and used in the analyses for this study
N= 731
9.3.4 Questionnaire development and piloting

Where available, validated, published measures were used as these have robust measurement properties and are therefore appropriate for measuring the concepts of interest. If no validated measures were available, existing measures were adapted. If there were no existing measures, I developed my own questions and obtained feedback on these from my supervisors, Professor Jane Wardle, Dr Rebecca Beeken and Dr Abigail Fisher, and from other colleagues in the HBRC.

Once the initial questionnaire had been developed, a paper version was piloted with one breast, one colorectal and one skin cancer survivor. The latter was keen to help and give feedback despite not being eligible for the survey. These were recruited through existing contacts at London Cancer and St Bartholomew’s Hospital in London. Patients were asked to complete the questionnaire and give feedback on its content, length and their understanding of the questions. Two patients completed the questionnaire remotely and provided this feedback by email. Another completed the questionnaire in my presence and was asked to ‘think aloud’ by voicing any comments or suggestions as they went through.

Overall, patients did not report issues with the length of the questionnaire. The patient who completed it in my presence took 18 minutes and 30 seconds to complete it, and another said it took them 15 minutes to read through it and anticipated it would take 30 minutes to complete. One patient commented that they would have preferred an online version of the questionnaire which led to this being created. Another suggested that wording should be clarified, for example, it was suggested that ‘whole milk’ be changed to ‘full-fat’ as this was better understood. Patients also made suggestions of other topics to be included in the questionnaire, including sex life, organic foods, alternative medicine, and dietary supplements. Although these were considered, it was not possible to accommodate them as they were beyond the scope of this study.

9.3.5 Measures

A full copy of the questionnaire can be found in Appendix 9.4. As this questionnaire formed part of a larger study (ASCOT), it included several additional measures that were
not used in this study. Only measures included in the analyses for this study are described below.

**9.3.5.1 Socio-demographic**

Socio-demographic questions included age (‘How old are you’), sex, ethnicity (‘Which of these best describes your ethnic group’ with response options: White British/White Irish/Any other White/Black African/Black Caribbean/Any other Black/Indian/Bangladeshi/Pakistani/Chinese/Any other Asian/Mixed White and Black African/Mixed White and Black Caribbean/Mixed White and Asian/Any other mixed), marital status (‘What is your current marital status’ with response options: married or living with partner/separated/divorced/widowed/single) and level of education (‘What educational or professional qualifications do you have (please tick all that apply)’ with response options: GCSE, school certificate, O level or CSE/Vocational qualifications (e.g. NVQ1+2)/A level or higher school certificate or equivalent (e.g. NVQ3)/Bachelor Degree or equivalent (e.g. NVQ4)/Masters or PhD or PGCE or equivalent/Still studying/No formal qualifications).

**9.3.5.2 Cancer and general health**

Patients were asked ‘What type of cancer have you been diagnosed with (please tick all that apply)’ with response options: breast/prostate/bowel (colorectal)/other. For each one they selected they were asked to report the approximate month and year of diagnosis. If this information was missing it was obtained from the NHS trusts, who retrieved it from patient records.

Patients were then asked to think about their most recent cancer and were asked to report the stage at diagnosis (‘At the time of your diagnosis, what stage was this cancer’ with response options: 1/2/3/4/don’t know). They were then asked when they completed treatment (‘How long is it since you completed your main treatment for this cancer’ with response options: I am still having my main treatment/it is less than 3 months since my main treatment/it is between 3 and 12 months since my main treatment/it is between 1 and 5 years since my main treatment/on active surveillance/don’t know or can’t remember).
The final question in this section asked about other health problems (‘Have you ever had any of the following health problems (please tick all that apply)’ with response options: osteoporosis/diabetes/asthma/emotional or psychiatric illness/stroke/Parkinson’s disease/Alzheimer’s disease or dementia/lung disease/arthritis/angina/heart attack/heart murmur/irregular heart rhythm/any other heart trouble/another cancer/other).

9.3.5.3 Physical activity

Physical activity was measured using an adapted version of the Godin Leisure-Time Exercise Questionnaire (Godin LTEQ) (Godin & Shephard, 1985). This measure has been used extensively in the cancer survivorship literature (Courneya, Booth, et al., 2008; Courneya et al., 2012; Hawkes et al., 2013; Karvinen, Courneya, North, & Venner, 2007; Trinh, Plotnikoff, Rhodes, North, & Courneya, 2011) and has been shown to have favourable reliability and validity compared with nine other self-report measures (Jacobs, Ainsworth, Hartman, & Leon, 1993).

The Godin LTEQ asks patients to report how often in an average week they engage in mild, moderate and strenuous exercise for at least 15 minutes during their free time. As many cancer survivors may struggle to define an ‘average’ week due to changes as a result of their cancer and treatment, I altered the wording to specify an average week during the past month. In addition, as the Godin LTEQ does not ask about the duration of exercise, this was added to the measure. The final questions can be found in Appendix 9.5.

Patients were also asked about how their current physical activity levels compared with before they were diagnosed with cancer (‘Is the amount of physical activity you do nowadays...’ with response options: more than before you were diagnosed with cancer/about the same as before you were diagnosed with cancer/less than before you were diagnosed with cancer’). This question was adapted from a previous questionnaire developed by researchers in the HBRC. Another question asked ‘Which of the following best describes you at the present time’ with response options: I think I should be doing more physical activity/I think I should be doing less physical activity/I don’t think I need
to change my physical activity/don’t know. This question was developed specifically for this study.

9.3.5.4 Diet

Diet was assessed predominantly using the Dietary Instrument for Nutrition Education (DINE) (Roe, Strong, Whiteside, Neil, & Mant, 1994). This measure was chosen through discussion with a Clinical Research Dietitian in the HBRC, Dr Helen Croker, who conducted a review of validated food frequency questionnaires and a review of dietary assessments that had been used in studies with cancer survivors. The DINE was chosen as a brief measure was required to avoid patient burden from the questionnaire becoming too long. The DINE was adapted to ensure that it captured a range of ethnically diverse foods and, where possible, included all foods in the WCRF guidelines (WCRF & AICR, 2007). A review of questions in the National Diet and Nutrition Survey\(^\text{16}\) and the Low Income Diet and Nutrition Survey\(^\text{17}\) was also conducted to ensure that the main components of the UK diet were included.

The adapted DINE included 12 questions to assess dietary fibre (e.g. ‘About how many times a week do you eat a serving of pasta, rice, noodles or couscous’ with response options: less than once a week or never/1-2 per week/3-5 per week/6 or more per week), and 19 questions to assess total fat (e.g. ‘About how many times a week do you eat a serving of cheese (any except cottage cheese)’ with response options: less than once a week or never/1-2 per week/3-5 per week/6 or more per week). A list of the fibre and total fat questions can be found in Appendices 9.6 and 9.7 respectively.

Two questions from the DINE were also used to assess intake of red meat (e.g. ‘About how many times a week do you eat a serving of beef (excluding burgers), pork, lamb or goat’ with response options: less than once a week or never/1-2 per week/3-5 per week/6 or more per week). A list of items and scoring can be found in Appendix 9.8.

\(^{16}\)http://nationaldiet.co.uk/

One question from the DINE was used to assess intake of processed meat (‘About how many times a week do you eat a serving of bacon, ham, salami, hot dogs, or sausages’ with response options: less than once a week or never/1-2 per week/3-5 per week/6 or more per week). Details of the scoring can be found in Appendix 9.9.

Four questions from the DINE were used to assess intake of sugar. One of these asked about snacks (‘About how many times a week do you eat a serving of biscuits, chocolate or savoury snacks (e.g. crisps, sev, Bombay mix, nuts)’ with response options: less than once a week or never/1-2 per week/3-5 per week/6 or more per week). The other three asked about cereals (e.g. ‘About how many times a week do you have sugary, chocolate, rice or corn cereals (e.g. Frosties, Coco Pops, Sugar Puffs, Corn Flakes, Rice Crispies, Special K’).

In addition to those in the DINE, three further questions were included to assess sugar intake. Two were taken from a previous questionnaire developed by researchers in the HBRC (McGowan, Croker, Wardle, & Cooke, 2012). These measured the consumption of sugar sweetened beverages (e.g. ‘How often do you drink regular squash, cordials, fizzy drinks and juice drinks’ with response options: never or rarely/once a week/2-3 times a week/4-6 times a week/once a day/twice a day/3 or more times a day). Another question asked about added sugar (‘About how many rounded teaspoons of sugar, honey, or syrup do you usually use in a day (e.g. in coffee, tea, milk, bread, cereals, fruit)’ this was an open question where patients were asked to write the total number of teaspoons per day. This question was adapted from the National Health and Nutrition Examination Survey (NHANES) Dietary Screener Questionnaire (National Cancer Institute, 2010). A full list of the sugar questions can be found in Appendix 9.10.

Fruit and vegetable intake was assessed using a two item dietary questionnaire (Cappuccio et al., 2003; Steptoe et al., 2003). This measure has been shown to have sufficient validity when compared to objective biological measures of fruit and vegetable consumption (Cappuccio et al., 2003). Patients were given examples of portions and asked ‘Over the past month, how many portions of [fruit/vegetables] did you usually eat’ with response options: less than 1 per week/1 per week/2-3 per week/4-6 per
week/1 per day/2 per day/3 or more per day. The full questions and examples can be found in Appendix 9.11.

Patients were also asked about how their current diet compared with their diet before they were diagnosed with cancer (‘Would you say your diet now is...’ with response options: healthier than before you were diagnosed with cancer/about the same as before you were diagnosed with cancer/less healthy than before you were diagnosed with cancer). This question was adapted from a previous questionnaire developed by researchers in the HBRC. Another question asked ‘Which of the following best describes you at the present time’ with response options: I think I should have a healthier diet/I don’t think I need to change my diet/don’t know. This question was developed specifically for this study.

9.3.5.5 Alcohol

Alcohol was assessed using an adapted version of the Alcohol Use Disorders Identification Test Consumption Questions (AUDIT-C), a three item screening test for active alcohol abuse or dependence and/or heavy drinking (Bush et al., 1998). This measure has been found to perform better than the full length AUDIT questionnaire at identifying heavy drinkers who may benefit from brief primary care interventions. For this study, the questions on frequency (‘How often do you have a drink containing alcohol’ with response options: never/monthly or less/2-4 times per month/2-3 times per week/4+ times per week) and quantity (‘How many units of alcohol do you drink on a typical day when you are drinking’ with response options: 1-2/3-4/5-6/7-9/10+) were used to calculate the number of alcoholic drinks consumed per day (see Section 9.2.6.1 and Appendix 9.12 for more details on the scoring). The frequency question was adapted to include the option ‘every day’ for the purpose of calculating who was meeting the WCRF recommendations. The measure also includes pictures depicting how much of certain drinks constitute one unit of alcohol, and more than one unit of alcohol. The full questions and pictures can be found in Appendix 9.4.

Patients were also asked about how their alcohol consumption compared with before they were diagnosed with cancer (‘Is the amount of alcohol you drink nowadays...’ with
response options: more than before you were diagnosed with cancer/about the same as before you were diagnosed with cancer/less than before you were diagnosed with cancer). This question was adapted from a previous questionnaire developed by researchers in the HBRC. Another question asked ‘Which of the following best describes you at the present time’ with response options: I think I should drink less alcohol/I don’t think I need to change my alcohol consumption/don’t know. This question was developed specifically for this study.

9.3.5.6 Tobacco

Tobacco use was assessed using questions adapted from the Health Survey for England (Craig et al., 2009). Patients were asked ‘Do you smoke/chew tobacco at all nowadays’ with response options: yes/no. This question was adapted to include tobacco chewing in order to align it with the WCRF guidelines (WCRF & AICR, 2007). Those who responded positively were then asked ‘Have you tried to quit since you were diagnosed with cancer’ with response options: yes/no. This question was developed for this study with the aim of examining how a cancer diagnosis may have influenced quit attempts. They were also asked ‘If you currently smoke/chew tobacco, which of the following best describes you at the present time’ with response options: I think I should quit smoking or chewing tobacco/I don’t think I need to change my smoking or tobacco habits/don’t know. This question was developed specifically for this study.

9.3.5.7 Anthropometric measures

Patients were asked to self-report their height (in centimetres or feet and inches) and weight (in kilograms or stone and pounds). In addition, they were asked how their weight compared with before they were diagnosed with cancer (‘Is your weight nowadays...’ with response options: more than before you were diagnosed with cancer/about the same as before you were diagnosed with cancer/less than before you were diagnosed with cancer). This question was adapted from a previous questionnaire developed by researchers in the HBRC. Another question asked ‘Which of the following best describes you at the present time’ with response options: I think I should be trying to lose weight/I think I should be trying to gain weight/I don’t think I need to change my weight/don’t know. This question was developed specifically for this study.
9.3.5.8 **Lifestyle information or advice received**

The questions about lifestyle information or advice received were based on those in a previous questionnaire developed by researchers in the HBRC, and adapted for use in this study. Patients were asked ‘In the time since you were first diagnosed with cancer, did a health professional (e.g. doctor/nurse/physiotherapist/dietitian) ever recommend any of the following’. This was followed by a list of topics reflecting the WCRF guidelines (WCRF & AICR, 2007), including ‘doing more exercise’ and ‘eating more fruit and vegetables’ with response options: yes/no. A full list of questions can be found in Appendix 9.4. Those who responded positively to any of the questions were then asked a series of follow-up questions. The first was the open question ‘Do you remember what was suggested? Please provide any details you can in the space below’. The second asked ‘Do you remember who gave you the information? Please tick all that apply’ with response options: oncologist/surgeon/nurse/GP/dietitian/physiotherapist/other (please specify). The third asked ‘Please tick the option which best describes the amount of information you received’ with response options: too much/about right/not enough.

9.3.5.9 **Interest in lifestyle information or advice**

As with the previous section, the questions about interest in lifestyle information or advice were based on those in a previous questionnaire, which was developed by researchers in the HBRC. Patients were asked about their interest in advice on lifestyle topics reflecting the WCRF guidelines (‘How interested would you be in any information/advice to… [help you have a healthy diet/ help you maintain a healthy weight/help you increase your physical activity/help you stop smoking/help you reduce your alcohol consumption/help you adopt an overall healthy lifestyle]’ with response options: not at all interested/a little interested/somewhat interested/very interested/not applicable.

Patients were then asked about preferences for the timing and format of lifestyle advice. The timing question asked ‘When do you think would be the best time to offer information about lifestyle (e.g. diet, physical activity) to people diagnosed with cancer? Please tick one option’ with response options: before treatment starts/during
treatment/immediately after treatment/3-6 months after treatment/6-12 months after treatment/more than 1 year after treatment. The format question asked ‘Would you be interested in any of the following formats of information/advice about making lifestyle changes’ followed by a list of formats including ‘short leaflet (up to 5 pages)’ and ‘internet information’ with response options: not at all interested/a little interested/somewhat interested/very interested/extremely interested. A full list of questions can be found in Appendix 9.4.

9.3.6 Analyses

9.3.6.1 Data treatment

Age (≤65 years/>65 years), ethnicity (White British/other), marital status (married/other), education (some educational qualifications/no educational qualifications), and time since treatment (currently receiving treatment/not currently receiving treatment) were all dichotomised for the main analyses to aid interpretation. The health problems question was also categorised (no health problems/1 health problem/2 or more health problems). For the cancer stage question, stages 3 and 4 were combined as only a small number of patients had stage 4 disease (n=26). The response option ‘don’t know’ was coded as missing for this question.

The questions on weight, physical activity, diet, alcohol, and smoking were scored and dichotomised according to whether patients were meeting each of the WCRF recommendations. The cut-offs for each recommendation are described in Table 9.1. Unfortunately the items in the questionnaire were not sufficient to examine total salt intake so this recommendation was excluded. This was because measuring salt intake is extremely difficult and would involve multiple questions, which was beyond the scope of this questionnaire. The dietary supplement recommendation was also excluded as the focus of this study was on health behaviours and there is no evidence for a benefit of dietary supplements in cancer prevention.
### Table 9.1 Cut-offs for meeting each WCRF recommendation

<table>
<thead>
<tr>
<th>Category</th>
<th>Recommendation</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Body fatness</strong></td>
<td>Patients were considered to be meeting this recommendation if they had a BMI of between 18.5 and 25 (WCRF &amp; AICR, 2007).</td>
<td>Details of the BMI scoring can be found in Appendix 9.13.</td>
</tr>
<tr>
<td><strong>Physical activity</strong></td>
<td>Patients were considered to be meeting this recommendation if they did 210 minutes of moderate activity or 105 minutes of vigorous activity per week (or a combination of the two) (WCRF &amp; AICR, 2007).</td>
<td>Details of the physical activity scoring can be found in Appendix 9.5.</td>
</tr>
<tr>
<td><strong>Foods and drinks that promote weight gain</strong></td>
<td>Patients were considered to be meeting this recommendation if they met the daily recommended intakes of total fat and sugar. Total fat intake was determined using the scoring algorithm of the DINE questionnaire (Roe et al., 1994). A score of less than 30 on the DINE is considered to be equivalent to less than 35% of total energy intake from fat, which is in line with recommendations (FAO, 2010; Roe et al., 1994). Details of the total fat items and scoring can be found in Appendix 9.7. Sugar intake was determined using a scoring algorithm based on the NHANES Dietary Screening Questionnaire (National Cancer Institute, 2010). The World Health Organisation recommends that no more than 10% of total energy intake is from sugar (World Health Organization, 2015). Assuming a 2000 calorie diet for women and 2500 for men, this is equivalent to no more than 50g or 70g per day respectively. Details of the sugar items and scoring can be found in Appendix 9.10.</td>
<td></td>
</tr>
<tr>
<td><strong>Plant foods</strong></td>
<td>Patients were considered to be meeting this recommendation if they met the daily recommend intakes of fruit and vegetables and fibre. Patients consuming a total of five or more portions per day were considered to be meeting the recommendation for fruit and vegetable intake (WCRF &amp; AICR, 2007). Details of these items and scoring can be found in Appendix 9.11. Fibre intake was determined using the scoring algorithm of the DINE questionnaire (Roe et al., 1994). A score of more than 30 on the DINE is considered to be equivalent to more than 20g per day which is similar to the recommended intake of at least 18g per day (British Nutrition Foundation, 2015).</td>
<td></td>
</tr>
</tbody>
</table>
**Table 9.1** Cut-offs for meeting each WCRF recommendation

<table>
<thead>
<tr>
<th>Food Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Animal foods</td>
<td>Patients were considered to be meeting this recommendation if they met the daily recommend intakes of red meat and processed meat. Intake of red meat was determined from two items in the DINE questionnaire. Patients were considered to be meeting the recommendation if they consumed less than 500 grams per week (WCRF &amp; AICR, 2007). Details of these items and scoring can be found in Appendix 9.8. Intake of processed meat was determined from a single item in the DINE questionnaire. As the recommendation is to avoid processed meat, patients were only considered to be meeting this recommendation if they did not consume it (WCRF &amp; AICR, 2007). Further details of the item and scoring can be found in Appendix 9.9.</td>
</tr>
<tr>
<td>Alcoholic drinks</td>
<td>Patients were considered to be meeting this recommendation if they drank no more than one drink per day (women) or two drinks per day (men). Daily alcohol intake was calculated from items in the AUDIT-C questionnaire. Further details of the scoring can be found in Appendix 9.12.</td>
</tr>
<tr>
<td>Tobacco</td>
<td>Patients were considered to be meeting this recommendation if they were not a current smoker.</td>
</tr>
</tbody>
</table>

The response options to the questions about patients’ perceptions of their weight, physical activity, diet and alcohol (e.g. ‘Which of the following best describes you at the present time?’ with response options: I think I should be doing more physical activity/I think I should be doing less physical activity/I don’t think I need to change my physical activity/don’t know) were dichotomised to allow them to be used as outcome measures in the logistic regression analyses. For all of these questions the ‘don’t know’ option was coded as missing. For the weight question, the option ‘I think I should be trying to gain weight’ was coded as missing because only 3% selected this option. For the physical activity question, the option ‘I think I should be doing less physical activity’ was coded as missing as only 1% of patients selected this option.
The response options to the questions about interest in advice (e.g. ‘How interested would you be in any information/advice to...help you have a healthy diet’) were dichotomised into interested (a little interested/somewhat interested/very interested) and not interested (not at all interested). Not applicable was coded as missing. The same was done for the questions about specific formats of advice (‘Would you be interested in any of the following formats of information/advice about making lifestyle changes’), where response options were dichotomised to interested (a little interested/somewhat interested/very interested/extremely interested) and not interested (not at all interested).

9.3.6.2 Missing data

Some variables had a large amount of missing data, so values were imputed based on patients’ responses to other questions. The analyses reported in this chapter were conducted with the imputed variables, but where applicable they were repeated using the non-imputed variables and these results are presented in the appendices. Details of each of these imputations are described below.

As described above, the Godin LTEQ asks patients three questions about how often they engage in mild, moderate and strenuous exercise. However, a large number of patients only answered one of these questions. When this was the case, it was assumed that patients did not engage in the other types of exercise, and missing values were imputed as zero times per week. If none of the three questions had been answered, then missing values remained as missing.

Similar imputations were conducted for some of the dietary questions. Patients were asked how often they consumed three different types of cereal (sugary, oat/wheat and bran), however, several patients only answered one of these questions (even though there was an option for ‘none’). If patients reported consuming one type of cereal and left the other questions blank, then their missing responses were imputed as ‘none’. If none of the three questions were answered, or if patients only selected ‘none’ then missing values remained as missing. The same steps were followed for the questions about different types of milk (full-fat, semi-skimmed, 1% fat, skimmed and non-dairy).
and bread (white, brown, wholemeal). In addition, if patients reported that they consumed sugar-free squash but left the regular squash question blank, it was assumed that they did not drink regular squash and this was imputed as ‘none’. A full list of all of these items can be found in Appendix 9.4.

Imputations were also conducted for some of the lifestyle advice questions. Patients were asked how interested they were in receiving advice on six different lifestyle topics (diet, weight, physical activity, smoking, alcohol and overall healthy lifestyle). However, several patients only reported that they were interested in some of these options and left others blank (even though there was a ‘not interested’ option). When this was the case, it was assumed that they were not interested in the other topics, so these were imputed as ‘not interested’. If none of the six questions were answered, or if patients only selected ‘not interested’ then missing values remained as missing. The same steps were followed for the questions about preferred formats of advice. A full list of all of these items can be found in Appendix 9.4.

9.3.6.3 Descriptive data

Descriptive statistics were produced to determine the proportion of patients who were meeting each of the WCRF lifestyle guidelines, who reported changing their lifestyle since being diagnosed with cancer, and who thought they should be making changes to their lifestyle. In addition, they were produced to determine the proportion of those who reported receiving lifestyle advice, who they had received it from, what they thought of the amount of advice, whether they were interested in lifestyle information or advice, and their preferred formats and timing of such information or advice.

9.3.6.4 Main analyses

Multivariable logistic regression models were conducted to examine the socio-demographic factors associated with meeting each of the WCRF lifestyle guidelines (a separate model was conducted for each recommendation, with meeting/not meeting the recommendation as the outcome). Each of these models adjusted for age, sex, marital status and education. Similar multivariable models were conducted to examine the health characteristics associated with meeting each WCRF recommendation. Each
of these models adjusted for cancer type, stage of disease and number of other health problems.

For each multivariable model, checks were made for the presence of multicollinearity between the predictor variables and where this was present it is indicated in the text. In addition, a crosstabulation of the potential predictor variables was conducted to check the frequencies in each group and if any were less than one or more than 20% were less than five this is indicated in the text. Ethnicity and current treatment were not included in the models as too few patients were non-White British or currently receiving cancer treatment.

Univariate logistic regression models were conducted to examine associations between meeting each of the WCRF recommendations and whether patients thought they needed to change that behaviour (e.g. is meeting the physical activity recommendation associated with thinking they should change their physical activity levels). Further univariate models were conducted to examine associations between meeting each of the WCRF recommendations and wanting information or advice on that topic (e.g. is meeting the physical activity recommendation associated with wanting information or advice on physical activity).

9.4 Results

9.4.1 Response rate

The exact response rate is difficult to determine due to a time lag between the research teams at the NHS trusts sending out the questionnaires and notifying me that these had been sent. However, as of 6th July 2015 when I began my analysis, 2,460 questionnaires were known to have been sent to patients, and 1,000 had been returned, suggesting a response rate of 41%. However, not all of these could be added to the database on time, resulting in 731 questionnaires for the analyses.

9.4.2 Sample characteristics

The socio-demographic and health characteristics of the sample are shown in Table 9.2. The mean age of the sample was 66 years and the majority of patients were female.
(62%), married (69%) and White British (91%). Only 11% were university educated and 32% had no formal qualifications. The most common cancer type was breast cancer (47%), followed by 37% with colorectal cancer and 16% with prostate cancer. A large proportion of patients did not know the stage of their cancer (43%), but of those that did, the largest group reported having stage II disease (18%), followed by stage III (16%), stage I (15%) and stage IV (4%). The majority of patients (64%) had completed their main treatment for cancer one to five years ago. A range of different health problems were reported, but the most common were arthritis (24%), diabetes (10%) and asthma (10%).
### Table 9.2 Socio-demographic and health characteristics of the sample (N=731)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean ± SD</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>66.1 ± 12.5</td>
<td></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>38 (278)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>62 (452)</td>
<td></td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/living with partner</td>
<td>69 (507)</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>4 (30)</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>9 (65)</td>
<td></td>
</tr>
<tr>
<td>Separated</td>
<td>2 (13)</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>16 (116)</td>
<td></td>
</tr>
<tr>
<td><strong>Educational qualifications</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GCSE/School certificate/O-level/CSE</td>
<td>48 (352)</td>
<td></td>
</tr>
<tr>
<td>Vocational qualifications (e.g. NVQ1+2)</td>
<td>12 (87)</td>
<td></td>
</tr>
<tr>
<td>A-level/Higher school certificate or equivalent (e.g. NVQ3)</td>
<td>17 (125)</td>
<td></td>
</tr>
<tr>
<td>Bachelor Degree or equivalent (e.g. NVQ4)</td>
<td>11 (78)</td>
<td></td>
</tr>
<tr>
<td>Masters/PhD/PGCE or equivalent</td>
<td>3 (19)</td>
<td></td>
</tr>
<tr>
<td>Still studying</td>
<td>0.4 (3)</td>
<td></td>
</tr>
<tr>
<td>No formal qualifications</td>
<td>32 (230)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>23 (169)</td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>91 (668)</td>
<td></td>
</tr>
<tr>
<td>White Irish</td>
<td>3 (18)</td>
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</tr>
<tr>
<td>Any other White</td>
<td>3 (19)</td>
<td></td>
</tr>
<tr>
<td>Black African</td>
<td>2 (11)</td>
<td></td>
</tr>
<tr>
<td>Black Caribbean</td>
<td>1 (4)</td>
<td></td>
</tr>
<tr>
<td>Any other Black</td>
<td>0.1 (1)</td>
<td></td>
</tr>
<tr>
<td>Indian</td>
<td>0.3 (2)</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>0.1 (1)</td>
<td></td>
</tr>
<tr>
<td>Any other Asian</td>
<td>0.4 (3)</td>
<td></td>
</tr>
<tr>
<td>Mixed White and Asian</td>
<td>0.1 (1)</td>
<td></td>
</tr>
<tr>
<td>Any other</td>
<td>0.1 (1)</td>
<td></td>
</tr>
</tbody>
</table>
CHAPTER 9: CANCER SURVIVORS’ CURRENT LIFESTYLE AND VIEWS ON LIFESTYLE ADVICE

Table 9.2 Socio-demographic and health characteristics of the sample (N=731)

<table>
<thead>
<tr>
<th>Cancer diagnosis</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>47 (343)</td>
</tr>
<tr>
<td>Prostate</td>
<td>16 (119)</td>
</tr>
<tr>
<td>Colorectal</td>
<td>37 (269)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cancer stage</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>15 (110)</td>
</tr>
<tr>
<td>II</td>
<td>18 (130)</td>
</tr>
<tr>
<td>III</td>
<td>16 (115)</td>
</tr>
<tr>
<td>IV</td>
<td>4 (26)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>43 (311)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Treatment</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Still having main treatment</td>
<td>8 (57)</td>
</tr>
<tr>
<td>Less than 3 months since main treatment</td>
<td>1 (10)</td>
</tr>
<tr>
<td>3-12 months since main treatment</td>
<td>12 (84)</td>
</tr>
<tr>
<td>1-5 years since main treatment</td>
<td>64 (465)</td>
</tr>
<tr>
<td>On active surveillance</td>
<td>10 (70)</td>
</tr>
<tr>
<td>Don’t know/can’t remember</td>
<td>1 (7)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other health problems</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Osteoporosis</td>
<td>8 (61)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>10 (76)</td>
</tr>
<tr>
<td>Asthma</td>
<td>10 (73)</td>
</tr>
<tr>
<td>Emotional or psychiatric illness</td>
<td>6 (44)</td>
</tr>
<tr>
<td>Stroke</td>
<td>3 (22)</td>
</tr>
<tr>
<td>Parkinson’s disease</td>
<td>1 (6)</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>0.3 (2)</td>
</tr>
<tr>
<td>Lung disease</td>
<td>3 (20)</td>
</tr>
<tr>
<td>Arthritis</td>
<td>24 (174)</td>
</tr>
<tr>
<td>Angina</td>
<td>3 (23)</td>
</tr>
<tr>
<td>Heart attack</td>
<td>5 (34)</td>
</tr>
<tr>
<td>Heart murmur</td>
<td>3 (18)</td>
</tr>
<tr>
<td>Irregular heart rhythm</td>
<td>8 (56)</td>
</tr>
<tr>
<td>Any other heart trouble</td>
<td>2 (15)</td>
</tr>
<tr>
<td>Another cancer</td>
<td>8 (60)</td>
</tr>
<tr>
<td>Other</td>
<td>19 (141)</td>
</tr>
</tbody>
</table>

Percentages were derived from the total sample so where numbers do not total 100% this is due to missing data or ‘select all that apply’ questions. *Patients asked to select all that apply. Ethnicities only reported if they were selected by at least one patient.
9.4.3 Current lifestyle and changes since being diagnosed with cancer

Figure 9.2 shows the proportion of patients meeting each of the WCRF lifestyle recommendations. None of the cancer survivors in this sample were meeting all seven recommendations. Only 34% were meeting the body fatness recommendation, with 38% being overweight, 22% being obese, 1% being very obese and 1% being underweight. Similarly low proportions of patients were meeting recommendations for physical activity (22%), energy density (31%), plant foods (18%), and animal foods (39%). In contrast, 90% of patients were meeting the recommendations for alcohol intake and 92% for tobacco. The results without imputations are shown in Appendix 9.14.

Figure 9.2 Proportion of patients meeting each of the WCRF lifestyle recommendations (N=731)

Percentages were derived from the total sample so where numbers do not total 100% this is due to missing data.
Table 9.3 shows findings from the multivariable analyses examining the relationship between socio-demographic factors and meeting each of the WCRF lifestyle recommendations. Women had higher odds of meeting the body fatness ($p<.001$), energy density ($p<.01$) and animal foods ($p<.01$) recommendations. In contrast, they were less likely to meet the physical activity recommendation ($p<.05$). Those who were married were more likely to meet recommendations for physical activity ($p<.01$) and tobacco ($p<.01$). Older age was associated with lower odds of meeting the recommendations for physical activity ($p<.01$) and animals foods ($p<.05$). In contrast, it was associated with higher odds of meeting the body fatness recommendation ($p<.05$). Those with educational qualifications were more likely to meet the plant foods recommendation ($p<.01$). The results without imputations are shown in Appendix 9.15.
### Table 9.3: Multivariable logistic regression models showing socio-demographic factors associated with meeting each of the WCRF recommendations

<table>
<thead>
<tr>
<th></th>
<th>Body fatness (N=678)</th>
<th>Physical activity (N=561)</th>
<th>Energy density (N=509)</th>
<th>Plant foods (N=673)</th>
<th>Animal foods (N=665)</th>
<th>Alcohol (N=690)</th>
<th>Tobacco (N=705)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>OR [95% CI]</td>
<td>OR [95% CI]</td>
<td>OR [95% CI]</td>
<td>OR [95% CI]</td>
<td>OR [95% CI]</td>
<td>OR [95% CI]</td>
<td>OR [95% CI]</td>
</tr>
<tr>
<td>≤65 years</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>&gt;65 years</td>
<td>1.56 [1.08-2.24]*</td>
<td>0.58 [0.38-0.87]**</td>
<td>0.69 [0.46-1.03]</td>
<td>1.24 [0.80-1.91]</td>
<td>0.65 [0.45-0.93]*</td>
<td>1.52 [0.78-2.94]</td>
<td>1.52 [0.78-2.98]</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Female</td>
<td>1.93 [1.35-2.75]***</td>
<td>0.62 [0.42-0.94]*</td>
<td>1.92 [1.28-2.88]**</td>
<td>1.40 [0.91-2.17]</td>
<td>1.73 [1.22-2.45]**</td>
<td>0.84 [0.43-1.67]</td>
<td>1.28 [0.67-2.45]</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Married</td>
<td>0.87 [0.61-1.24]</td>
<td>2.25 [1.41-3.58]**</td>
<td>1.18 [0.78-1.77]</td>
<td>1.59 [1.00-2.55]</td>
<td>0.93 [0.66-1.32]</td>
<td>1.53 [0.81-2.90]</td>
<td>2.73 [1.48-5.05]**</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Some</td>
<td>1.33 [0.92-1.92]</td>
<td>0.79 [0.50-1.25]</td>
<td>1.48 [0.94-2.31]</td>
<td>2.14 [1.30-3.54]**</td>
<td>0.96 [0.66-1.38]</td>
<td>0.57 [0.26-1.26]</td>
<td>1.24 [0.64-2.43]</td>
</tr>
</tbody>
</table>

OR=odds ratio, CI=confidence interval, ORs adjusted for age, sex, marital status and education * p < .05, **p < .01, ***p < .001
Table 9.4 shows findings from the multivariable analyses examining the relationship between health factors and meeting each of the WCRF lifestyle recommendations. Those diagnosed with prostate cancer had higher odds of meeting the physical activity recommendation ($p<.01$). There was a trend suggesting that those with additional health problems were less likely to meet the physical activity recommendation, although this was only significant for those with one health problem ($p<.05$). The results without imputations are shown in Appendix 9.16.
Table 9.4 Multivariable logistic regression models showing health factors associated with meeting each of the WCRF recommendations

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Body fatness (N=369) OR [95% CI]</th>
<th>Physical activity (N=332) OR [95% CI]</th>
<th>Energy density (N=285) OR [95% CI]</th>
<th>Plant foods (N=362) OR [95% CI]</th>
<th>Animal foods (N=364) OR [95% CI]</th>
<th>Alcohol (N=368) OR [95% CI]</th>
<th>Tobacco (N=378) OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Prostate</td>
<td>0.67 [0.33-1.38]</td>
<td>2.75 [1.37-5.54]**</td>
<td>0.51 [0.24-1.10]</td>
<td>0.70 [0.30-1.63]</td>
<td>0.53 [0.27-1.04]</td>
<td>1.11 [0.30-4.07]</td>
<td>0.49 [0.12-2.01]</td>
</tr>
<tr>
<td>Colorectal</td>
<td>1.03 [0.62-1.71]</td>
<td>1.01 [0.55-1.85]</td>
<td>0.93 [0.53-1.61]</td>
<td>0.63 [0.34-1.17]</td>
<td>0.64 [0.39-1.05]</td>
<td>1.77 [0.56-5.55]</td>
<td>0.57 [0.19-1.73]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cancer stage</th>
<th>Body fatness (N=369) OR [95% CI]</th>
<th>Physical activity (N=332) OR [95% CI]</th>
<th>Energy density (N=285) OR [95% CI]</th>
<th>Plant foods (N=362) OR [95% CI]</th>
<th>Animal foods (N=364) OR [95% CI]</th>
<th>Alcohol (N=368) OR [95% CI]</th>
<th>Tobacco (N=378) OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>II</td>
<td>1.07 [0.62-1.87]</td>
<td>1.35 [0.71-2.59]</td>
<td>1.16 [0.63-2.17]</td>
<td>0.98 [0.50-1.89]</td>
<td>0.67 [0.39-1.17]</td>
<td>0.42 [0.13-1.39]</td>
<td>0.41 [0.12-1.45]</td>
</tr>
<tr>
<td>III or IV</td>
<td>0.66 [0.38-1.15]</td>
<td>1.24 [0.67-2.30]</td>
<td>0.84 [0.47-1.51]</td>
<td>0.91 [0.48-1.73]</td>
<td>0.84 [0.50-1.42]</td>
<td>0.56 [0.17-1.92]</td>
<td>0.95 [0.25-3.68]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health problems</th>
<th>Body fatness (N=369) OR [95% CI]</th>
<th>Physical activity (N=332) OR [95% CI]</th>
<th>Energy density (N=285) OR [95% CI]</th>
<th>Plant foods (N=362) OR [95% CI]</th>
<th>Animal foods (N=364) OR [95% CI]</th>
<th>Alcohol (N=368) OR [95% CI]</th>
<th>Tobacco (N=378) OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>1</td>
<td>0.79 [0.48-1.32]</td>
<td>0.55 [0.31-0.98]*</td>
<td>1.12 [0.65-1.94]</td>
<td>0.74 [0.41-1.34]</td>
<td>0.79 [0.48-1.30]</td>
<td>0.96 [0.40-2.28]</td>
<td>1.08 [0.33-3.54]</td>
</tr>
<tr>
<td>≥2</td>
<td>0.63 [0.37-1.08]</td>
<td>0.55 [0.30-1.01]</td>
<td>0.96 [0.53-1.74]</td>
<td>0.69 [0.36-1.31]</td>
<td>0.69 [0.41-1.16]</td>
<td>4.26 [0.94-19.40]</td>
<td>0.81 [0.26-2.52]</td>
</tr>
</tbody>
</table>

OR=odds ratio, CI=confidence interval, ORs adjusted for diagnosis, cancer stage and number of health problems, * p <.05. **p<.01
Table 9.5 shows patients’ reported change in lifestyle since they were diagnosed with cancer. Just over half of patients reported that their weight (53%), physical activity (51%), diet (74%) and alcohol consumption (51%) were about the same as before they were diagnosed with cancer. However, some reported making positive changes including having a healthier diet (20%), drinking less alcohol (32%) and 50% of smokers reported trying to quit. Although some patients reported doing more physical activity since their cancer diagnosis (9%), a larger number reported doing less (39%). More patients reported gaining weight (27%) than losing weight (19%).
Table 9.5 Reported change in lifestyle since diagnosis (N=731)  

<table>
<thead>
<tr>
<th></th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Weight</strong></td>
<td></td>
</tr>
<tr>
<td>More than before cancer diagnosis</td>
<td>27 (200)</td>
</tr>
<tr>
<td>About the same as before cancer diagnosis</td>
<td>53 (388)</td>
</tr>
<tr>
<td>Less than before cancer diagnosis</td>
<td>19 (136)</td>
</tr>
<tr>
<td><strong>Physical activity</strong></td>
<td></td>
</tr>
<tr>
<td>More than before cancer diagnosis</td>
<td>9 (67)</td>
</tr>
<tr>
<td>About the same as before cancer diagnosis</td>
<td>51 (370)</td>
</tr>
<tr>
<td>Less than before cancer diagnosis</td>
<td>39 (283)</td>
</tr>
<tr>
<td><strong>Diet</strong></td>
<td></td>
</tr>
<tr>
<td>Healthier than before cancer diagnosis</td>
<td>20 (148)</td>
</tr>
<tr>
<td>About the same as before cancer diagnosis</td>
<td>74 (538)</td>
</tr>
<tr>
<td>Less healthy than before cancer diagnosis</td>
<td>6 (40)</td>
</tr>
<tr>
<td><strong>Alcohol</strong></td>
<td></td>
</tr>
<tr>
<td>More than before cancer diagnosis</td>
<td>4 (28)</td>
</tr>
<tr>
<td>About the same as before cancer diagnosis</td>
<td>51 (369)</td>
</tr>
<tr>
<td>Less than before cancer diagnosis</td>
<td>32 (237)</td>
</tr>
<tr>
<td><strong>Tobacco (smokers only, n=50)</strong></td>
<td></td>
</tr>
<tr>
<td>Tried to quit since cancer diagnosis</td>
<td>50 (25)</td>
</tr>
<tr>
<td>Not tried to quit since cancer diagnosis</td>
<td>38 (19)</td>
</tr>
</tbody>
</table>

Percentages derived from the total sample - where numbers do not total 100% this is due to missing data.
9.4.4 Perceptions of current lifestyle

Table 9.6 shows patients’ perceptions of their current lifestyle. The majority of patients thought they should try to lose weight (54%) and do more physical activity (50%), and the majority of smokers thought they should quit smoking (63%). In contrast, most patients did not think they needed to change their diet (62%) or alcohol consumption (70%).

<table>
<thead>
<tr>
<th></th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Weight</strong></td>
<td></td>
</tr>
<tr>
<td>I think I should be trying to lose weight</td>
<td>54 (397)</td>
</tr>
<tr>
<td>I think I should be trying to gain weight</td>
<td>3 (23)</td>
</tr>
<tr>
<td>I don’t think I need to change my weight</td>
<td>37 (268)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>5 (34)</td>
</tr>
<tr>
<td><strong>Physical activity</strong></td>
<td></td>
</tr>
<tr>
<td>I think I should be doing more physical activity</td>
<td>50 (366)</td>
</tr>
<tr>
<td>I think I should be doing less physical activity</td>
<td>1 (4)</td>
</tr>
<tr>
<td>I don’t think I need to change my physical activity</td>
<td>41 (296)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>6 (42)</td>
</tr>
<tr>
<td><strong>Diet</strong></td>
<td></td>
</tr>
<tr>
<td>I think I should have a healthier diet</td>
<td>28 (207)</td>
</tr>
<tr>
<td>I don’t think I need to change my diet</td>
<td>62 (453)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>8 (60)</td>
</tr>
<tr>
<td><strong>Alcohol</strong></td>
<td></td>
</tr>
<tr>
<td>I think I should drink less alcohol</td>
<td>12 (86)</td>
</tr>
<tr>
<td>I don’t think I need to change my alcohol consumption</td>
<td>70 (511)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>4 (27)</td>
</tr>
<tr>
<td><strong>Tobacco (smokers only, n=50)</strong></td>
<td></td>
</tr>
<tr>
<td>I think I should quit smoking/chewing tobacco</td>
<td>62 (31)</td>
</tr>
<tr>
<td>I don’t think I need to change my smoking/tobacco habits</td>
<td>26 (13)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>12 (6)</td>
</tr>
</tbody>
</table>

Percentages derived from the total sample - where numbers do not total 100% this is due to missing data
Encouragingly, for the majority of lifestyle topics, those who were not meeting the recommendations were more likely to think they should change their lifestyle. Those not meeting the recommendation for physical activity were nearly four times as likely to think they should do more physical activity (OR 3.89 [95% CI 2.63-5.76], \(p<.001\)). For diet, those not meeting the plant foods recommendation were over two and a half times as likely to think they should be eating a healthier diet (OR 2.52 [95% CI 1.53-4.13], \(p<.001\)), but there were no significant differences for the red meat (OR 0.86 [95% CI 0.61-1.21], \(p=.384\)) or energy density (OR 1.39 [95% CI 0.94-2.05], \(p=.099\)) recommendations. Not meeting the alcohol recommendation was associated with higher odds of thinking they should drink less alcohol (OR 14.15 [95% CI 7.19-27.84], \(p<.001\)). Those not meeting the weight recommendation were over seven times as likely to think they should lose weight (OR 7.65 [95% CI 5.29-11.05], \(p<.001\)) than those who were a healthy weight. The results without imputations are shown in Appendix 9.17.

### 9.4.5 Lifestyle advice received since cancer diagnosis

Figure 9.3 shows the proportion of patients who reported receiving a recommendation about lifestyle since their cancer diagnosis. Fewer than half of patients (45%) reported receiving any lifestyle recommendation. The most commonly received recommendation was to do more exercise (20%), followed by eating more fruit and vegetables (19%) and avoiding foods or drinks high in fat, sugar or salt (18%), and eating less red or processed meat (14%). Fewer had received a recommendation about stopping smoking (9%) or alcohol (6%). The most common weight recommendation was to lose weight (13%), followed by keeping their weight the same (10%) and gaining weight (4%).
Lifestyle recommendations were most commonly received from a nurse (22%, n=164). However, 9% (n=64) received a recommendation from an oncologist, 8% (n=56) from a surgeon, 10% (n=74) from their GP, 6% (n=43) from a dietitian, 3% (n=20) from a physiotherapist, and 3% (n=18) from another source. Other sources that were reported included Macmillan Cancer Support, a speech therapist and another doctor.

Of those who had received information about lifestyle, 78% (n=255) thought the amount of information was about right, 13% (n=44) thought there was not enough, and 1% (n=2) thought there was too much.
9.4.6 Interest in lifestyle information and advice

Figure 9.4 shows the proportion of patients who were interested in receiving information or advice about lifestyle. The majority of patients (79%) reported that they were interested in receiving some information or advice about lifestyle. The most desired topic of advice was diet (67%), followed by maintaining a healthy weight (66%), having an overall healthy lifestyle (66%), and increasing physical activity (61%). Among current smokers, 50% were interested in advice on stopping smoking, and among alcohol drinkers, 25% were interested in advice on reducing their alcohol consumption. The results without imputations are shown in Appendix 9.18.

Figure 9.4 Proportion of patients interested in receiving information or advice about lifestyle (N=731)

Percentages were derived from the total sample so where numbers do not total 100% this is due to missing data or the patient selecting ‘not applicable’.
Encouragingly, for the majority of lifestyle topics, those not meeting recommendations were more likely to want information or advice on that topic. This was the case for information or advice on maintaining a healthy weight (OR 2.52 [95% CI 1.67-3.79], p<.001), increasing physical activity (OR 1.56 [95% CI 1.00-2.44], p<.05), reducing alcohol consumption (OR 3.74 [95% CI 1.98-7.09], p<.001), and quitting smoking (OR 23.92 [95% CI 10.22-56.03], p<.001). There was no association between meeting the plant foods (OR 1.06 [95% CI 0.65-1.75], p=.807), animals foods (OR 0.85 [95% CI 0.57-1.26], p=.407) and energy density (OR 1.06 [95% CI 0.67-1.68], p=.810) recommendations, and wanting information or advice on having a healthy diet. The results without imputations are shown in Appendix 9.19.

9.4.7 Preferences for lifestyle information or advice

Figure 9.5 shows patients’ preferences for different formats of lifestyle information or advice. The preferred format of lifestyle information was a short leaflet (56%), and this was the only format where more patients were interested than not interested. The second most popular format was a long leaflet (42%), followed by a single individual session (39%) and the internet (38%). The least popular formats were multiple group sessions (22%) and an App for mobile or tablet (22%). The results without imputations are shown in Appendix 9.20.
Figure 9.5 Patient preferences for different formats of lifestyle information or advice (N=731)

Percentages were derived from the total sample so where numbers do not total 100% this is due to missing data.

Figure 9.6 shows patients’ preferred timing of information or advice about lifestyle. The most popular time to receive such advice or information was immediately after treatment (28%), followed by before treatment starts (24%). The least popular time was more than one year after treatment (4%).
9.4.8 Characteristics of non-responders

The response rate for this study was estimated at around 41% which is more than a previous study of health behaviours in the US (33%) (Blanchard et al., 2008) but less than a recent patient-reported outcomes survey conducted as part of the National Cancer Survivorship Initiative (66%) (Department of Health & NHS, 2012). Unfortunately no information was available from the NHS trusts on the characteristics of non-responders. However, the socio-demographic characteristics of this sample and data from the 2011 Census in the same regions are shown in Table 9.7. These suggest that men and unmarried individuals are underrepresented in this sample, but ethnicity appears to be comparable. The sample in this study had a higher proportion of individuals with no qualifications than the general population in the same areas, but this could be attributed to age. Similarly, the higher proportion of married individuals in this
sample could be attributed to the older age of the sample relative to the general population.

### Table 9.7 Socio-demographic characteristics of patients in this study compared with 2011 Census data for the same regions

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Present study</th>
<th>Chelmsford</th>
<th>Southend-on-Sea</th>
<th>Basildon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>62%</td>
<td>51%</td>
<td>51%</td>
<td>51%</td>
</tr>
<tr>
<td>White British</td>
<td>92%</td>
<td>90%</td>
<td>87%</td>
<td>90%</td>
</tr>
<tr>
<td>Married or cohabiting</td>
<td>69%</td>
<td>63%</td>
<td>56%</td>
<td>45%</td>
</tr>
<tr>
<td>No educational qualifications</td>
<td>32%</td>
<td>19%</td>
<td>25%</td>
<td>27%</td>
</tr>
</tbody>
</table>

### 9.5 Discussion

#### 9.5.1 Overview of the findings

This study aimed to build on the findings of the previous studies in this thesis and address some of the remaining gaps in knowledge in relation to the current lifestyle of cancer survivors, the advice they had received about lifestyle and their interest in lifestyle information or advice. Specifically, it aimed to determine: 1) The proportion of cancer survivors meeting each of the WCRF lifestyle recommendations, the socio-demographic and health characteristics associated with meeting these recommendations, and whether they report making changes to their lifestyle following their diagnosis, 2) Cancer survivors’ perceptions of their current lifestyle and whether meeting the WCRF recommendations influences these perceptions, 3) The proportion of cancer survivors who received a recommendation about lifestyle since their cancer diagnosis, and how satisfied they were with the information they were given, 4) The proportion of cancer survivors interested in receiving lifestyle information, whether meeting the WCRF recommendations influences their interest, and what their preferences are for this information.
The results showed that none of the cancer survivors in this sample were meeting all seven of the recommendations and only a minority were meeting recommendations for body fatness (34%), physical activity (22%), and for the intake of energy dense (31%), plant (18%) and animal foods (39%). In contrast, the majority of patients were meeting recommendations for alcohol (90%) and tobacco (92%). There were some socio-demographic differences, with women being more likely to meet body fatness and dietary recommendations, but less likely to meet physical activity recommendations. Although not significant for all recommendations, there was evidence that being married and having educational qualifications were associated with being more likely to meet lifestyle recommendations. Older age was associated with being less likely to meet recommendations for physical activity and animal foods, but more likely to meet the body fatness recommendation. There were also some differences by health status with prostate cancer survivors being more likely to meet the physical activity recommendation, but those with additional health problems being less likely to meet this recommendation. Although the majority of patients reported that their lifestyle was similar to before they were diagnosed with cancer, some reported having a healthier diet and drinking less alcohol, and half of the smokers reported that they had tried to quit smoking.

The majority of patients thought they should be trying to lose weight and do more physical activity, and most smokers thought they should quit smoking. In contrast, most patients did not think they needed to change their diet or alcohol consumption. With the exception of red meat and energy density, those not meeting the recommendations were most likely to think they should change.

Fewer than half (45%) of patients recalled receiving a recommendation about lifestyle since they were diagnosed with cancer. Those who did had most commonly been advised to do more exercise (20%) and had received this recommendation from a nurse (22%). Most patients who had received a recommendation thought that the amount of information they had been given was about right. The majority of patients expressed an interest in receiving information about lifestyle, particularly information about diet and maintaining a healthy weight. Their preferred format of information was a short leaflet.
and most thought this information would be best immediately after treatment. Encouragingly, for all topics except diet, those who were not meeting the recommendations were more likely to want advice about lifestyle.

9.5.2 Interpretation of the findings

Of concern was the finding that no cancer survivors in this sample were meeting all recommendations, not only because of the wealth of evidence supporting them (WCRF & AICR, 2007), but meeting multiple recommendations has been associated with clinical benefits among breast cancer survivors (Bruno et al., 2015). The proportion of cancer survivors meeting the physical activity, diet and weight recommendations in this sample was low. For physical activity, it was lower than previous studies (Blanchard et al., 2008; Bruno et al., 2015; Wang et al., 2015), but this could be due to the WCRF having more stringent criteria than other organisations such as the ACS and the ACSM (210 vs. 150 minutes of moderate physical activity per week) (Rock et al., 2012; Schmitz et al., 2010).

For plant foods, the proportion meeting the recommendation was comparable to previous studies (Blanchard et al., 2008), but for animal foods it was again a bit lower (Bruno et al., 2015). However, the only previous study to examine this recommendation was among a younger sample of breast cancer survivors, which may explain this discrepancy (Bruno et al., 2015). Similar, to previous studies, the majority of cancer survivors were meeting guidelines for alcohol and smoking (Blanchard et al., 2008; Bruno et al., 2015; Wang et al., 2015).

In line with previous studies, this study found that older age was associated with lower odds of meeting the physical activity recommendation (Niu et al., 2015). This is consistent with the findings of Study 1 which showed that physical activity reduces over time in both cancer survivors and those with no history of cancer. A greater proportion of women were meeting the recommendation for body fatness and diet. These findings are unsurprising as a UK survey of 2011 adults found a greater proportion of men were overweight (Cancer Research UK, 2012), and women have been shown to be more likely to actively control their weight (Wardle, Griffith, Johnson, & Rapoport, 2000). Being married was associated with higher odds of meeting physical activity and smoking recommendations, which may highlight the importance of social support in promoting a
healthy lifestyle. Married and cohabiting couples have similar health behaviours and there is evidence that a partner can influence whether their partner quits smoking, loses weight or becomes physically active (Homish & Leonard, 2005; Jackson SE, Steptoe A, & Wardle J, 2015). The results of this study suggest that older adults, non-married individuals and men may be less aware of the benefits of a healthy lifestyle following a cancer diagnosis and may require additional support to help them make lifestyle changes. These findings further highlight the importance of cancer survivors’ social networks and how they can help cancer survivors to make changes. Taking these factors into consideration is therefore important when providing lifestyle advice.

Examination of the health characteristics of the sample found that prostate cancer survivors were more likely to meet the physical activity recommendations. It is possible that this may be an effect of sex, as men were also found to be more physically active than women. This is in line with previous studies of older adults which have consistently found that women are less physically active than men, when measured by subjective and objective criteria (Sun, Norman, & While, 2013). However, it is also possible that this difference is due to the existence of NICE guidance on physical activity for prostate cancer survivors (NICE, 2014). This would suggest that the guidance is not only being implemented but that it is having an impact on the physical activity levels of prostate cancer survivors. Therefore, these findings could provide further support for the need for clinical guidance for other groups of cancer survivors and for other lifestyle topics. Those with additional health problems were less likely to be physically active. This may be due to the high prevalence of arthritis which may hinder attempts to exercise.

The results found that 50% of smokers had attempted to quit since their cancer diagnosis, which is similar to reports from previous studies (Blanchard et al., 2003). However, all of these individuals remained current smokers, suggesting that their quit attempts had not been sustained. This may explain why Study 1 did not find long-term evidence of quitting. The most common positive change reported by participants was to their diet, although the proportion was lower (20%) than previous studies (30-47%) (Blanchard et al., 2003; Maunsell et al., 2002; Patterson et al., 2003; Salminen et al., 2002). However, this difference could be due to the way the question was phrased, as
in previous studies participants were asked only about changes, whereas in this study they were asked specifically to compare their diet to before their diagnosis. It is possible that although many cancer survivors make changes, they acknowledge that their diet is not substantially different to before their diagnosis. In line with this argument, the majority of patients reported that their weight, physical activity levels and alcohol consumption were similar to before their diagnosis. A substantial proportion of patients (39%) also admitted to being less physically active than before their cancer diagnosis, which is consistent with the findings of Study 1.

Encouragingly, patients who were not meeting the WCRF lifestyle recommendations were more likely to think they should do more physical activity, eat more plant foods and drink less alcohol. Similarly, the majority of smokers thought they should quit smoking. By acknowledging they need to change, patients have already overcome the first hurdle to making changes, and may potentially be more receptive of lifestyle advice. However, it should also be acknowledged that a substantial proportion of smokers did not think they needed to quit, highlighting a need for education on the added benefits of smoking cessation following a cancer diagnosis. Similarly, the majority of patients did not think they need to change their diet, despite many not meeting recommendations, highlighting a need for improved education. Unsurprisingly, those not meeting the body fatness recommendation were more likely to think they should lose weight. However, as described in Chapter 2, weight loss has been associated with poorer disease outcomes for cancer survivors, even among those who are overweight or obese (Caan et al., 2005, 2012b). In the absence of good trial evidence, lifestyle advice should focus on having a healthy diet and being physically active rather than trying to achieve a specific weight goal.

Only a minority of patients reported receiving a lifestyle recommendation since they were diagnosed with cancer. While this finding is consistent with previous patient studies (Anderson, Steele, et al., 2013; James-Martin et al., 2014; Jones & Courneya, 2002), it is conflicting with the results of Study 4, which found that the majority of health professionals reported giving lifestyle advice. One explanation for this discrepancy is that patients may have forgotten receiving a recommendation, which would be
understandable given the circumstances and the large amount of information they will have received. Alternatively, it is possible that health professionals only give advice to a minority of their patients. Either way, if patients cannot recall being given lifestyle advice, then it is unlikely to have had any lasting impact on their behaviour. Determining patients’ preferences for the source and timing of advice, will help to maximise the impact of this advice.

The majority of patients were interested in receiving information about lifestyle (79%). This was higher than a previous UK survey (Department of Health & NHS, 2012), but is in line with findings from Norway and qualitative studies (Anderson, Steele, et al., 2013; Gjerset et al., 2011; James-Martin et al., 2014). Encouragingly, those not meeting the WCRF lifestyle recommendations were more likely to be interested in information on maintaining a healthy weight, increasing physical activity, reducing alcohol consumption, and quitting smoking. This highlights an opportunity for intervention as it suggests that those with suboptimal health behaviours may be ready to change. In order to capitalise on this opportunity, it is vital that all cancer survivors are engaged in a discussion about lifestyle at some point in the cancer care pathway.

The preferred timing to receive lifestyle information was immediately after treatment. This is consistent with previous studies (Anderson, Steele, et al., 2013; Gjerset et al., 2011), and may be a point of a ‘teachable moment’ where cancer survivors are motivated to make positive changes and have a fresh start (McBride & Ostroff, 2003). Rather surprisingly, the preferred format of lifestyle information was a short leaflet, followed by a longer leaflet. This is encouraging as these are likely to be some of the most economical forms of information to provide in routine care. A substantial proportion of patients were also interested in online information, although this was lower than a previous study (Hartoonian et al., 2014). This further highlights a need for organisations, such as those in Study 3, to provide adequate information about lifestyle on their websites.
9.5.3 Limitations

This study addressed a number of the limitations outlined in the previous studies. Study 1 was unable to examine changes in diet, so a detailed measure of dietary intake was included in this study. Similarly, in Studies 1 and 2, the physical activity measure only asked about sports, so this study included a more comprehensive measure of physical activity. Study 5 only asked brief questions about doctors giving advice on physical activity, healthy eating and weight loss. This study asked more detailed questions about lifestyle advice and included questions on smoking and alcohol, as well as asking about advice from other health professionals. Study 5 also had a relatively small sample of cancer survivors, which this study addressed with a larger sample.

However, it also had a number of additional important limitations. First, although patients’ cancer diagnoses were confirmed by the NHS trusts, all other data were self-reported and may therefore be subject to bias. The use of self-reported height and weight meant that BMI was likely to be underestimated (Cameron & Evers, 1990). Therefore, even though the majority of patients were already overweight or obese (61%), it is possible that this number may be even higher. Dietary intake was assessed using a food frequency questionnaire and, as described previously, these have been associated with a high level of systematic error (Natarajan et al., 2006). There is evidence that these questionnaires may cause people to underestimate their energy intake, particularly women, minority groups, and those who are younger or overweight (Black & Cole, 2001; Johansson et al., 1998). Given the high proportion of women (62%) and overweight or obese patients in this sample, this may be particularly applicable here. Therefore, similar to weight, although only a minority of patients were meeting dietary recommendations, it is possible that this may be an underestimate and actual numbers may be even lower. Similar under or over-reporting may occur for other health behaviours.

Self-reported measures are also subject to recall bias as patients may not always be able to remember events that occurred several weeks, months or years ago. This may be particularly relevant to the questions about the lifestyle advice they had received since they were diagnosed with cancer. Although all patients were diagnosed fairly recently in
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2012 or 2013, there is still plenty of time for them to have forgotten about being given advice or information. It is therefore possible that the proportion of patients who received advice may have been underestimated.

A common issue with printed questionnaires is that of missing data, as patients are free to answer whichever questions they choose. This issue can be overcome with online questionnaires where patients are required to complete all questions before they can move forward in the questionnaire. However, although this questionnaire was provided in both print and online versions only two patients chose to complete it online. Although some data were potentially missing due to patients accidentally missing a row, other questions consistently had a large amount of missing data. One example of this was the physical activity questions, which asked patients how many times they engaged in strenuous, moderate or mild exercise. Although the expectation was that patients complete all three questions, many patients only answered one. For the purpose of this study, it was assumed that they did not perform the other types of exercise and these were imputed as zero. However, without being able to check with the patient directly, it is not possible to know if this assumption was correct.

One of the main aims of this study was to examine the proportion of cancer survivors who were meeting the WCRF lifestyle guidelines. However, measuring salt intake would have been very difficult using a food frequency questionnaire and may not have yielded accurate data (McLean, 2014). As a result, the decision was taken not to include questions on salt intake so as to avoid burdening patients with additional questions that may not be useable. In addition to BMI, it may also have been useful to have asked patients their waist circumference in order to get a more detailed assessment of levels of overweight and obesity. However, many patients may have needed to measure this, which may have resulted in a large amount of missing data.

There were also limitations in the scoring of the questionnaire. Energy density was determined by combining the recommended total fat and sugar intake scores. Although this may have given a reasonable estimate of energy density, it was not possible to score energy density as a number of calories per 100g as outlined in the WCRF Second Expert
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Report (WCRF & AICR, 2007). The same applies to the plant and animal foods recommendations, as although combining more than recommendation provides a reasonable estimate, it does not necessarily capture all of the foods outlined in the WCRF Second Expert Report (WCRF & AICR, 2007). In addition, for questions which only asked about frequency of consumption (e.g. for red meat and alcohol), portion sizes needed to be estimated. Although these estimations were based on the literature, they may not accurately reflect the portion sizes of all individuals.

Multivariable logistic regression was used to examine associations between socio-demographic and health factors and meeting each of the WCRF recommendations. As described in Chapter 7, with an alpha of 0.05, the probability of a type I error in any given analysis is one in twenty. However, with multiple comparisons in a model, the chances of a type I error is increased. Therefore, although trends can be seen across some of the recommendations, these results should be interpreted with caution. In addition, although logistic regression examines associations between variables, it is not possible to determine causation.

Unfortunately, there was no information about the characteristics of non-responders to the survey. Examination of the sample characteristics and comparison with data from the 2011 Census suggested that men and non-married individuals may be underrepresented in this sample, and those with educational qualifications may be overrepresented. However, the nature of the study meant that the mean age of the sample was higher than the general population, which may explain some of these differences in marital status and education. As with all studies of this nature, it is likely that responders to this survey were more interested in lifestyle issues than those who did not take the time to complete it, and therefore the levels of interest found may have been overestimated.

9.5.4 Conclusions

Overall, the results of this study show that with the exception of alcohol and smoking, the proportion of cancer survivors meeting the WCRF lifestyle recommendations is low. There were some socio-demographic and health differences highlighting groups which
should be targeted for intervention. Although some patients reported making positive changes, the majority said that their lifestyle was similar to before their cancer diagnosis. Encouragingly, patients who were not meeting lifestyle recommendations were more likely to think they should change their behaviour and more likely to want information about lifestyle. This highlights a valuable opportunity to provide lifestyle information to those who may benefit from it the most. The preferred time to receive lifestyle information was at the end of treatment, suggesting that this may be the optimal time to intervene as patients are more motivated. The majority of patients preferred to receive lifestyle information in the form of a leaflet, although a substantial proportion were also interested in internet information. Together, these findings highlight some key areas for intervention, and provide insight into the best ways of doing this.
CHAPTER 10: GENERAL DISCUSSION

10.1 Introduction

With increasing numbers of people surviving cancer (Maddams et al., 2012), there has been growing interest in how to minimise the physical and psychosocial impact of a cancer diagnosis. Healthy lifestyle behaviours may help improve the long-term outcomes of cancer survivors. However, the health behaviours of cancer survivors have been found to be suboptimal, and there has been little research to date on whether cancer survivors change their lifestyle following their diagnosis. There is also limited research on cancer survivors’ views on lifestyle, the lifestyle information and advice that is available to them, and their preferences regarding such information.

This thesis aimed to provide further insight into the health behaviours of cancer survivors and the lifestyle information and advice that is available to them. Study 1 was the first prospective study in the UK to examine changes in health behaviours from pre-to post-cancer diagnosis. Study 2 then aimed to qualitatively examine cancer survivors’ beliefs about lifestyle and their sources of information. Study 3 was a review of the lifestyle information that is available to cancer survivors online. Study 4 examined the factors determining whether health professionals give advice about lifestyle. Study 5 examined the views of social network members and cancer survivors on doctors giving lifestyle advice to cancer patients. Study 6 was a large patient survey which aimed to determine the factors associated with meeting the WCRF lifestyle guidelines, perceptions of current lifestyle, experience of receiving lifestyle advice, and interest in and preferences for such advice. This chapter summarises the main findings of this thesis, their contribution to the literature and their wider implications. Limitations and future research directions are also discussed.

10.2 Summary of findings and contribution to the literature

Chapter 3 outlined the aims of this thesis with four research questions which the subsequent studies have attempted to address. This section summarises the main
findings of each study in relation to each of the original questions, and discusses their contribution to the literature.

10.2.1 What are the health behaviours of cancer survivors, how do these change following a cancer diagnosis, and what factors are associated with meeting lifestyle recommendations?

This research began with a prospective longitudinal study to examine changes in physical activity, alcohol consumption and smoking across three time-points (0-2 years before a cancer diagnosis, 0-2 years post-diagnosis and 2-4 years post-diagnosis) using data from a population-based sample in the UK (Study 1). Previous studies had indicated that the health behaviours of cancer survivors were suboptimal (Bellizzi et al., 2005; Blanchard et al., 2008; Courneya, Katzmarzyk, et al., 2008; Eakin et al., 2007; Grimmett et al., 2009; Wang et al., 2015), but no studies had examined changes over time among cancer survivors in the UK.

The results showed no significant difference in change over time in the proportion of smokers in the cancer group (T0: 12.0%, T1: 9.4%, T2: 9.9%) and the control group (T0: 10.2%, T1: 9.0%, T2: 8.3%), suggesting that a cancer diagnosis was not a prompt for smoking cessation. This was in contrast to previous studies which had found higher rates of quitting in the cancer group following their diagnosis (Karlsen et al., 2012; Keenan, 2009; Newsom, Huguet, McCarthy, et al., 2012; Westmaas et al., 2014). There was also no difference in the proportion of heavy alcohol drinkers in the cancer group (T0: 22.9%, T1: 19.2%, T2: 20.1%) and control group (T0: 22.4%, T1: 22.0%, T2: 21.6%). The cancer group were less physically active than the control group at all time-points, but although this decreased over time in both groups, it did not do so significantly more in the cancer group (T0: 13.2%. T1: 9.4%, T2: 9.9%) compared with the control group (T0: 15.9%, T1: 15.1%, T2: 14.4%). Overall, this study found little evidence that cancer survivors make sustained positive changes to their health behaviours following a cancer diagnosis, highlighting a need for intervention.

Although not the main focus of the study, participants in Study 2 reported an increased awareness of lifestyle following their cancer diagnosis which had prompted them to
make changes. One woman reported that she had quit smoking when she was diagnosed with cancer, but other than that, the majority of reported changes were to diet. These changes included reducing their intake of fatty foods or eating more fruit and vegetables. Study 1 was unable to examine changes in diet so it is not possible to know if these reported changes would be evident at a population level. Although some participants in this study mentioned that they had tried to increase their physical activity levels, most admitted that such changes were modest. This may explain why Study 1 and other prospective studies have failed to show improvements in physical activity levels following a cancer diagnosis (Newsom, Huguet, McCarthy, et al., 2012; Newsom, Huguet, Ramage-Morin, et al., 2012).

To further understand the discrepancy between the findings of Studies 1 and 2, Study 6 included a question on how patients thought their lifestyle compared to before they were diagnosed with cancer. Overall this found that the majority of patients reported that their lifestyle was similar to before they were diagnosed with cancer. However, some reported having a healthier diet and drinking less alcohol. As diet was not included in Study 1, it is not possible to know if such changes would have been observed on a population level. This study also found that 50% of smokers had attempted to quit since being diagnosed with cancer. However, these individuals still identified as current smokers, suggesting that their quit attempts had not been successful or they had relapsed. This may explain why Study 1 did not show significantly higher quitting rates in the cancer group.

Although previous research and Study 1 had indicated that the health behaviours of cancer survivors were suboptimal, it was not clear how many cancer survivors were meeting each of the WCRF lifestyle guidelines outlined in Chapter 2. To address this gap, Study 6 aimed to determine this in a large survey of breast, prostate and colorectal patients. This found that none of the cancer survivors were meeting all of the WCRF guidelines and only a minority were meeting recommendations for body fatness (34%), physical activity (22%), and for the intake of energy dense (31%), plant (18%) and animal foods (39%). In contrast, the majority of patients were meeting recommendations for alcohol (90%) and tobacco (92%). These findings were generally comparable to previous
studies (Blanchard et al., 2008; Bruno et al., 2015; Wang et al., 2015), although the proportion meeting physical activity guidelines was a little lower. This may be due to the WCRF recommending more minutes of physical activity than other organisations such as the ACS and ACSM (30 minutes moderate physical activity every day vs. 30 minutes five days per week) (Rock et al., 2012; Schmitz et al., 2010). Overall, these findings highlight a need for intervention to help cancer survivors have a healthy lifestyle.

Study 6 also examined the socio-demographic and health factors associated with meeting each of the WCRF lifestyle recommendations. In line with previous studies, this study found that women and those who were over 65 years had lower odds of meeting the physical activity recommendation, which is in line with previous studies (Niu et al., 2015; Sun et al., 2013). This gender difference may also explain why those with prostate cancer were more likely to meet this recommendation. In contrast, women were more likely to meet recommendations for body fatness and diet, which is consistent with previous studies suggesting they are more likely to control their weight (Wardle et al., 2000). Those who were married and more highly educated were also more likely to meet some of the recommendations. These findings highlight some of the groups which may benefit from additional information and support to help them make lifestyle changes.

In summary, the findings from Studies 1, 2 and 6 suggest that the health behaviours of cancer survivors in the UK are suboptimal. With the exception of alcohol and smoking, only a minority of cancer survivors appear to be meeting the WCRF lifestyle guidelines. Although some cancer survivors report making changes to their lifestyle following their diagnosis, the majority admit that these changes are modest. With the exception of diet and alcohol, most reported that their lifestyle was similar to before their diagnosis. On a population level, there was little evidence that a cancer diagnosis was a prompt for making lifestyle changes. These findings highlight a need for increased information and support to help cancer survivors make healthy lifestyle changes following their diagnosis.
10.2.2 Are cancer survivors aware of the potential benefits of a healthy lifestyle for their long-term health?

Study 2 examined cancer survivors’ beliefs about the role of lifestyle in their long-term health and survival. Although not the main focus of this study, participants were also asked about the role of lifestyle in the development of their cancer, so these results were presented for comparison. Few participants thought that lifestyle was an important factor in the development of their cancer, but all acknowledged its importance for long-term health. Generally their beliefs were in line with the WCRF lifestyle recommendations, such as it is beneficial to be physically active, eat plenty of vegetables and avoid red meat (WCRF & AICR, 2007). This is encouraging given that psychological models propose that those with positive beliefs about a particular health behaviour are more likely to engage in that behaviour (Ajzen, 1985; Janz & Becker, 1984; Leventhal et al., 1997). However, some also thought that dietary supplements were beneficial even though there is no scientific evidence for this and they are not recommended for cancer prevention. This highlights a need for improved education in this domain. Although some participants discussed their beliefs about lifestyle in relation to cancer specifically, most seemed to think lifestyle was more important for general health or for the prevention of other chronic conditions, such as heart disease.

Building on the findings of Study 2, Study 6 examined cancer survivors’ perceptions of their own lifestyle and whether they thought they needed to make changes. This found that most patients thought they should be trying to lose weight (54%) and do more physical activity (50%), and the majority of smokers thought they should quit (63%). In contrast, most patients did not think they needed to change their diet (62%) or alcohol consumption (70%). These beliefs were generally in line with the WCRF lifestyle recommendations; although most patients did not think they needed to change their diet, despite only 18% to 39% meeting dietary recommendations. Also, although wanting to lose weight is in line with the WCRF recommendation for those who are overweight, the evidence suggests that weight maintenance is preferable (Caan et al., 2005, 2012b). Encouragingly, patients who were not meeting the WCRF lifestyle recommendations were more likely to think they should do more physical activity, eat more plant foods and drink less alcohol. Similarly, the majority of smokers thought they
should quit smoking. This suggests that patients were aware that their lifestyle was suboptimal and think they should be making changes.

In summary, the findings of Studies 2, 5 and 6 show that cancer survivors think lifestyle is important for long-term health, although they do not necessarily relate this to their cancer diagnosis. Although the majority of cancer survivors in Study 6 were not meeting the WCRF recommendations, most thought they should have a healthier lifestyle, suggesting that they think they should be making changes. Those not meeting the recommendations were most likely to think they should change. These findings are encouraging as psychological models suggest that positive beliefs are associated with an increased likelihood of performing a behaviour (Ajzen, 1985; Janz & Becker, 1984; Leventhal et al., 1997).

10.2.3 What lifestyle information is available to cancer survivors and what determines whether they receive such information?

Similar to previous studies with patients, Study 2 found that the majority of participants had not received any information or advice about lifestyle when they were diagnosed with cancer (Anderson, Steele, et al., 2013; James-Martin et al., 2014; Jones & Courneya, 2002). This had led some motivated participants to seek out information about lifestyle themselves. Although some participants had obtained information from reputable organisations such as Macmillan Cancer Support, others reported searching the internet more generally. Those who had not sought out any information about lifestyle had often obtained their information from the media. This finding raises concern as there is evidence that the majority of health claims in the media are not supported by sufficient evidence (Cooper et al., 2011). This highlights a need for cancer survivors to be directed to reliable sources of information about lifestyle.

Following on from Study 2, Study 3 aimed to identify the lifestyle information and resources provided for cancer survivors online by the statutory and charity sectors, and cancer centres in the UK. Only half of the 20 organisations that were searched had lifestyle information for cancer survivors on their websites. The Christie NHS Foundation Trust (The Christie NHS Foundation Trust, 2015), Macmillan Cancer Support (Macmillan
Cancer Support, 2014) and Prostate Cancer UK (Prostate Cancer UK, 2014) had the most comprehensive guides, covering physical activity, diet, weight management, smoking and alcohol. Notably, the NHS website did not have any relevant information. Given that statutory and charity sector organisations, and cancer centres are a favoured source of information for cancer survivors, the overall level of information provided was suboptimal. This is concerning, as if cancer survivors cannot find the information they require from these organisations, they may turn to less reliable sources which may put them at risk of misinformation. In addition, having access to appropriate lifestyle information may help build cancer survivors’ self-efficacy for making lifestyle changes (Bandura, 1986). These findings therefore highlight a need for organisations to update their websites to include lifestyle information for cancer survivors, or at least direct cancer survivors to appropriate sources of information.

As the majority of participants in Study 2 reported that they had not received lifestyle advice following their diagnosis, Study 4 aimed to understand the factors associated with whether health professionals give such advice. This found that the majority (87%) reported giving some lifestyle advice to their patients, although fewer gave advice to the majority of their patients (up to 57%). Over a third (36%) of health professionals were unfamiliar with lifestyle guidelines for cancer survivors and doctors were less likely to be familiar than nurses. Those who were unfamiliar with guidelines and those who had doubts about the relationship between lifestyle and cancer outcomes were less likely to give advice. In contrast, those who reported the patient being too unwell as a potential barrier were more likely to give lifestyle advice on all topics except alcohol. This supports the idea that health professional behaviour may be explained by a dual process model, which may incorporate both automatic and reflective processes (Presseau et al., 2014). In line with this model, health professionals may be more likely to give lifestyle advice if they reflect on the perceived utility and outcomes of such advice. Overall, these findings highlight a need for improved education, particularly among doctors, on the benefits of a healthy lifestyle for those diagnosed with cancer. Such education is an important part of ensuring cancer survivors receive advice, although there is also a need for clinical guidance on what health professionals should be recommending.
Expanding on the findings of Study 2, Study 6 aimed to determine the proportion of cancer survivors who reported receiving a lifestyle recommendation following their diagnosis, who they received it from, and what they thought of the amount of information they were given. Only a minority (45%) of patients reported receiving a lifestyle recommendation. This ranged from 6% for alcohol to 20% for physical activity. Recommendations had most commonly been received from a nurse (22%). Of those who had received a recommendation about lifestyle, 78% thought the amount of information was about right, 13% thought there was not enough, and 1% thought there was too much. These findings are consistent with Study 2 and previous studies which have found that the majority of cancer survivors do not receive advice about lifestyle (Anderson, Steele, et al., 2013; James-Martin et al., 2014; Jones & Courneya, 2002). Again, these findings highlight a need for cancer survivors to be given lifestyle advice in order to avoid them obtaining information from unreliable sources.

In summary, the findings of Studies 2, 3, 4 and 6 suggest that only a minority of cancer survivors receive professional advice about lifestyle following their cancer diagnosis. This supports a need for health professional education and clinical guidance to ensure cancer survivors receive sufficient information about lifestyle. In addition, as cancer survivors are increasingly seeking out lifestyle information themselves, there is a need for statutory and charity organisations, and cancer centres to provide information about lifestyle on their websites or to direct cancer survivors to appropriate sources of information. Having access to appropriate lifestyle information may help build cancer survivors’ self-efficacy, and increase the likelihood of them making lifestyle changes (Bandura, 1986).

10.2.4 Are cancer survivors interested in lifestyle information, what are their preferences regarding such information, and do cancer survivors and their social networks think lifestyle advice should be given to individuals diagnosed with cancer?

Study 2 found that cancer survivors were interested in information about lifestyle but the majority reported that they had not been given advice about it. In line with previous studies, this had resulted in many of them seeking out information themselves.
Anderson, Steele, et al., 2013). Some participants had contacted charities for information, such as Macmillan Cancer Support, but others had searched the internet for information. Although participants in this study were not asked specifically about their preferred sources of information, these findings gave an indication of where they may initially look for information.

Having established in Study 2 that cancer survivors think lifestyle is important for their long-term health, Study 5 examined cancer survivors’ and their social network members’ views on lifestyle advice for individuals who have been diagnosed with cancer. The ‘social network members’ group comprised anyone who reported that they knew someone close who had been diagnosed with cancer. The majority of social network members (over 80%) thought advice on physical activity, healthy eating and weight loss (for overweight patients) would be beneficial, encouraging, and believed that doctors had a duty to provide it. An even greater proportion (over 90%) thought it would be helpful. Encouragingly, fewer than 15% thought it would be insensitive, although slightly more (14-18%) expressed concern that lifestyle advice could be perceived as blaming the patient. The only demographic differences observed were slightly more positive attitudes towards advice among younger and more highly educated respondents. These findings are encouraging as friends and family members are an important source of information and advice for many people who are diagnosed with cancer (Macario et al., 1998; Matthews et al., 2002; Pecchioni & Sparks, 2007). In addition, psychological theory emphasises the influence of significant others as a factor influencing an individual’s behaviour (Ajzen, 1985), and social support plays an important role in behaviour change (Barber, 2012; H.-K. Yang et al., 2013).

When cancer survivors were asked the same questions, the findings were similarly positive. More than 80% thought that lifestyle advice would be beneficial, encouraging and helpful, and the same (84-87%) thought it was the doctor’s duty to provide it. Fewer than 25% believed such advice would be insensitive, interfering, unnecessary or would imply blame. Together, the findings from Studies 2 and 5 show that not only do cancer survivors think lifestyle is important for long-term health, but they are receptive
to the idea of being given advice about lifestyle. This finding is encouraging as it suggests they are open to the idea of making lifestyle changes.

Following on from Studies 2 and 5, Study 6 aimed to examine cancer survivors’ interest in lifestyle information and their preferences for such information in more detail. This found that 79% of patients were interested in receiving information or advice about lifestyle. This was higher than a previous UK survey (Department of Health & NHS, 2012), but is similar to other surveys and qualitative studies (Anderson, Steele, et al., 2013; Gjerset et al., 2011; James-Martin et al., 2014). Interest in specific topics of information ranged from 25% for alcohol consumption (among alcohol drinkers) to 57% for diet information. Encouragingly, those not meeting the WCRF lifestyle recommendations were more likely to be interested in information on maintaining a healthy weight, increasing physical activity, reducing alcohol consumption and quitting smoking, suggesting that they may be ready to change their behaviour.

In line with previous studies, Study 6 also found that the preferred timing to receive information or advice about lifestyle was immediately after treatment (Anderson, Steele, et al., 2013; Gjerset et al., 2011). This may be a point when cancer survivors want to have a fresh start so may be motivated to make positive changes. The preferred format of lifestyle information was a short leaflet. Several patients were also interested in internet information, though not as many as had been found in a previous study (Hartoonian et al., 2014). Ensuring patients are routinely provided with print and online lifestyle information may therefore be an important step in helping them to make behaviour changes.

In summary, the findings of Studies 2, 5 and 6 show that the vast majority of cancer survivors are interested in receiving information or advice about lifestyle, particularly diet, weight and an overall healthy lifestyle. Encouragingly, those not meeting the WCRF lifestyle recommendations were found to be most interested in lifestyle information. Cancer survivors’ social network members also thought that lifestyle advice was important for those diagnosed with cancer and that it is a doctor’s duty to provide such advice. Cancer survivors’ preferred format of lifestyle information was a short leaflet,
but they were also interested in internet information. The preferred timing for advice was immediately after treatment, suggesting that this may be the point of a ‘teachable moment’, where cancer survivors are motivated to make positive changes (McBride & Ostroff, 2003).

10.3 Implications

The findings of this thesis have considerable implications for the development of lifestyle interventions to help improve the health behaviours of cancer survivors in the UK. Although several theory-based behaviour change interventions have shown promise with regard to improving the health behaviours of cancer survivors, they are not necessarily appropriate for implementing on a large scale, as they are resource intensive and therefore expensive. For example, the Reach out to Enhance Wellness (RENEW) intervention was successful in increasing fruit and vegetable intake and endurance exercise among survivors of breast, prostate and colorectal cancer in the US, but relied on 12 months of telephone support from health counsellors (Morey et al., 2009). Smoking and alcohol were also excluded from this intervention. There have also been no multiple behaviour change interventions in the UK that have included physical activity, diet, weight, smoking and alcohol. There is therefore a need for the development of effective but inexpensive interventions which can be rolled out on a large scale.

In response to this need, the findings of this thesis have been used to inform the development of a low intensity lifestyle intervention as part of the ASCOT study. The ASCOT intervention is a tailored lifestyle programme, designed using psychological theory of habit-formation. In psychology, ‘habits’ have been defined as actions that are triggered automatically in response to a situation in which the behaviour has been performed repeatedly and consistently in the past (Lally & Gardner, 2013). Habit-formation advice is particularly appropriate for a brief intervention as it relatively simply involves instructing the patient to repeat an action consistently in the same context, in order to help them adopt healthy lifestyle habits (Lally & Gardner, 2013). The ASCOT intervention consists of a booklet and a telephone call, in which a researcher guides participants through the booklet and directs them to the areas they should focus on.
There is also a website resource for additional information and support. The intervention is currently being evaluated in a randomised controlled trial among breast, prostate and colorectal cancer survivors. The primary outcome is change in a composite health behaviour score, but secondary outcomes include the proportion of participants meeting each of the WCRF lifestyle recommendations.

The findings of this thesis have informed the development of the ASCOT intervention in a number of ways. All participants who completed the questionnaire for Study 6 were given the opportunity to take part in the ASCOT trial and their responses to the questionnaire are being used to tailor the intervention. As part of my analyses for study 6, I developed syntax to allow researchers to determine which participants were meeting each of the WCRF lifestyle recommendations. This is now being used to identify which health behaviours participants in the trial would benefit from focusing on. During the telephone part of the intervention, the researcher gives the participant feedback on whether they are meeting each lifestyle recommendation, and advises them on which areas they should focus on. If the intervention is efficacious, it is hoped that this discussion could be carried out by a health professional in routine care.

As well as being used to tailor the ASCOT intervention, the studies in this thesis were used to inform its development. For example, as several participants in Study 2 reported that they had searched the internet for lifestyle information, it was decided that the ASCOT intervention should include a website component. In addition, as participants in this study reported difficulties with identifying appropriate information, a list of reliable websites was added to the booklet. In Study 4, 25% of health professionals reported a lack of clear guidelines about what they should be recommending, and a further 25% thought that they were not the best person to give lifestyle advice. If efficacious, it is hoped that health professionals could be trained to deliver the ASCOT intervention in routine care, which may help overcome some of these issues. In Study 6, participants reported that their preferred time to receive lifestyle information was at the end of treatment, so this will be taken into consideration when thinking about rolling out the ASCOT intervention on a larger scale. In addition, Study 6
participants reported that their preferred formats were leaflets, but they also expressed an interest in website information.

While ASCOT and other such interventions are in development, cancer survivors can be referred to existing lifestyle programmes, such as exercise schemes and smoking cessation services. As discussed in Chapter 7 (Study 4), several local schemes are available, such as Aquaterra, a partnership with Islington Public Health which offers a free 12 week exercise programme to cancer survivors living in the borough. However, few programmes are available nationwide, so patient access may be limited. One way of overcoming this issue could be to make existing rehabilitation programmes for other chronic diseases available to cancer survivors.

In the UK, there is clinical guidance recommending cardiac rehabilitation for secondary prevention of myocardial infarction (National Clinical Guidelines Centre, 2013). As a result, eligible patients are invited to join cardiac rehabilitation programmes around four to eight weeks after they leave hospital (British Heart Foundation, 2015). A core component of cardiac rehabilitation is exercise, which has known benefits for cancer survivors (Lahart et al., 2015; Schmid & Leitzmann, 2014), highlighting its potential in this population. Cardiac patients and cancer survivors also experience similar symptoms and side effects, including pain, fatigue and depression (Lie, Bunch, Smeby, Arnesen, & Hamilton, 2012; Mitchell et al., 2011; Mock et al., 2000; Pachman et al., 2012; Walker et al., 2013), so may benefit from similar rehabilitation programmes. The Cardiac Rehabilitation In patients with Bowel Cancer (CRIB) study aims to examine the potential of an existing cardiac rehabilitation programme to take referrals for colorectal cancer patients (Munro et al., 2014). The first phase of this study has been to assess the feasibility of delivering cardiac rehabilitation to colorectal cancer patients (Hubbard et al., 2015). The intervention and trial procedures will then be refined in preparation for a large-scale randomised controlled trial.

In addition to informing behaviour change interventions, the findings of this thesis highlight a clear need to identify ways of incorporating lifestyle advice into the cancer care pathway. As discussed in Chapter 2, the National Cancer Survivorship Initiative was
set up in 2010 to try and address the needs of individuals living with or beyond cancer in the UK (Department of Health, 2010). This initiative officially drew to a close in 2013, but in its place the Living With and Beyond Cancer (LWBC) Programme was set up in 2014. This is a partnership between NHS England and Macmillan Cancer Support which aims to incorporate the findings of the National Cancer Survivorship Initiative into mainstream NHS services. Part of this programme involves ensuring that patients have access to the ‘Recovery Package’, a combination of four interventions including holistic needs assessments, a treatment summary, a cancer care review, and a patient education and support event such as a ‘health and well-being clinic’ (NHS Improvement, Support, & Department of Health, 2013).

The ‘Recovery Package’ presents a number of opportunities for cancer survivors to be given information and support about lifestyle. Health and well-being clinics are run by volunteers and health professionals to provide information on a range of topics, including diet and lifestyle. They therefore present an ideal situation for cancer survivors to be given information leaflets about lifestyle and be directed to online resources, as these were found to be their preference in this thesis. This may also be an opportune time to deliver a brief lifestyle intervention such as ASCOT. In addition, these clinics provide a valuable opportunity to meet other cancer survivors and build support networks which may help with behaviour changes. Ensuring all cancer survivors have access to these clinics may help improve the health behaviours of this population.

The cancer care review may also be a good opportunity for cancer survivors to be given information and advice about lifestyle. This involves a discussion between the patient and their GP which aims to answer any queries and assess the patient’s support needs. This presents a perfect opportunity for a GP to raise the topic of lifestyle and provide any information or direct cancer survivors to relevant services, such as smoking cessation services. Given that discussions initiated by a health professional have been associated with healthier behaviours among cancer survivors (Jones & Courneya, 2002), advice in this context may be particularly influential. Again, this is also a potential opportunity for a brief intervention such as ASCOT to be delivered.
The findings of this thesis also highlight a need for health professionals to be appropriately trained to discuss lifestyle with their cancer patients and to deal with any questions they may have. Where possible, this training should be made available as part of their Continued Professional Development (CPD). However, there are currently limited training programmes about lifestyle for health professionals working with cancer survivors. In response to the lack of training available, a recent study developed and evaluated an e-learning resource for health professionals, to help them provide nutrition advice and support to cancer survivors (Murphy, Worswick, Pulman, Ford, & Jeffery, 2015). The resource was developed with input from dietitians and included a test of existing knowledge, core principles of human nutrition, advising cancer survivors about nutrition and eating well, and a retest to evaluate learning. A qualitative evaluation was conducted using focus groups and interviews with a mixed group of 43 health professionals. This found that the training was positively received and some improvements in knowledge were demonstrated. Although further quantitative evaluation is required, these findings highlight the potential of online training for improving the knowledge of health professionals in this area.

10.4 Limitations

Although the research in this thesis produced some interesting results, there are many limitations that need to be considered when interpreting the findings. This section outlines some of the common limitations which apply to several of the studies in this thesis. The specific limitations of each study have been outlined in the relevant chapters.

10.4.1 Self-reported data

The use of self-reported data throughout this thesis is a significant limitation. Although self-reported measures are easy to administer on a large scale, they are subject to bias. Self-reported measures may result in participants giving socially desirable responses. Social desirability bias is a well-documented phenomenon in psychology and refers to the tendency of research subjects to give socially desirable responses rather than accurate ones. This may be particularly relevant when reporting sensitive lifestyle
topics, such as weight or smoking, where individuals may feel they are being judged on their behaviours. In line with this, studies have found that people typically overestimate their height and underestimate their weight which may have resulted in BMI being underestimated (Gorber et al., 2007). Health professionals may also give socially desirable responses when answering questions on their familiarity with guidelines or whether they give lifestyle advice, as they may think that it is their responsibility to know or do so.

Self-reported measures are also subject to recall bias which can threaten the internal validity of a study (Hassan, 2005). Recall of information depends on memory and participants may not always be able to remember events that occurred several weeks, months or years ago. There is evidence that 20% of the critical details of an event are irretrievable after one year and 60% are irretrievable after five years (Bradburn, Rips, & Shevell, 1987), highlighting the substantial bias that can arise from long recall periods. Throughout this thesis, where possible measures were chosen that used a recent recall period, such as ‘during the past month’, in order to minimise this bias. However, some questions by nature required participants to recall events from longer ago. For example, in Study 6, patients were asked about whether they received lifestyle advice when they were diagnosed with cancer, which could have involved recalling an event from as far back as 2012. Similarly, in Study 4 health professionals were asked to recall details of the lifestyle recommendations they were familiar with, which they may potentially have come across a long time ago.

10.4.2 Non-response and missing data

The external validity of a study relies on the assumption that study participants are representative of the population from which they are drawn. However, bias can be introduced by non-response or attrition.

In ELSA, the response rate at wave 1 was 70% and some participants reported being unable to take part because they were too unwell (Marmot et al., 2003). This would have resulted in a healthy responder bias, where participants who took part were healthier on average. In Study 1, participants were required to have three consecutive
waves of data available for at least one variable of interest, in order for it to be possible to analyse changes in health behaviours over time. This would have compounded the healthy responder bias as those who dropped out of the study may have died or been too ill to participate any longer. As described in Chapter 4, those who remained in ELSA and were subsequently included in the analysis for this study were younger, wealthier and had better health behaviours than the total ELSA sample, which is likely to have biased the results.

Non-response may also have biased the results of the surveys in Studies 4 to 6. In Study 4, the health professional survey was emailed to a large number of health professionals, of which a relatively small proportion responded. Unfortunately, no information was available on non-responders, but one could speculate that they would have been less interested in the topic of lifestyle or too busy to complete the survey. Either of these may have resulted in them being less likely to be familiar with lifestyle guidelines for cancer survivors or less likely to give lifestyle advice. It is therefore possible that the findings of this study may have been overestimated.

Data for Study 5 were collected by an independent social research agency. Although measures were taken to ensure the sample was representative of British adults aged ≥50 years (see Appendix 8.2), there was no information available on individuals who refused to take part, so again these results may be subject to bias. However, as the questions about lifestyle advice were completed as part of a larger survey, this would have minimised the likelihood that non-responders were less interested in lifestyle specifically. Nonetheless, there is likely to be a certain level of bias in the results due to non-response.

It was estimated that the response rate for Study 6 was around 41% and no information was available on non-responders. Comparison with 2011 Census data revealed that the analysed sample had a higher proportion of women and married individuals, which may have biased the results. The survey was titled ‘health and lifestyle questionnaire’ so it is likely that respondents were more interested in this topic than those who did not take
the time to complete it, so levels of interest in lifestyle advice may have been overestimated.

Even among responders, there was a varying amount of missing data across measures. Data are unlikely to be missing at random so this may have resulted in bias. For example, in Study 6 there was a large amount of missing data for the physical activity questions, which could be attributed to patients not being very physically active and therefore not wanting to answer. It is therefore possible that physical activity levels in this study may have been overestimated. The same logic may also apply to other questions.

Study 4 was an online survey and participants could only move forward if they answered the question, so data were only missing if a participant dropped out of the survey completely. Although this minimised the amount of missing data, it is likely that those who dropped out were different to those who completed it, which would have resulted in bias. For example, it is possible that those who dropped out were busier and may therefore be less likely to give lifestyle advice. Study 1 had no missing data as participants were only included if they had data available for three consecutive waves. Study 5 also had no missing data as this survey was completed as part of a computer-assisted interview so participants were required to respond to all questions.

### 10.4.3 Cross-sectional data

With the exception of Study 1 which had a prospective design, all survey data in this thesis (Studies 4-6) were cross-sectional. Therefore, although associations between variables were examined, it is not possible to infer causation. For example, in Study 6 those not meeting the WCRF lifestyle guidelines were more likely to want advice on some topics. I inferred from this that individuals with less healthy behaviours were aware that they were unhealthy, and therefore wanted advice to help them make changes. However, it is equally possible that those who were meeting the WCRF recommendations had already sought out information which had helped them to do so, and were therefore less interested in receiving further advice. Further prospective longitudinal research is required to confirm these findings.
10.5 Future research

While the studies in this thesis have found some interesting results on the health behaviours of cancer survivors and the lifestyle information available to them, there are still a number of gaps in the literature which warrant further investigation.

Study 6 in this thesis was conducted among breast, prostate and colorectal cancer survivors so it is not possible to generalise to other cancer sites. More research is needed to determine the proportion of other groups of cancer survivors who are meeting the WCRF recommendations, who receive lifestyle advice, and who are interested in information about lifestyle.

The majority of studies in this thesis were cross-sectional in nature, and although Study 1 was longitudinal, it was unable to examine all aspects of lifestyle due to the availability of data in ELSA. As a result, it would be interesting to investigate how the proportion of cancer survivors meeting WCRF recommendations changes over time as they move through the cancer care pathway. Examining whether their preferences for information change over time would also be of interest, and would allow interventions to be tailored to the patient’s need at that point in time.

As all of the studies in this thesis used subjective measures of health behaviours, it would be useful to confirm the findings using objective measures. This would provide a more robust estimate of the proportion of cancer survivors meeting each of the WCRF lifestyle guidelines. However, in most cases such measures would only be possible in large epidemiological studies for practical and economic reasons. The use of accelerometers in studies would allow for more accurate assessments of physical activity, and these have been incorporated into the most recent wave of ELSA (Steptoe et al., 2012). Smoking can be measured objectively by examining levels of carbon monoxide in expired air and serum concentrations of cotinine, the major metabolite of nicotine (Hald, Overgaard, & Grau, 2003). Objectively measured height and weight would provide a more accurate estimate of BMI, but this would require a consultation with a health professional. Such measures are available in ELSA but were only collected every other wave so could not be used for Study 1. However, a similar study has since
been conducted using this data from more recent waves (Jackson, Williams, Steptoe, & Wardle, 2014). Aspects of diet, such as fruit and vegetable consumption can also be measured objectively by examining levels of biomarkers, such as plasma ascorbic acid, beta-carotene and alpha-tocopherol 24-hour urinary potassium excretion (Cappuccio et al., 2003). A variety of new techniques are available to objectively measure alcohol consumption including transdermal alcohol sensors, which measure the concentration of alcohol in perspiration (Leffingwell et al., 2013).

Another area for future research is the development of lifestyle interventions for cancer survivors that can be incorporated into the cancer care pathway. As described above, the findings of this thesis have already been used to inform the development of the ASCOT intervention, and this is currently being evaluated among breast, prostate and colorectal cancer survivors. If the ASCOT intervention is successful in improving the health behaviours of breast, prostate and colorectal cancer survivors, a larger randomised controlled trial could be conducted to examine its impact on recurrence and survival. Future studies may also want to examine its effectiveness in changing behaviour among other groups of cancer survivors. If the intervention is unsuccessful, then future research will need to continue to investigate the best ways to help cancer survivors improve their health behaviours.

10.6 Final comments

The findings of this thesis show that only a minority of cancer survivors are meeting lifestyle recommendations and there is little evidence that they make positive changes to their lifestyle following their cancer diagnosis, highlighting a need for intervention in this population. They also show that although cancer survivors think lifestyle is important for health and are interested in lifestyle information, the majority do not receive such information following their diagnosis. These findings highlight a need for lifestyle information to be incorporated into the cancer care pathway, to ensure the best possible long-term outcomes for this population.
REFERENCES


REFERENCES

prevention in clinical practice Third Joint Task Force of European and other Societies on Cardiovascular Disease Prevention in Clinical Practice (constituted by representatives of eight societies and by invited experts). European Heart Journal, 24(17), 1601–1610. doi: 10.1016/S0195-668X(03)00347-6


REFERENCES


Bérubé, S., Lemieux, J., Moore, L., Maunsell, E., & Brisson, J. (2014). Smoking at time of diagnosis and breast cancer-specific survival: new findings and systematic...


REFERENCES


prognosis among women with early stage breast cancer. *Cancer Causes & Control, 19*(10), 1319–1328. doi: 10.1007/s10552-008-9203-0


REFERENCES


REFERENCES

Demark-Wahnefried, W., Polascik, T. J., George, S. L., Switzer, B. R., Madden, J. F., Ruffin, M. T., ... Vollmer, R. T. (2008). Flaxseed Supplementation (not Dietary Fat Restriction) Reduces Prostate Cancer Proliferation Rates in Men Presurgery. *Cancer Epidemiology, Biomarkers & Prevention : A Publication of the American Association for Cancer Research, Cosponsored by the American Society of Preventive Oncology, 17*(12), 3577–3587. doi: 10.1158/1055-9965.EPI-08-0008


298


Hashibe, M., Brennan, P., Benhamou, S., Castellsague, X., Chen, C., Curado, M. P., ...

Hassan, E. (2005). Recall Bias can be a Threat to Retrospective and Prospective Research Designs. The Internet Journal of Epidemiology, 3(2).


REFERENCES


Joshu, C. E., Mondul, A. M., Menke, A., Meinhold, C., Han, M., Humphreys, E. B., … Platz, E. A. (2011). Weight gain is associated with an increased risk of prostate cancer


Macmillan Cancer Support/ICM. (2011). *Online survey of 400 health professionals who deal with cancer patients (100 GPs, 100 practice nurses, 100 oncologists, and*
100 oncology nurses, of whom 52 were oncology clinical nurse specialists. Fieldwork conducted 23 May-12 June 2011. Survey results are unweighted.


REFERENCES


REFERENCES


illness among Canadians aged 50 or older. Statistics Canada, Catelogue No. 82-003-XPE. Health Reports, 23(4), 3–7.


QSR International Pty Ltd. (2012). NVivo qualitative data analysis software (Version 10).


320


focus on long-term survivors. *Journal of the National Cancer Institute*, 97(18), 1354–1365. doi: 10.1093/jnci/dji278


REFERENCES

Epidemiology Biomarkers & Prevention, 23(9), 1783-1792. doi: 10.1158/1055-9965.EPI-14-0046


Wilkes, S., & Evans, A. (1999). A cross-sectional study comparing the motivation for smoking cessation in apparently healthy patients who smoke to those who smoke and have ischaemic heart disease, hypertension or diabetes. Family Practice, 16(6), 608–610. doi: 10.1093/fampra/16.6.608


Appendix 4.1 Version of Study 1 published in the British Journal of Cancer

Is a cancer diagnosis a trigger for health behaviour change? Findings from a prospective, population-based study

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Background: A healthy lifestyle following a cancer diagnosis may improve long-term outcomes. No studies have examined health behaviour change among UK cancer survivors, or tracked behaviours over time in survivors and controls. We assessed smoking, alcohol and physical activity at three times (2–3 years before a cancer diagnosis, 0–2 years post-diagnosis and 2–4 years post-diagnosis) and at matched times in a comparison group.

Methods: Data were from wave 1–3 of the English Longitudinal Study of Ageing, a cohort of older adults in England. Behavioural measures were taken at each wave. Generalized estimating equations were used to examine differences by group and time, and group-by-time interactions.

Results: Of the 5146 adults included in the analyses, 433 (8.4%) were diagnosed with cancer. Those with a cancer diagnosis were less likely to be physically active (P < 0.001) and more likely to be sedentary (P < 0.001). There were no group differences in alcohol or smoking. Smoking, alcohol and activity reduced over time in the whole group. Group-by-time interactions were not significant for smoking (P = 0.17), alcohol (P = 0.28), activity (P = 0.57) or sedentary behaviour (P = 0.86), although there were trends towards a transient improvement from pre-diagnosis to immediately post-diagnosis.

Conclusion: We found little evidence that a cancer diagnosis motivates health protective changes. Given the importance of healthy lifestyles, strategies for effective support for behaviour change in cancer survivors need to be identified.

References: Study 1 included in the long-term cancer survivors’ study (Dericks-Waldersee et al., 2007; Meron, 2009).

Evidence from some early surveys and qualitative studies has indicated that some cancer survivors make positive lifestyle changes following diagnosis, including increasing physical activity (Houshbell et al., 2001; Blanchard et al., 2003; Patterson et al., 2003) and eating more healthily (Houshbell et al., 2001; Maskarinec et al., 2001; Maskarinec et al., 2003; Salmon et al., 2002; Patterson et al., 2003), although interpretation of these results is limited by small sample sizes, the possibility of retrospective bias, and the absence of a control group. However, the observation of health behaviour changes has led to the suggestion that a cancer diagnosis could be a “teachable moment”, in which individuals are motivated to adopt risk-reducing health behaviours (e.g., McBride et al., 2008).
In contrast to the qualitative studies, larger scale prevalence studies typically find that levels of smoking, alcohol consumption and physical activity in cancer survivors are similar to the general population (Bellem et al. 2005; Blanchar et al. 2008; Cunnynge et al. 2008; Grimmani et al. 2009; Smith et al. 2011). However, it is possible that pre-diagnostic lifestyles are less healthy as the cancer samples, and therefore parity with the general population post-diagnosis constitutes improvement.

There have now been a number of longitudinal studies. Two studies have used data from the Health and Retirement Study (HRS), a population-based cohort of older adults in the United States. One analysed data only on smokers and found significantly higher odds of quitting in the 2 years after a cancer diagnosis compared with smokers without any serious diagnosis (Kernan, 2006). The other analysed the full HRS sample and found a significantly greater reduction in smoking rates among those who had received a diagnosis of cancer within the previous 2 years (from 23.7% to 16.1%) than those without any new serious diagnosis (22.8% to 20.8%). But there was no significant group difference in alcohol intake, and a greater reduction in physical activity in the cancer group (Shin et al. 2012a). However, because the comparison groups in these analyses were not only free of cancer, but also free of heart disease, diabetes, stroke or lung disease, it is difficult to determine the specific influence of a diagnosis of cancer.

In men from the Diet, Cancer and Health Study in Denmark (Karch et al. 2011), a cancer diagnosis was associated with significantly reduced tobacco consumption from pre- to post-cancer diagnosis (an average of 8 years), compared with the rest of the sample, although there were no differences in alcohol use or weight. Results from the same study for women with breast cancer showed no evidence of differential change in body mass index, tobacco or alcohol (Björklund et al. 2013). In a Canadian sample (Nault et al. 2012), a cancer diagnosis was associated with a greater reduction in smoking rates (from 17.2% to 8.5%) 2 years after a cancer diagnosis than in the healthy comparison group (23% to 28%), but no significant group differences in diet, alcohol or physical activity.

All previous studies have been limited to two time points. The primary aim of the present study was therefore to examine the effect of a cancer diagnosis on changes in health behaviours across three times (6–2 years before a cancer diagnosis, 0–2 years post-diagnosis and 2–4 years post-diagnosis) using data from a population-based sample in the United Kingdom.

MATERIALS AND METHODS

Design and participants. Data were from waves 1–5 of the English Longitudinal Study of Ageing (ELSA), which were collected biennially between 2002 and 2010. ELSA is a population-based cohort of adults aged >50 years drawn from participants in the Health Survey for England (HSE) in 1998, 1999 and 2000. It is a ‘cache’ study to the HSE and has a perfusion harmonised data collection protocol (Stephenson et al. 2012). The initial core sample size at wave 1 was 11,594, of whom an average of 47% have taken part in all biennial examinations.

The cancer survivor group comprised respondents who reported a new cancer diagnosis in waves 2–4 (n = 433) and individuals with no cancer diagnosis in any wave (n = 4215) and data on at least one health behaviour for these consecutive waves are shown in Table 1. The cancer diagnosis group was older (60.2 vs 66.5 years; P < 0.001) and had a more equal gender balance than the comparison group, but the groups did not differ in wealth (P = 0.059). The analysed sample was slightly younger, wealthier and had slightly better health behaviours (were less likely to smoke and were more active), than the full ELSA sample (data not shown).

Smoking. Figure 1 shows the proportion of smokers in each group at each time. There was a significant group effect, indicating that the proportion of smokers was not significantly different overall.
Changes in health behaviours of cancer survivors

between groups (P = 0.34). There was a significant effect of time, with the proportion of smokers decreasing over time independent of group (P < 0.001). Between T0 and T1, smoking rates dropped from 12.0% to 9.4% in the cancer group and 10.2% to 9.0% in the comparison group. Between T1 and T2, smoking rates increased from 9.4% to 9.9% in the cancer group and dropped from 8.6% to 8.3% in the comparison group. The group-by-time interaction was not statistically significant (P = 0.17).

Daily alcohol consumption. Figure 2 shows the proportion of daily alcoholic drinkers in each group at each time. The group difference was not statistically significant (P = 0.09). There was a borderline significant effect of time, with the proportion of daily drinkers decreasing over time independent of group (P = 0.06). Between T0 and T1, daily alcohol consumption dropped from 22.9% to 19.2% in the cancer group and from 22.4% to 22.9% in the comparison group. Between T1 and T2, daily alcohol consumption rose from 19.2% to 20.1% in the cancer group and dropped from 22.7% to 21.6% in the comparison group. However, the group-by-time interaction was not significant (P = 0.26).

Physical activity. Figure 3 shows the results for being moderately or vigorously active at least once a week. The cancer group was less physically active than the comparison group overall (P < 0.001). The proportion of respondents who were physically active reduced over time independent of group (P < 0.05). The pattern of results suggested a greater change between T0 and T1 in the group getting a cancer diagnosis (13.2% to 9.4% vs 15.9% to 13.1% in the comparison group) while between T1 and T2, physical activity increased (9.4% to 9.9% in the cancer group and dropped from 15.1% to 14.8% in the comparison group). However, the group-by-time interaction was not statistically significant (P = 0.17).

Sedentary behaviour. Figure 4 shows the results for being sedentary (no mild, moderate or vigorous activity). The cancer group was more sedentary than the comparison group independent of time (P = 0.03), and the proportion of participants who

Table 1. Demographic characteristics of sample - percentage (%), mean (sd)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Cancer group (n = 473)</th>
<th>Comparison group (n = 432)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>69.92 (5.67)</td>
<td>68.52 (5.97)</td>
<td>0.000</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>41.0% (210)</td>
<td>41.2% (201)</td>
<td>0.200</td>
</tr>
<tr>
<td>Female</td>
<td>58.9% (233)</td>
<td>58.8% (231)</td>
<td></td>
</tr>
<tr>
<td>Wealth quintiles</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 (poorest)</td>
<td>17.9% (21)</td>
<td>18.1% (21)</td>
<td>0.603</td>
</tr>
<tr>
<td>2</td>
<td>18.4% (22)</td>
<td>18.3% (22)</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>22.4% (27)</td>
<td>21.2% (23)</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>20.3% (24)</td>
<td>20.1% (23)</td>
<td></td>
</tr>
<tr>
<td>5 (highest)</td>
<td>20.5% (25)</td>
<td>21.0% (23)</td>
<td>0.955</td>
</tr>
</tbody>
</table>

Figure 1. The proportion of each group who worked at each time point adjusted for age, sex and wealth.

Figure 2. The proportion of each group who drank alcohol daily at each time point (adjusted for age, sex and wealth).

Figure 3. The proportion of each group who were moderately or vigorously active ≥ 1 per week at each time point (adjusted for age, sex and wealth).

Figure 4. The proportion of each group who were sedentary at each time point (adjusted for age, sex and wealth).
Changes in health behaviours of cancer survivors

This longitudinal study investigated the impact of a cancer diagnosis on health behaviour change in a population-based sample of older adults living in England. In comparison with participants not receiving a cancer diagnosis, we saw no evidence that a cancer diagnosis was associated with sustained improvements in lifestyle from before diagnosis to at least 2 years after diagnosis. In both groups, the overall pattern of health behaviour change over the 4-year period indicated beneficial trends for smoking and alcohol consumption (declining rates), and adverse trends on sedentary behaviour (increasing) and vigorous physical activity (declining). Across the three time points, there were no overall significant group differences in alcohol or smoking, but individuals who received a cancer diagnosis were less active and more sedentary overall.

Although a cancer diagnosis was not associated with significant differential change across the three time points in any of the behaviours, there was a difference in the patterns of the results, with approximately linear trends in the comparison group, but non-linear trends in the cancer group. A slightly larger proportion of participants receiving a cancer diagnosis had quit smoking and reduced their alcohol intake by the first assessment after diagnosis, but this was followed with a slight rebound by the next follow-up. The activity effect – albeit indicating adverse changes – showed a similar pattern. We therefore tested the effects separately for each time transition from T0 to T1, the group-by-time interactions approached significance for all three health behaviours (P = 0.07, 0.07, 0.11). The T1 to T2 difference did not approach statistical significance, but nonetheless diminished the health behaviour differences that had emerged immediately post-diagnosis. The consistency of this pattern across the three behaviours suggests that with a larger sample size, we might have seen significant up and downs in health behaviours associated with a cancer diagnosis compared with steadier trend lines in the comparison group.

Previous research has found evidence for higher rates of smoking cessation for patients with a cancer diagnosis (McBain et al., 2006; Kennedy, 2009; Kardam et al., 2012; Newman et al., 2012a). For two of the studies, this could be because the comparison group was not only free of a cancer diagnosis, but also free from heart disease, diabetes stroke and lung disease, and these conditions could also contribute to the motivations to change (Bracks, 2009; Newman et al., 2012a). All three of the other samples (from the United States, Canada and Denmark) had higher smoking rates, especially the Danish men, than were observed in ELSA. This may be partly because UK adults get excellent quitting advice, but it could also mean any remaining smokers among UK adults are a relatively hard core group (Bracks, 2009). Either way, the observation that 75% or smokers with a cancer diagnosis failed to quit suggests that a cancer diagnosis is an uncommon opportunity for intervention. The need for assistance to quit smoking has been reported by patients following heart disease and may apply equally following a cancer diagnosis (Wickram and Bracks, 1999).

None of the previous studies, either longitudinal (Kardam et al., 2012) or cross-sectional (Bracks et al., 2005; Cro OPPS and CO MCH, 2005; ELSA and CO MCH, 2007), have found evidence that a cancer diagnosis is associated with significant change in alcohol intake, and the overall effect in this study was also non-significant. However, the possibility of a transient acute effect was indicated by the post hoc analysis, and may have been masked in studies assessing alcohol consumption longer after the diagnosis. The sample was a whole had low levels of activity, and those who received a cancer diagnosis were even less active, consistent with findings from cross-sectional studies (Grimmett et al., 2009; Smith et al., 2011). We did not see evidence of differential change in physical activity except for the non-significant trend for an acute worsening in immediately post-diagnosis. This result gives no support to the idea that individuals who get a cancer diagnosis make positive activity changes either immediately after diagnosis or in the subsequent 2 years. A similar pattern was found for sedentary behaviour, with a larger proportion of the cancer diagnosis group being sedentary from before they received their diagnosis and no improvement after diagnosis. The finding that the whole sample became progressively more sedentary over time highlights the need for interventions to increase activity and reduce sedentary time among older adults. Specific advice on being more active in the context of a cancer diagnosis could also contribute to improved long-term outcomes.

Overall, our findings provide little evidence that a cancer diagnosis is associated with spontaneous positive lifestyle changes over and above lifestyle trends among older adults. There were encouraging downward trends over time in smoking and alcohol regardless of diagnosis. The slightly higher smoking rates among those who got a cancer diagnosis dropped to match the comparison group over time, but the differential change was not statistically significant in the sample. Participants in both groups became steadily more sedentary, and there was no sign that cancer survivors became more active either immediately post-diagnosis or 2 years after that.

Given that life events such as a cancer diagnosis have been hypothesised to motivate positive lifestyle change (Karlam, 2009), it is surprising that our results provided little evidence of such change. One explanation may be that cancer survivors make some immediate, but short-lived, changes. However, it is also possible that cancer patients in the United Kingdom are not receiving adequate support and advice on lifestyle change. This would be consistent with findings from UK surveys indicating that less than half of cancer specialists routinely discuss exercise with their patients (Oxley et al., 2008; Macmillan Cancer Support, 2012).

Cancer survivorship has been on the agenda in the United States since the 1990s, whereas it is relatively new to prominence in the United Kingdom following the Cancer Reform Strategy in 2007 (Department of Health, 2007), so there are likely to be improvements in this UK statistic. We have shown that the friends and relations of patients with a cancer diagnosis are...
Changes in health behaviours of cancer survivors

Looking at the figure, it seems that the authors are discussing changes in health behaviours of cancer survivors. They mention that these changes can be influenced by lifestyle factors and can impact the quality of life for cancer survivors. The text suggests that interventions targeting health behaviours might be beneficial for cancer survivors.

The reference list at the bottom of the page contains a variety of sources, including studies on diet, exercise, and other lifestyle factors. The authors cite works by various researchers, which indicates a comprehensive approach to the subject.

In conclusion, the authors highlight the importance of understanding how cancer survivors manage their health and well-being, and they emphasize the need for further research in this area. The text is supported by a variety of references, which suggests a well-researched and evidence-based approach to the topic.

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**Acknowledgements**

Kate Williams and Jane Wardle are supported by funding from Cancer Research UK. Andrew Skegro is supported by funding from the British Heart Foundation. The English Longitudinal Study of Ageing was developed by a team of researchers based at University College London, the Institute of Fiscal Studies and the National Centre for Social Research, with funding from the National Institute on Ageing (grants 2ROIAG0644-01A1 and 2ROIAG061960) and a consortium of UK government departments coordinated by the Office for National Statistics. A grant to Jane Wardle from Cancer Research UK (C14148/A14134) supported these analyses. The data are held with the UK Data Archive.
APPENDICES

Changes in health behaviours of cancer survivors


Appendix 4.2 Demographic characteristics and health behaviours of the analysed sample and the total ELSA sample who were excluded because they did not meet the inclusion criteria

<table>
<thead>
<tr>
<th></th>
<th>Total analysed sample</th>
<th>Excluded from analysis</th>
<th>t(df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Mean ± SD</td>
<td>Mean ± SD</td>
<td>t(df)</td>
<td>p</td>
</tr>
<tr>
<td></td>
<td>65.1 ± 9.0</td>
<td>68.1 ± 11.5</td>
<td>-13.88(7410.5)</td>
<td>.000</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th>% (N)</th>
<th>% (N)</th>
<th>χ²(df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>44.2 (2268)</td>
<td>42.8 (1031)</td>
<td>1.36(1)</td>
<td>.243</td>
</tr>
<tr>
<td>Female</td>
<td>55.8 (2864)</td>
<td>57.2 (1380)</td>
<td>1.36(1)</td>
<td>.243</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Wealth quintiles</th>
<th>% (N)</th>
<th>% (N)</th>
<th>χ²(df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (lowest)</td>
<td>18.6 (935)</td>
<td>22.7 (522)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>18.7 (939)</td>
<td>23.1 (532)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>21.1 (1963)</td>
<td>18.6 (427)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>20.1 (1011)</td>
<td>19.2 (442)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 (highest)</td>
<td>21.6 (1085)</td>
<td>16.4 (376)</td>
<td>56.42(4)</td>
<td>.000</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Smoking</th>
<th>% (N)</th>
<th>% (N)</th>
<th>χ²(df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoker</td>
<td>14.3 (737)</td>
<td>17.2 (681)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-smoker</td>
<td>85.7 (4423)</td>
<td>82.8 (3268)</td>
<td>14.93(1)</td>
<td>.000</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Alcohol</th>
<th>% (N)</th>
<th>% (N)</th>
<th>χ²(df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily</td>
<td>24.2 (1133)</td>
<td>22.9 (762)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than daily</td>
<td>75.8 (3557)</td>
<td>77.1 (2569)</td>
<td>1.77(1)</td>
<td>.183</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Physical activity</th>
<th>% (N)</th>
<th>% (N)</th>
<th>χ²(df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mod/vig activity ≥ once per week</td>
<td>20.1 (1032)</td>
<td>14.6 (571)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mod/vig activity &lt; once per week</td>
<td>79.9 (4109)</td>
<td>85.4 (3335)</td>
<td>45.31(1)</td>
<td>.000</td>
</tr>
</tbody>
</table>
## Appendix 4.3 Linear-by-linear association tests of the outcome variables by group

<table>
<thead>
<tr>
<th></th>
<th>Cancer group</th>
<th></th>
<th>Comparison group</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Linear-by-linear association (df)</td>
<td>p</td>
<td>Linear-by-linear association (df)</td>
<td>p</td>
</tr>
<tr>
<td>Smoking</td>
<td>2.99(1)</td>
<td>.084</td>
<td>11.24(1)</td>
<td>.001</td>
</tr>
<tr>
<td>Alcohol</td>
<td>0.24</td>
<td>.624</td>
<td>0.90(1)</td>
<td>.344</td>
</tr>
<tr>
<td>Physical activity</td>
<td>1.74(1)</td>
<td>.187</td>
<td>5.13(1)</td>
<td>.024</td>
</tr>
</tbody>
</table>

*df=degrees of freedom*
Appendix 5.2 Poster advertising Study 2

We are looking for cancer survivors to take part in an interview study about their lifestyle (including eating and exercise) and long-term health. The study is being conducted by researchers at University College London and is funded by Cancer Research UK.

Who can take part?

To take part you must:

- Be over the age of 18 years
- Have been diagnosed with cancer at some point in adulthood (excluding childhood cancers)
- Not currently be receiving treatment for cancer
- Live in the UK

What will it involve?

If you are interested in taking part, we will give you more information about the study and arrange a time for your interview. You can either come to our offices in central London or we can conduct the interview by telephone, whichever is more convenient for you. The interview will last approximately 45 minutes to 1 hour. We will ask you a series of questions; you will be free to choose how much information you share and this will be kept confidential by the researchers. We will use the information to help us to understand more about cancer survivors’ views about lifestyle following cancer recovery and whether they would welcome information about healthy living (and if so, in what format and from whom).

Interested in taking part?

Please contact Kate Williams (Mon-Fri) or Helen Croker (Tues-Thurs):
Kate Williams: 020 7679 1736 or k.williams11@ucl.ac.uk
Helen Croker: 020 7679 5634 or h.croker@ucl.ac.uk

Any personal information will be used only for the purposes of this research study and will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998. Ethical approval has been given by UCL Research Ethics Committee.
Appendix 5.3 Information sheet for Study 2

Information Sheet for Participants in Research Studies

You will be given a copy of this information sheet.

Title of Project: Interviews to explore cancer survivors’ views of lifestyle and long-term health

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 0793/004

Name: Helen Croker

Work Address: CRUK Health Behaviour Research Centre, UCL, 1-19 Torrington Place, London, WC1E 6BT

Contact Details: h.crokar@ucl.ac.uk, 020 7679 5634

We would like to invite you to participate in an interview study, results from this will form part of a student project. You should only participate if you want to. Choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information.

Details of Study: The aim of this study is to help us to learn more about what people who have survived cancer think about lifestyle (including eating and activity) and their long-term health. You have been asked to participate because you have expressed interest in the study following promotion of the study by cancer support groups. To be eligible to take part, you should be an adult, not currently undergoing any treatment for cancer and you should not have had a cancer develop in childhood. The next stage of the study will involve us interviewing you at UCL or by telephone (depending on what you would prefer).

In the interviews you will be asked a series of questions and will be encouraged to express your views in your own words. You will be free to choose how much information you share and this will be kept confidential by the researchers. You will not have to answer any questions that you do not want to. We will use the information to help us to understand more about cancer survivors’ views about lifestyle following cancer recovery and whether they would welcome information about healthy living (and if so, in what format and from whom). We are hoping to interview approximately 15 people, and interviews will last approximately 45 minutes - 1 hour and will be tape-recorded. These recordings will be transcribed shortly after interview and will then be deleted. The transcriptions will be anonymous and no identifiable information will be saved with the transcriptions. You will be offered a summary of the results.

It is up to you to decide whether or not to take part in an interview. If you decide to take part you will be given this information sheet to keep and asked to sign a consent form. You are still free to withdraw at any time during the interview and do not need to give a reason.

If you agree to take part you will be asked whether you would be happy to be contacted about taking part in future research. Your participation in this study will not be affected should you choose not to be re-contacted.

All data will be collected and stored in accordance with the Data Protection Act 1998.

STUDY Team:
Helen Croker, Clinical Research Fellow, UCL
Kate Williams, PhD student, UCL
Dr Rebecca Boekel, Research Psychologist, UCL
Professor Jane Wardle, Professor of Clinical Psychology, UCL

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 0793/004
Appendix 5.4 Consent form for Study 2

Informed Consent Form for Participants in Research Studies

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project: Interviews to explore cancer survivors’ views of lifestyle and long-term health

This study has been approved by the UCL Research Ethics Committee (Project ID Number: 0753/004)

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you.

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Participant’s Statement

[Print name], confirm that:

- I have read the information sheet and had the project explained to me, and understand what the study involves.
- I have had the opportunity to ask questions about the study, received satisfactory answers to my questions and been advised of who to contact if I have any other questions.
- I understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
- I agree to the interview being tape-recorded and I am aware of and consent to the data from my recording being used for this project.
- I consent to the processing of my personal information for the purposes of this research study and understand that it will not be used for any other purpose.
- I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- I agree to take part in this study.

Signed: ______________________  Date: __________

Researcher’s statement:

[Print name] confirm that I have carefully explained the purpose of the study to the participant.

Signed: ______________________  Date: __________

STUDY Team:

John Smith, Field Researcher; Emily Johnson, Ethical Review Committee; Sarah Green, Research Coordinator.
Appendix 5.5 Socio-demographic questionnaire for Study 2

### Demographic questionnaire

1. **What is your age?**
   - [ ] [ ] Prefer not to say

2. **What is your gender?**
   - [ ] Male
   - [ ] Female
   - [ ] Prefer not to say

3. **Which of these best describes your ethnic group?**

<table>
<thead>
<tr>
<th>White</th>
<th>Mixed</th>
<th>Asian or Asian British</th>
<th>Black or Black British</th>
<th>Chinese/other</th>
</tr>
</thead>
<tbody>
<tr>
<td>[ ] White British</td>
<td>[ ] White and Black Caribbean</td>
<td>[ ] Indian</td>
<td>[ ] Black Caribbean</td>
<td>[ ] Chinese</td>
</tr>
<tr>
<td>[ ] Any other White background</td>
<td>[ ] White and Asian</td>
<td>[ ] Bangladeshi</td>
<td>[ ] Any other Black background</td>
<td>[ ] Prefer not to say</td>
</tr>
<tr>
<td>[ ] Any other Mixed background</td>
<td>[ ] Any other Asian background</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. **What is your marital status?**

<table>
<thead>
<tr>
<th>Single/never married</th>
<th>Married/living with partner</th>
<th>Married separated from spouse</th>
<th>Divorced</th>
<th>Widowed</th>
<th>Civil partnership</th>
<th>Prefer not to say</th>
</tr>
</thead>
<tbody>
<tr>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

*Please turn over*
5. What is the highest level of education qualification you have obtained?

<table>
<thead>
<tr>
<th>Option</th>
<th>Radio Button Selection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Degree or higher degree</td>
<td></td>
</tr>
<tr>
<td>Higher education qualification below degree level</td>
<td></td>
</tr>
<tr>
<td>A-levels or higher</td>
<td></td>
</tr>
<tr>
<td>ONC/BTEC</td>
<td></td>
</tr>
<tr>
<td>Still studying</td>
<td></td>
</tr>
<tr>
<td>O Level or GCSE equivalent (Grade A - C)</td>
<td></td>
</tr>
<tr>
<td>O Level or GCSE (Grade D - G)</td>
<td></td>
</tr>
<tr>
<td>No formal qualifications</td>
<td></td>
</tr>
<tr>
<td>Other ..............................................................................</td>
<td>Prefer not to say</td>
</tr>
</tbody>
</table>

6. Please tick the box which best describes your living arrangement:

<table>
<thead>
<tr>
<th>Option</th>
<th>Radio Button Selection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own outright</td>
<td></td>
</tr>
<tr>
<td>Own mortgage</td>
<td></td>
</tr>
<tr>
<td>Rent from Local Authority/</td>
<td></td>
</tr>
<tr>
<td>Housing Association</td>
<td></td>
</tr>
<tr>
<td>Rent privately</td>
<td></td>
</tr>
<tr>
<td>Squatting</td>
<td></td>
</tr>
<tr>
<td>Other (e.g. living with</td>
<td></td>
</tr>
<tr>
<td>family/friends)</td>
<td></td>
</tr>
<tr>
<td>Prefer not to say</td>
<td></td>
</tr>
</tbody>
</table>

7. Are you currently:

<table>
<thead>
<tr>
<th>Option</th>
<th>Radio Button Selection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed full-time</td>
<td></td>
</tr>
<tr>
<td>Employed part-time</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td></td>
</tr>
<tr>
<td>Self-employed</td>
<td></td>
</tr>
<tr>
<td>Full-time homemaker</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td></td>
</tr>
<tr>
<td>Still studying</td>
<td></td>
</tr>
<tr>
<td>Disabled or too ill to work</td>
<td></td>
</tr>
<tr>
<td>Prefer not to say</td>
<td></td>
</tr>
</tbody>
</table>

8. Have you ever been diagnosed with cancer?

<table>
<thead>
<tr>
<th>Option</th>
<th>Radio Button Selection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Not sure</td>
<td></td>
</tr>
</tbody>
</table>

If yes, which type? (please print)

When were you diagnosed? (please print year)

Please turn over
9. Do you smoke?
- [ ] Current smoker
- [ ] Former smoker
- [ ] Never smoker

10. How often do you have a drink containing alcohol?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Monthly or less</th>
<th>2 - 4 times per month</th>
<th>2 - 3 times per week</th>
<th>4+ times per week</th>
</tr>
</thead>
</table>

11. How often do you take part in any sports/activities that are **vigorously energetic**?

<table>
<thead>
<tr>
<th></th>
<th>More than once a week</th>
<th>Once a week</th>
<th>1 – 3 times a month</th>
<th>Hardly ever, or never</th>
</tr>
</thead>
</table>

12. How often do you take part in any sports/activities that are **moderately energetic**?

<table>
<thead>
<tr>
<th></th>
<th>More than once a week</th>
<th>Once a week</th>
<th>1 – 3 times a month</th>
<th>Hardly ever, or never</th>
</tr>
</thead>
</table>

13. How often do you take part in any sports/activities that are **mildly energetic**?

<table>
<thead>
<tr>
<th></th>
<th>More than once a week</th>
<th>Once a week</th>
<th>1 – 3 times a month</th>
<th>Hardly ever, or never</th>
</tr>
</thead>
</table>

14. What is your height?

[ ] cm OR [ ] ft [ ] in

15. What is your weight?

[ ] kg OR [ ] st [ ] lbs

[ ] Prefer not to say
## Appendix 5.6 Topic guide for Study 2

<table>
<thead>
<tr>
<th>Topics</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introductions and background</td>
<td>Who we are and aims of study</td>
</tr>
<tr>
<td></td>
<td>Check length of interview (45-60 mins)</td>
</tr>
<tr>
<td>Cancer history</td>
<td>When diagnosed</td>
</tr>
<tr>
<td></td>
<td>Type of cancer</td>
</tr>
<tr>
<td></td>
<td>Treatment</td>
</tr>
<tr>
<td></td>
<td>Recovery</td>
</tr>
<tr>
<td>Social context</td>
<td>Brief overview of family set up and any support received/ receiving</td>
</tr>
<tr>
<td></td>
<td>in relation to cancer diagnosis/ treatment/ recovery</td>
</tr>
<tr>
<td>Beliefs about factors involved in causing cancer and in keeping healthy in the future</td>
<td>Causal factors</td>
</tr>
<tr>
<td></td>
<td>Any particular things related to diet or physical activity?</td>
</tr>
<tr>
<td></td>
<td>Anything else (e.g. smoking, alcohol, stress, weight)?</td>
</tr>
<tr>
<td>Keeping healthy in the future (e.g. reducing risk of cancer recurrence or of long-term health condition such as heart disease or diabetes)</td>
<td>Any particular things related to diet or physical activity?</td>
</tr>
<tr>
<td></td>
<td>Anything else (e.g. smoking, alcohol, stress, weight, supplements)</td>
</tr>
<tr>
<td>Experiences with making changes to behaviour since recovering from cancer</td>
<td>Have you tried anything/ doing anything different from before your diagnosis?</td>
</tr>
<tr>
<td></td>
<td>Any particular things related to diet or physical activity?</td>
</tr>
<tr>
<td></td>
<td>Anything else (e.g. stopping smoking, cutting down alcohol, reducing stress, losing weight, taking supplements)?</td>
</tr>
<tr>
<td></td>
<td>Reasons for doing this and whether think helping?</td>
</tr>
<tr>
<td></td>
<td>Plan to continue?</td>
</tr>
<tr>
<td>Sources of information regarding lifestyle and long-term health</td>
<td>Who from</td>
</tr>
<tr>
<td></td>
<td>Have doctors/ other health professional/ anyone else talked about this?</td>
</tr>
<tr>
<td></td>
<td>Any other sources of information?</td>
</tr>
<tr>
<td></td>
<td>How received</td>
</tr>
<tr>
<td></td>
<td>How did you feel about getting this information – was it welcome?</td>
</tr>
<tr>
<td>Other information wanted</td>
<td>Any other information you wanted or that you have tried to access?</td>
</tr>
<tr>
<td></td>
<td>If so, what type of information, when and from whom would you prefer it?</td>
</tr>
<tr>
<td>Anything else?</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 6.1 Version of Study 3 published in *JMIR Cancer*

**JMIR CANCER**

**Williams et al.**

**Original Paper**

Availability of Information About Lifestyle for Cancer Survivors in England: A Review of Statutory and Charitable Sector Organizations and Cancer Centers

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**Abstract**

**Background:** Health behavior change following a cancer diagnosis has the potential to improve long-term outcomes. However, many patients do not receive professional advice about lifestyle and are therefore increasingly using the Internet to seek further information. The statutory and charitable sectors and cancer centers all play an important role in providing information and have been found to be favored by cancer survivors searching for information. However, to date there has been no systematic evaluation of the lifestyle information available online for cancer survivors.

**Objective:** The purpose of this review was to identify the lifestyle information provided for cancer survivors by statutory and charitable sector organizations and cancer centers in the United Kingdom. We aimed to identify information on tobacco, physical activity, diet, weight, and alcohol designed for people who have been diagnosed with breast, prostate, or colorectal cancer.

**Methods:** The National Health Service (NHS) website was the focus of the search for information provided by the statutory sector. Cancer centers were identified from the Organisation of European Cancer Institutes and an Internet search, and charitable sector organizations were identified by searching the Charity Commission database. The three largest generic, breast, prostate, and colorectal cancer charitable organizations were included. A systematic search of the organizations was conducted to identify lifestyle information for cancer survivors.

**Results:** Ten organizations had some lifestyle information for cancer survivors on their websites. The Christie NHS Foundation Trust, Macmillan Cancer Support, and Prostate Cancer UK had the most comprehensive guides, covering physical activity, diet, weight management, smoking, and alcohol. The NHS website did not provide any information but had a link to Cancer Research UK's information about diet. Eight organizations suggested talking to a health professional before making any changes.

**Conclusions:** The majority of organizations included in this review would benefit from updating their websites to include adequate information and advice about lifestyle for cancer survivors, or they risk cancer survivors turning to less reliable sources of information. Health professionals should be appropriately trained to deal with questions about lifestyle and to advise cancer survivors about lifestyle changes following their diagnosis.


**KEYWORDS**
cancer, survivorship, guideline, health behavior, lifestyle, diet, physical activity, body weight, smoking, alcohol drinking
Introduction

Background

There are more than 2 million people in the United Kingdom living with a cancer diagnosis, and this number is predicted to rise to over 5 million by 2040 [1]. Compared with the general population, cancer survivors are at an increased risk of cardiovascular disease, diabetes, osteoporosis, and other primary cancers [2,3]. Given these increasing numbers, addressing these long-term and late effects of cancer is an increasingly urgent issue to help reduce the burden on health services. In addition to being linked to cancer risk [4,5], smoking, poor diet, low levels of physical activity, and higher body weight have all been associated with increased risk of cancer recurrence and mortality in survivors [6-11], as well as influencing other major causes of morbidity and mortality. This has led to increasing interest in the role of lifestyle change as a means of improving long-term outcomes among cancer survivors.

There is a wealth of evidence linking lifestyle change, such as increasing physical activity levels, with improvements in quality of life and symptoms among cancer survivors [12]. Evidence is more limited for the impact on cancer outcomes, although there is emerging evidence that becoming physically active and intentionally losing weight (if overweight) may be associated with improvements in physiological markers among breast cancer survivors [12,13]. Also among breast cancer survivors, there is some evidence that following a bowel-diet post-diagnosis may be associated with a reduced risk of cancer recurrence [14]. Further studies are underway to examine the impact of behavior change on survival [15], but nonetheless, findings to date highlight the potential of behavior change to improve long-term outcomes for cancer survivors.

Prior Work

A cancer diagnosis has been considered as a candidate “teachable moment” – a time or setting at which motivation to adopt risk-reducing health behaviors is raised [16]. In line with this, surveys and qualitative studies have found that some cancer survivors report making positive lifestyle changes following their diagnosis, including eating more healthily [7-19] and being more physically active [19-21]. However, despite these reported changes, the health behaviors of cancer survivors in the United Kingdom have been found to be suboptimal, with only around 51% engaging in moderate physical activity, 15% continuing to smoke, and 6% consuming two or more alcoholic drinks per day [22]. Furthermore, studies that compare lifestyle change over time in groups that either do or do not receive a cancer diagnosis have failed to show evidence of sustained positive lifestyle changes following a cancer diagnosis and typically show a reduction in physical activity [23-25].

A range of factors may influence whether cancer survivors make lifestyle changes following their diagnosis. Mobility impairments, Ill health, weather, and time have all been cited as barriers to exercise participation in this population [26,27]. and unreliable information has been reported as a barrier to making dietary changes [28]. Lack of access to reliable information may partly be due to the absence of professional advice in the cancer context. This is consistent with surveys of health professionals that indicate that few of them discuss lifestyle factors such as physical activity with their cancer patients [29,30]. A recent survey of 300 cancer survivors conducted by the UK Department of Health also found that over 20% of cancer survivors would like more advice on diet and lifestyle, suggesting that many of them are not receiving sufficient information on the topic [31]. This has been echoed by qualitative studies that have found cancer survivors report a lack of information about physical activity, diet, and weight [32].

If cancer survivors desire more information about lifestyle but do not receive much advice within the medical setting, they may choose to seek out information themselves, as was found in a qualitative study of colorectal cancer survivors in the United Kingdom [33]. Internet use is increasing among older adults. A recent report found that 53% of those over the age of 65 years are now online, and 76% of these use the Internet on a typical day [34]. Given that cancer is primarily a disease of older people [35], this age group comprises a large proportion of cancer survivors. A recent analysis of the Health Information National Trends Survey found that the Internet was the preferred source of information by 54% of cancer survivors, highlighting a shift from more traditional sources [36]. Similarly, breast cancer survivors have been shown to use the Internet for information, even after their treatment had ended; this was the most frequently cited source of information at 16 months post diagnosis [37]. This suggests that cancer survivors may desire and continue to seek information long after regular contact with their care team has ended. Another study found that cancer survivors were more likely to use the Internet to search for health-related purposes than the general population [38].

Qualitative research with breast and prostate cancer survivors in the United Kingdom suggests that those who use the Internet for information prefer non-commercial websites, and trust websites supported by the National Health Service (NHS) or other recognized “Centres of Excellence” such as charitable organizations and cancer centers [39]. Given the rising number of cancer survivors and the shift from health professional care to supported self-management [40], it is likely that such websites will increasingly be used to obtain information about a range of topics including diet. Supporting self-management involves educating people about their condition and equipping them with the tools to help them choose healthy behaviors [41]. It is therefore crucial to examine the lifestyle information provided by these sectors in order to highlight any gaps and ensure that cancer survivors not only have access to reliable information but are provided with the tools to help them overcome barriers and make the behavior changes that could ultimately improve their long-term outcomes. If cancer survivors are unable to find the information they are looking for on these websites, they may turn to less reliable websites that put them at risk of misinformation.

Aims of the Current Study

The purpose of this review was to identify the lifestyle information and resources provided for cancer survivors by the statutory and charitable sectors and cancer centers in the United Kingdom. Specifically, we aimed to identify information on...
Methods

Identification of Statutory Sector Organizations

We first sought to identify any lifestyle information for cancer survivors provided by the UK Department of Health or NHS. The focus of the search was centered on the NHS Choices website [43], a Department of Health funded website that aims to provide objective and trustworthy information and guidance to the public on all aspects of health and health care. It is the largest health website in the United Kingdom and is certified by the Information Standard as a producer of reliable health and social care information [44].

Identification of Cancer Centers

Comprehensive cancer centers accredited by the Organization of European Cancer Institutes (OECI) were also included in the search. This included cancer centers based in the NHS or in universities. As only a limited number of cancer centers are accredited by the OECI, this search was supplemented with a Google search for “cancer center”, with cancer centers based in the NHS, charitable sector, or universities from the first page of results being included. Cancer centers in the private sector were excluded.

Identification of Charitable Sector Organizations

The Charity Commission is the official register of charitable organizations in England and Wales [45]. Searches for generic, breast, prostate, and colorectal cancer charitable organizations were done separately using the advanced search function. To identify generic cancer charitable organizations the keyword “cancer” was searched for in “charity name”, “charity objects”, and “charity activities”. The search was refined by selecting only charitable organizations operating throughout England and Wales and those who described their operations as providing “advocacy/advice/information”. This was to ensure that the included voluntary sector organizations could reasonably be expected to provide advice on lifestyle. The three largest generic cancer organizations were selected from this list, provided they met the inclusion criteria outlined below. Organization size was defined by income in 2012, which was the information available from the Charity Commission. The three largest organizations were chosen as the researchers agreed these were the most publically well known in England and also appeared at the top of Internet search results. The search was then carried out using the keywords “breast cancer”, “prostate cancer”, and “colorectal cancer”, and the three largest organizations for each of these cancer types were selected. The colorectal cancer search was repeated using the terms “bowel cancer”, “colon cancer”, and “rectal cancer”.

Charitable Organization Inclusion Criteria

The inclusion criteria for charitable organization consisted of the following: registered in the Charity Commission database; within the top three cancer types (breast, prostate, colorectal or generic); and operating in England (defined by income in 2012), listed in the Charity Commission database as providing advocacy, advice, or information, operating in England or Wales (there was no single category for England), aimed at adults, and colorectal and generic cancer charitable organizations must be for both men and women.

Search for Lifestyle Information

The NHS Choices website was searched using the terms “cancer survivors”, “cancer AND physical activity”, “cancer AND exercise”, “cancer AND diet”, “cancer AND weight”, “cancer AND alcohol”, and “cancer AND smoking” in the website’s search function and manually searching the results and following relevant links. The cancer search was repeated in the websites of the cancer centers and charitable organizations but without the word “cancer”, as these sites were already specific to cancer information. If filters were available they were used to refine the results to pages aimed at cancer patients or survivors. If the website did not have a search function, a manual search of the site was conducted using the drop-down menus. The searches were conducted between November 2014 and January 2015.

Lifestyle Information Inclusion Criteria

Information was included on physical activity, diet, weight management, alcohol, or smoking, aimed at improving the general or long-term health of cancer survivors. Lifestyle information designed to improve acute outcomes of cancer and its treatment (e.g., manage a short-term diet problem, control cancer symptoms) was excluded as this was focused on long-term survivorship. Information on cancer prevention was also excluded unless cancer survivors were specifically directed toward it.

Data Synthesis

The initial searching of the 20 websites to identify lifestyle information for cancer survivors was conducted by KW, then a selection (N=4) was checked by PC. Any uncertainties or discrepancies were discussed and agreed on with the other authors (JRB and AF). Once all the relevant lifestyle information had been agreed on, KW extracted the content. This included identifying any specific recommendations made by the organization and the basis of these recommendations. Other details about the information were also recorded including the format (e.g., print, video, podcasts) and resources or advice for helping patients change their lifestyle behaviors.

Results

Statutory Sector Organizations

As outlined in the method section, the NHS Choices website was used to identify lifestyle information for cancer survivors provided by the UK government [43].
APPENDICES

Cancer Centers
Three comprehensive cancer centers in England were accredited by the NCRI. These were the King’s Health Partners Integrated Cancer Centre [46], the Cancer Research UK Cambridge Institute [47], and the Christie NHS Foundation Trust [48]. The top Google search results for cancer centres also found Maggie’s [49], University College Hospital Macmillan Cancer Centre [50], The Royal Marsden Hospital [51], and the Clatterbridge Cancer Centre [52].

Charitable Sector Organizations
The search for genetic cancer charitable organizations found 183 results. Once these had been narrowed down using the inclusion and exclusion criteria, the three largest charitable organizations were Cancer Research UK [53], Macmillan Cancer Support [54], and the World Cancer Research Fund (WCRF) [55]. The search for breast cancer, prostate cancer, and colorectal cancer charitable organizations found 13, 15, and 5 results respectively. The three largest for each cancer site were Breast Cancer Now [56], Breast Cancer Care [57], Breast Cancer Campaign [58], Prostate Cancer UK [59], Movember Europe [60], the Orchid Cancer Appeal [61], Bowel Cancer UK [62], Beatson West of Scotland Cancer Centre [63], and Bowel Cancer Information [64].

Availability of Lifestyle Information
All the website searches yielded a large number of results, but the majority were not relevant. The NHS Choices website did not contain any lifestyle information for cancer survivors, but it did provide a link to a Cancer Research UK page on diet. It also included a page on lifestyle changes after chronic illness, however this was not included as it did not specifically mention cancer. Three organizations (3/3 cancer centers and 7/12 charitable organizations) had lifestyle information for cancer survivors available on their website. Of these, the Christie NHS Foundation Trust [46], Macmillan Cancer Support [53], and Prostate Cancer UK [59] had the most comprehensive guides, covering physical activity, diet, weight management, smoking, and alcohol. Multimedia Appendix 1 shows a summary of the online lifestyle information provided by the different sources.

Summary of Lifestyle Information
All ten organizations with lifestyle information for cancer survivors had information on diet and physical activity, but only seven had information on alcohol [48,51,53,54,57,59,63], six on weight management [48,51,53,54,57,59], and four on smoking [48,54,59,63] (Multimedia Appendix 1). The information from six organizations made reference to other guidelines, most often those produced by the WCRO [48,51,53,54,57,59]. Eight suggested discussing lifestyle with a health professional (including the general practitioner, cancer doctor, cancer nurse specialist, physiotherapist, or dietitian) before making any changes [48,51,53,54,57,59,62,63].

Physical Activity
Ten organizations had information on physical activity. Eight of these provided specific recommendations on the duration and intensity of physical activity that cancer survivors should aim for [48,51,53,56,57,59,63], of which five recommended 150 minutes of moderate physical activity per week, in varying forms (eg, 30 minutes 5 times per week [51,53,54,57,59] and the other three recommended 30 minutes every day [48,55,56,63]. Some also highlighted the importance of reducing sedentary behavior [53]. Bowel Cancer UK and Maggie’s did not specify duration or intensity but emphasized the importance of being active [49,62].

Information about physical activity was provided in a variety of formats. Two had DVDs [54,57], one had a podcast [48], and others had booklets, leaflets, or fact sheets available to download or order in paper format [44,56,62,63]. Others had brief advice about becoming active on their own [51,53,59]. Some organizations offered exercise classes that patients could join to help them get active.

The majority of organizations gave suggestions on the types of physical activity cancer survivors could do, for example, walking, swimming, or housework [48,51,54,55,57,59,62], and some provided specific exercises for cancer survivors to try at home [46]. There was occasional information about the benefits of being physically active following a cancer diagnosis, for example, “exercise for cancer patients can reduce the risk of cancer coming back” [48,55,56,57]. Patients were encouraged to start exercise gently and build up slowly and some organizations gave examples of how to do this, for example, “5 minutes of housework in the morning followed by a 5 minute walk to the shop, followed by a 10 minute dog walk” [48].

Several organizations provided information about safety during exercise and when to be careful, for example, “people with low immunity should avoid public gyms” or “stop exercising if you feel dizzy or are sick during exercise” [48,55,56,62].

A range of resources were provided to help cancer survivors be physically active. The leaflets included case studies of patients with tips on exercising with cancer, and advice on finding local exercise programs. The DVDs had information on how to become more active, including advice from experts, case studies from other cancer survivors, and exercise demonstrations [54,57].

Diet
All organizations recommended that cancer survivors eat a balanced diet, and the majority provided further details. They highlighted the importance of eating plenty of fruit, vegetables, and starchy foods, and limiting intake of energy dense foods (high in sugar or saturated fat) and red or processed meat. Prostate Cancer UK also provided a list of more specific and unusual foods that may be beneficial (eg, green tea and tomatoes), although they acknowledged that evidence is limited. The website provided information about diet in a range of formats. Some had booklets available for patients to download and print at home [46,51,55,62,63]. Others had videos for patients to watch [48,57], and podcasts for them to listen to [48]. In some cases, the website itself did not provide much information but had details about free courses patients could sign up to in order to learn more about diet [48].

All of the organizations with information about diet gave guidelines for what cancer survivors should be eating. Most provided a diagram of the “Eating Plate” [65] to help cancer survives.
survivors understand the different food groups on which they should be basing their diet [48,51,57,59,62,63]. Some then gave examples of the types of foods that came under each food group, for example, "meat, fish, eggs, tofu, soy products, pulses and Quorn are a good source of protein" [48,57,62] and reasons why these foods are healthy or healthy, for example, "fiber keeps bowel working regularly" or "oil and processed ones are associated with an increased risk of some cancers." In order to help cancer survivors eat appropriate amounts of different types of foods, several organizations gave examples of portion sizes, for example, a serving would be "three heaped tablespoons of cooked vegetables" [48,54,55,57]. To inspire patients, many organizations also provided recipe ideas for meals and snacks, for example, breakfast could be "half a gram cereal topped with sliced banana and semi-skimmed milk" [48,51,54,55].

As well as this fairly general information on what to eat, several organizations provided information about what to eat following specific cancers or treatments, or when experiencing particular symptoms. For example, Beating Bowel Cancer provided an explanation of how bowel cancer treatment and surgery affects the bowels and how this may impact on diet [63]. They also included tips for eating and avoiding bowel symptoms, for example, "eat at regular intervals, and don't eat on the move." Other organizations gave information on what to eat when losing or gaining weight. For example, the Royal Marsden suggested that when losing weight, it is best to "eat when your appetite is best and have small regular meals" [51].

Some organizations provided some tools to help cancer survivors with their diet. For example, the Royal Marsden gave some tips for overcoming problems with eating, such as "if you are too tired, get friends to help with shopping or have snacks that don't require much preparation" [51]. The Beating Bowel Cancer leaflet contained quotes from other patients with tips on what they found useful, for example, "Ginger beer really helped with nausea when undergoing chemotherapy," as well as tips for family members [63]. Similarly, the Breast Cancer Care DVD was largely narrated by patients who told their stories about how they changed their diet following their cancer diagnosis [57].

Weight Management

Seven organizations provided information on weight management for cancer survivors [48,51,54,55,57,59,62]. They all recommended maintaining a healthy weight (within the normal Body Mass Index range), and the WCRF recommended being as lean as possible without becoming underweight. Several organizations recommended that overweight people should try to lose their excess weight but emphasized that this should be done gradually (at around 0.5–1 kg a week) and should be done in consultation with a health professional [51,54,57,59,62,63]. In contrast, the Royal Marsden recommended that those who are overweight should not try to lose weight during treatment as this would make them more susceptible to infections and poor wound healing [51].

Several organizations provided advice on how to lose weight with a focus on healthy eating and physical activity. Four had advice on their websites to help people get started, including tips on weight loss (and weight gain for those who had lost weight during treatment) [51,54,57,59]. Two included information about weight in their booklets about diet [48,51].

Alcohol

Seven organizations provided information on alcohol [48,51,54,55,57,59,63]. Those were almost identical and recommended 2–3 units per day for women and 3–4 units for men (these organizations stated this as the number of drinks: 1 for women and 2 for men) [51,55,63]. The Christie NHS Foundation Trust did not provide a specific recommendation but recommended drinking less alcohol [48]. They did not provide much advice on how to limit alcohol consumption, but one (Prostate Cancer UK, 2014) referred to the NHS Choices website.

Smoking

Four organizations provided information on smoking [48,54,59,63], recommending that smokers should quit. These organizations did not provide their own advice on how to stop smoking but referred smokers to smoking cessation services and the NHS Choices website for further support.

Discussion

Principal Results

The purpose of this review was to identify lifestyle information specifically for cancer survivors provided by the statutory and charity sectors in the United Kingdom. Ten organizations had lifestyle information for cancer survivors on their websites. The Christie NHS Foundation Trust [48], Macmillan Cancer Support [54], and Prostate Cancer UK [59] had the most comprehensive guides, covering physical activity, diet, weight management, smoking, and alcohol. The NHS website did not provide any lifestyle information for cancer survivors but had a link to Cancer Research UK's information about diet.

The absence of lifestyle information for cancer survivors on the NHS website is a matter of concern, given that the NHS is the preferred source of information for many patients [59]. It is encouraging that the NHS Choices website provides links to Cancer Research UK's webpage on diet, but it would be helpful if they also directed cancer survivors to advise on physical activity and other health behaviours. Although there was no information on the main NHS website, the Christie NHS Foundation Trust [48] had very comprehensive information on its website, suggesting that lifestyle information from statutory organizations is provided to cancer patients at a local level. However, not all cancer centers provided lifestyle information, which may lead to a geographical disparity in access to lifestyle information. Even if some cancer centers have lifestyle information on their websites, patients from other centers may not know it exists or where to find it.

In the charitable sector, Macmillan Cancer Support [54] and Prostate Cancer UK [59] had the most comprehensive information on their websites, containing with their leading cancer charities. Macmillan Cancer Support in particular had dedicated sections on their websites, making it easy for cancer survivors to navigate and find the lifestyle information they need. Several of the other charitable organizations (eg, Cancer...
Research UK [53] and Breast Cancer Care [57] had information on each health behavior in a different section, making it more difficult to assemble the relevant information. This highlights a challenge that cancer survivors may face when searching for information about lifestyle.

Comparison With Prior Work
Where lifestyle recommendations were given, they were similar to UK government guidelines for the general population [6,7,9,10]. They included not smoking, limiting alcohol intake, maintaining a healthy weight, being moderately physically active for at least 150 minutes per week, and eating a diet high in fruit and vegetables and low in fat, sugar, and red and processed meat. This is likely to be due to the lack of research evidence to inform development of specific recommendations for cancer survivors. In 2007, the WCRF reviewed the evidence for the role of diet and physical activity in both cancer prevention and survival and concluded that cancer survivors should follow general population recommendations for cancer prevention [5]. More recent study results have been generally consistent with these recommendations, demonstrating associations between cancer survival and physical activity [7,12], low-fat diet [14], not smoking [7], and limited alcohol consumption [22]. However, five organizations suggested that cancer survivors who are overweight or obese should attempt to lose weight [40,43,52,57,59]. This recommendation is less well supported by the literature as weight loss has been associated with poorer disease outcomes for cancer survivors, even among those who are overweight or obese [23,74]. In the absence of good trial evidence, organizations may choose to be cautious about recommending weight loss for cancer survivors and instead emphasize the importance of a healthy diet and physical activity. If they wish to provide weight recommendations, the evidence suggests that avoiding weight gain would be preferable. The Royal Marsden’s recommendations were more in line with the evidence saying that it is not a good idea to lose weight during treatment, even if overweight [51]. Such inconsistencies in recommendations may be confusing for cancer survivors, particularly those who lose or gain weight during treatment.

Implications
Our findings have considerable implications for the organizations included in this review. On the whole, the level of information provided was suboptimal, as only half of the organizations provided any information about lifestyle and only three provided any information on all health behaviors. This was the case even though we included the NHS website and those of charitable organizations that used all of their resources to provide “advocacy, advice or information.” These findings are concerning given that statutory and charitable sector organizations and cancer centers have been found to be a favored source of information for cancer survivors and are likely to be the first point of call for those seeking information [39]. With the rise of Internet use among older adults [44] and the increasing focus on self-management, the websites of these organizations are likely to experience increasing traffic [40]. However, cancer survivors are unable to find the information they are looking for on these websites, they may turn to less reliable sources. Given the abundance of misreporting about lifestyle and cancer in the media and online [75], this could put cancer survivors at risk of misinformation and potentially hinder their chances of giving themselves the best long-term outcomes. As a result, it is crucial that the information on the majority of these websites is improved. Specifically, the main NHS website would benefit from including information about lifestyle specifically for cancer survivors, or alternatively add clear links to hospitals already providing good quality information and advice such as the Christie NHS Foundation Trust or the Royal Marsden. Other organizations would benefit from recognizing their particularities so that recommendations are easy to identify and all lifestyle information can be found in one section rather than having to search for behaviors separately [53,57].

Several of the organizations referred patients to other sources of information and emphasized the importance of talking to a health professional before making any lifestyle changes. The latter may be problematic for long-term survivors as they may no longer have regular contact with their health care team. If patients are required to make an appointment with their general practitioner before making lifestyle changes, they may be less likely to make these changes, whether through loss of motivation or other barriers. Those who do have contact with their health care team may find that their doctor or nurse may be unable to advise them about lifestyle. Health professionals have reported lack of specialist knowledge about risk factors for cancer or a barrier to discussing lifestyle [76]. This makes them reluctant to raise the issue of lifestyle change without the appropriate support to help patients make changes. It is therefore important to ensure that clinicians receive appropriate education about the importance of a healthy lifestyle following a cancer diagnosis and that they are trained in how to discuss these issues with patients. Provision should also be made for cancer speak to a specialist if they would like, such as a dietician or exercise physiologist, where such referrals schemes are in place. Another important source of information for cancer survivors is other survivors who may have already experienced particular issues with lifestyle. Some of the organizations had incorporated the experience of long-term survivors into the information they provided in order to give a unique perspective and help motivate newer survivors.

This study also has implications for Internet research in general. Evaluating the content of these websites is crucial in order to hold organizations accountable for the information they provide. This may drive up quality in a way that enhances feedback on a website may not. Evaluations such as these can drive positive change in Internet material and should be repeated at regular intervals to ensure that the quality of these websites continues to improve.

Limitations
This study has a number of limitations. Although it included 20 UK-based statutory and charitable organizations and cancer centers, it is likely that users in the United Kingdom who search for information about lifestyle would also encounter websites based in North America or other English-speaking nations. Therefore, a wider search, incorporating all English-language websites, could be useful. Also, in addition to reviewing...
information by statutory and charity organizations, it may be useful to expand the evaluation to incorporate commercial organizations (e.g., private health care companies) as users who potentially encounter them when searching for lifestyle information online. However, research has shown that patients do not favor such sites [39]. All searches were conducted between November 2014 and January 2015, and the organizations may continually update the information on their website. However, this review provides an important snapshot of the availability of lifestyle information for cancer survivors at present. Historically, charitable organizations have websites in order to fundraise rather than to provide information, which may explain the limited information available. However, all of the included charitable organizations described their operations as providing “advice”—advice online, as information such as how to cook or how to exercise. This review focused on the availability of lifestyle information online, but there are a range of other areas of information that are also important to cancer survivors such as psychological, sexual, and well-being issues, that were not included in this review.

Conclusions
Although several organizations had some information on lifestyle for cancer survivors, there was no advice on the NHS website and only three organizations had comprehensive guides, encompassing diet, physical activity, weight, alcohol, and smoking. These organizations should consider adding or updating their websites to include adequate information and advice about lifestyle for cancer survivors, or they risk cancer survivors turning to less reliable sources of information. The majority of recommendations emphasized that cancer survivors should talk to a health professional before making any lifestyle changes. Health professionals should be appropriately trained to deal with questions about lifestyle and to advise cancer survivors about lifestyle changes following their diagnosis.

Acknowledgments
All authors are supported by funding from Cancer Research UK. The authors would also like to thank Fergal Connolly for his help with second-reviewing the websites.

Conflicts of Interest
None declared.

Multimedia Appendix 1
Summary of online lifestyle information for cancer survivors.
[PDF file (Adobe PDF file), 145KB - cancer_121105_app1.pdf]

References
Appendix 7.3 Full survey for Study 4

Introduction to the study

We would like to invite you to complete this brief survey about your views on lifestyle advice (e.g. on physical activity, diet, smoking) for people diagnosed with cancer. Your responses will help inform the development of an intervention to improve the lifestyle behaviours of cancer survivors and ultimately improve their long-term health outcomes.

The survey contains a maximum of 24 questions and should take no more than 10 minutes to complete. All questions require a response but if the question is not relevant to you, please type ‘N/A’.

To be eligible to take part you must meet the following criteria:

1) Be a cancer specialist (e.g. oncologist, surgeon, nurse or allied health professional)
2) Currently be in a position where you are working directly with cancer patients
3) Work in the UK

If you would like to take part please continue to the next page. You are free to withdraw at any time without giving a reason.

All data will be collected and stored in accordance with the Data Protection Act 1998 and will not be shared or used for any other purpose. This study has been approved by the UCL Research Ethics Committee (Project ID Number): 4459/001

If you would like more information please contact the researchers using the contact details below. We can provide you with a summary of our findings on request.
Consent

Thank you for your interest in taking part in this research. If you have any questions arising from the information on the previous page, please contact the researchers on k.williams.11@ucl.ac.uk

We need to request formal consent so please could you read the following statements and check the box below if you agree to take part

1) I have read the study information on the previous page, and understand what it involves.

2) I understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.

3) I consent to the processing of my personal information for the purposes of this research study.

4) I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

5) I agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

*1. I have read the above statements and I agree to complete this survey.

☐ I agree
2. Are you familiar with any guidelines specifically for cancer patients for any of the following lifestyle topics? Please select all that apply.

- Physical activity
- Diet
- Weight management
- Smoking
- Drinking alcohol
- I am not familiar with any guidelines on these topics
### Guidelines for cancer patients

*3. Do you remember the name of the guidelines (or who produced them)? Please give any details if you can.

<table>
<thead>
<tr>
<th>Name of Guidelines</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Patients asking about lifestyle**

*4. Could you estimate how many of your patients ask you for information about the following lifestyle topics?*

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>1-25%</th>
<th>26-50%</th>
<th>51-75%</th>
<th>76-100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight management</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drinking alcohol</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Enquiring about patients' lifestyles

5. Thinking of all your patients who have completed primary treatment for cancer, with how many of your patients do you enquire about the following lifestyle topics?

By enquire we mean asking patients directly about lifestyle (e.g. do you smoke).

<table>
<thead>
<tr>
<th>Topic</th>
<th>0%</th>
<th>1-25%</th>
<th>25-50%</th>
<th>51-75%</th>
<th>&gt;75%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight management</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drinking alcohol</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6. What circumstances would prevent you from enquiring about any of these topics?
7. Again thinking of all your patients who have completed primary treatment for cancer, do you give your patients advice on any of the following lifestyle topics? By advice we mean giving direct advice, i.e. making a referral or giving information on where to get help. Please select all that apply.

- Increasing physical activity
- Eating a healthy diet
- Maintaining a healthy weight
- Quitting smoking
- Reducing alcohol consumption
- None of the above
# Lifestyle advice for cancer patients

*8. How many of your patients do you give advice about the following lifestyle topics?*

*If you did not select a topic on the previous page, please select 'none' for that topic.*

<table>
<thead>
<tr>
<th>Topic</th>
<th>None</th>
<th>1-25%</th>
<th>26-50%</th>
<th>51-75%</th>
<th>&gt;75%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increasing physical activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating a healthy diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintaining a healthy weight</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quitting smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reducing alcohol consumption</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*9. What form does this advice take?*

*If you did not select a topic on the previous page, please select 'not applicable' for that topic.*

<table>
<thead>
<tr>
<th>Topic</th>
<th>Not applicable - I don’t give advice on this topic</th>
<th>Verbal advice</th>
<th>Written advice (leaflet/ pamphlet)</th>
<th>Refer to website</th>
<th>Refer to another health professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increasing physical activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating a healthy diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintaining a healthy weight</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quitting smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reducing alcohol consumption</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other (please specify)
<table>
<thead>
<tr>
<th><strong>Lifestyle advice for cancer patients</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>10. What circumstances would prevent you from giving specific advice about any of these topics?</strong></td>
</tr>
<tr>
<td><img src="image_url" alt="Image" /></td>
</tr>
</tbody>
</table>
## Lifestyle advice for cancer patients

**11. Would any of the following factors put you off giving your patients advice (if the topic was relevant to the patient)? Please select all that apply.**

- [ ] Lack of time
- [ ] Lack of patient interest
- [ ] Not being the right person to give advice
- [ ] Patient too frail/unwell
- [ ] Seam to blame the patient
- [ ] Lack of clear guidelines
- [ ] Cultural differences of beliefs
- [ ] Not convinced it would affect cancer outcome
- [ ] Thinking the advice would not change their behaviour
- [ ] None of the above
- [ ] Other (please specify)
### Appendix

<table>
<thead>
<tr>
<th>A resource for cancer patients</th>
</tr>
</thead>
</table>

**12. Would you be interested in a resource containing relevant lifestyle information that you could give to your patients?**

- [ ] Yes
- [ ] No
A resource for cancer patients

13. Which of these would be your first choice of formats for this resource?
- [ ] Leather/pamphlet to give to patients
- [ ] Website to send patients to
- [ ] Other (please specify):

[Text box for input]
A resource for cancer patients

14. Would you perceive any problems in providing any of these resources for your patients?

- [ ] Yes
- [ ] No
A resource for cancer patients

*15. Please give details of any problems you perceive.
A few details about yourself

16. What is your profession?
- [ ] Physician
- [ ] Surgeon
- [ ] Nurse
- [ ] Allied health professional (please specify)

17. What is your job title? For example, Consultant Medical Oncologist


18. What groups of cancer patients do you work with? Please select all that apply.

- All cancer sites
- Breast
- Lung
- Prostate
- Colorectal
- Melanoma
- Non-Hodgkin Lymphoma
- Bladder
- Kidney
- Brain, Other CNS & Intracranial Tumours
- Pancreatic
- Leukaemia
- Uterine
- Oesophageal
- Ovarian
- Stomach
- Oral
- Myeloma
- Liver
- Cervical
- Thyroid
- Other site (please specify)

19. How old are you?

- Under 25 years
- 26-35 years
- 36-49 years
- 50-55 years
- 55-65 years
- 65+ years

20. What is your gender?

- Male
- Female
21. Which region of the UK do you work in?

- North East England
- North West England
- Yorkshire and the Humber
- East Midlands
- West Midlands
- East of England
- London
- South East England
- South West England
- Wales
- Scotland
- Northern Ireland
- Channel Islands
Future research

* 22. Would you be willing for us to contact you about taking part in a brief follow-up interview to this questionnaire?
   - Yes
   - No

* 23. We are planning to develop a lifestyle intervention that could be given to cancer patients at the end of primary treatment. Would you be willing for us to contact you in the future about the possibility of being involved with this?
   - Yes
   - No

24. If you are willing for us to contact you, please provide a contact email:
Thank you

Thank you for taking the time to complete our survey. If you have any questions, please contact the researchers using the details below.

Research team:
Professor Jane Wardle
Dr Abigail Fisher
Dr Rebecca Sheikh
Kate Williams

Contact details:
Department of Epidemiology and Public Health
University College London
1-19 Torrington Place
London WC1E 6BT
UK

k.williams.15@ucl.ac.uk
Tel: 020 7679 1736
**Appendix 7.4 Crosstabulation of predictor variables showing the frequencies in each group**

<table>
<thead>
<tr>
<th></th>
<th>Nurse</th>
<th>Doctor</th>
<th>Allied HP</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤45 years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
<td>15</td>
<td>1</td>
</tr>
<tr>
<td>Female</td>
<td>45</td>
<td>22</td>
<td>17</td>
</tr>
<tr>
<td>&lt;45 years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
<td>24</td>
<td>1</td>
</tr>
<tr>
<td>Female</td>
<td>77</td>
<td>18</td>
<td>7</td>
</tr>
</tbody>
</table>

HP=health professional
Appendix 8.1 Version of Study 5 published in the *British Journal of Cancer*

*Health behaviour advice to cancer patients: the perspective of social network members*

K Williams¹, R J Beeken¹ and J Wardle²,³

¹Department of Epidemiology and Public Health, Health Behaviour Research Centre, University College London, Gower Street, London WC1E 6BT, UK

*Background:* Survival for many cancers is improved by healthy lifestyles, but giving lifestyle advice to cancer patients may seem insensitive. We investigated attitudes of members of cancer patients’ social networks towards doctors giving lifestyle advice.

*Methods:* We identified social network members through a population survey of UK adults (n=2041, age ≥50) by asking respondents whether anyone close to them had ever had cancer (n=1293). Individuals with a cancer diagnosis themselves (n=202) were termed cancer survivors. Attitudes towards doctors giving advice to cancer patients on physical activity, diet and weight were each assessed with eight items.

*Results:* Most social network members (66%–73.3%) and survivors (65%–73.3%) agreed that advice on diet, activity and weight would be “beneficial”, “helpful” and “encouraging”, and 84–87% thought it was the doctors’ duty to provide it. Few network members (10–18%) or survivors (10–24%) believed it was unnecessary, “interfering”, “intrusive” or implied “blames”. Adjusted analyses using composite scores showed that attitudes did not differ between the groups.

*Conclusion:* Few cancer survivors or members of social networks of individuals with cancer thought lifestyle advice would be unnecessary, and most thought it would be beneficial. These results help counter doubt about the acceptability of lifestyle advice in the cancer context.

With increasing number of people surviving cancer (Lennard et al., 2008; Madalon et al., 2009), the long-term and late effects, which include a raised risk of diabetes, osteoporosis, cardiovascular disease and second primary cancers, pose a growing problem (Brown et al., 1993; Treas et al., 2006). All these conditions are linked with aspects of lifestyle such as smoking, diet and physical activity (Hux et al., 2001; Mohd et al., 2003). Office of the Surgeon General (US), Office on Smoking and Health (US), 2004; Washburne et al., 2006). Given that cancer survivors report rates of unhealthy lifestyle behaviours similar to the general population (Bellini et al., 2005; Robin et al., 2007; Grunnet et al., 2009) this implies considerable scope for behaviour change interventions in the oncology context, which may be delivered either through primary care or by oncology specialists.

Health professionals can have an important role in encouraging favourable health behaviours. A third of cancer patients reported being interested in receiving advice on health promotion in one patient survey (Temark-Wahlströf et al., 2006), and an exercise recommendation from an oncologist significantly increased self-reported activity in newly diagnosed breast cancer patients (Jones et al., 2004). However, surveys in the United Kingdom find that fewer than half of cancer specialists routinely discuss exercise with their patients (Daley et al., 2008; Macmillan Cancer Support/ICM, 2011). Similar results have been reported in the United States, with only 10% of cancer patients being given advice on physical activity and even fewer than 10% being given dietary advice (Temark-Wahlströf et al., 2006).

Among the barriers to giving lifestyle advice in this patient group is concern that it could be seen as insensitive or implying blame at a time when the patient is trying to cope with the stress of diagnosis and treatment (Macmillan Cancer Support/ICM, 2011). However, the emergence of the concept of “survivorship” may reflect a more positive perspective, and with it, growing interest in the idea that health behaviour advice could be part of routine cancer care. Although evidence to date suggests that such advice would be positively received by most cancer patients, we do not know whether their family...
APPENDICES

BRITISH JOURNAL OF CANCER

ATTITUDES TO LIFESTYLE ADVICE FOR CANCER PATIENTS

Material and Methods

Design and participants. To identify an unbiased sample of individuals comprising the social networks of individuals diagnosed with cancer, we used data from a population-based survey of UK adults (age >50 years). Participants were asked: ‘Has anyone close to you ever had cancer? (including you)’. They were also asked: ‘Have you ever been diagnosed with cancer yourself (include do not wish to answer)’. Participants who had received a cancer diagnosis were classified as cancer survivors, and those who reported that someone close had been affected by cancer were classified as social network members.

Data collection was carried out by a social research agency (TNS) who interviewed participants in their homes using computer-assisted personal interviewing (CAPI) on weekends between 1809 and 2001, and at weekends in March/April 2012. Random location, quota sampling was used to ensure the sample matched census data. Queries were set for sex and weight status, and for women, the presence of children in the home.

Measures. Age, sex, ethnicity (categorized into non-white or white), education (non-school only, or university), marital status (married, separated, divorced, and bald at the time of interview), and self-assessed social network members were recorded. Social economic status (SES) information was based on the National Readership Survey classification (AB, C2, D, E), and (National Readership Survey 2007). Group AB includes those with or who have had higher than intermediate managerial or professional occupations, group C1 have supervisory or junior managerial occupations, group C2 are skilled manual workers, group D are semi- and unskilled manual workers and group E are state pensioners or lowest grade workers.

Attitudes towards advice on diet and activity were assessed with 6 items for each domain (a total of 12 items) developed by the author with input from experts in the field. ‘Doctors giving advice on diet and activity are important to patients at the end of treatment’ would be beneficial if they are feeling unwell and were asked in the same stem of the questions specified cancer patients (those who are overweight). If there were more response options: strongly disagree, disagree, agree and strongly agree, which were scored from 1 to 5. These were combined into two categories for some analyses (agree/strongly agree and disagree/strongly disagree). As well as being analysed individually, responses were averaged to create an overall attitude score for each domain, with higher scores indicating more positive attitudes. The reliability of all three scales was high (physically activity Cronbach’s alpha = 0.86, healthy eating alpha = 0.86, weight loss alpha = 0.89).

Statistical analysis. Data were analysed using SPSS version 19 (IBM Corp., 2010). The SF6d were dichotomised for the analysis (AB, C1, C2, D, E). Don’t know responses were coded as missing for all analyses. Descriptive statistics were produced to determine the proportion of respondents who agreed or disagreed with each item about physical activity, healthy eating, and weight loss advice by combining agree/strongly agree and disagree/strongly disagree responses. Chi-square analyses were used to examine demographic differences between network members and survivors. Pairwise tests were used to compare the three overall attitude scores. Analysis of variance was used to examine the differences in the three mean attitude scores by demographic factors and cancer experience.

RESULTS

A total of 2021 adults completed the survey. Of these, 68% (n = 1390) knew someone close who had ever had cancer and were termed social network members, and 11% (n = 223) were cancer survivors, giving a total sample of 1613 for analysis.

Demographic characteristics are shown in Table 1. Social network members were significantly younger than the cancer survivors (P<0.001), but the groups did not differ by sex, SES, ethnicity, education or marital status. The majority of the samples were married and from white ethnic backgrounds, and women were over-represented. More respondents either had no formal qualifications or school level only than were university educated, and more were in the lower than higher SES categories.

Table 1: Demographic characteristics of social network members and cancer survivors

<table>
<thead>
<tr>
<th></th>
<th>Social network members</th>
<th>Cancer survivors</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td><strong>N</strong></td>
<td><strong>%</strong></td>
<td><strong>N</strong></td>
</tr>
<tr>
<td>Under 50</td>
<td>438</td>
<td>53.7</td>
<td>88</td>
</tr>
<tr>
<td>50-64</td>
<td>417</td>
<td>50.3</td>
<td>116</td>
</tr>
<tr>
<td>65+</td>
<td>21</td>
<td>16.0</td>
<td>4</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>507</td>
<td>43.6</td>
<td>54</td>
</tr>
<tr>
<td>Female</td>
<td>716</td>
<td>56.4</td>
<td>128</td>
</tr>
<tr>
<td><strong>Socioeconomic status (SES)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AB/C1/C2/D/E</td>
<td>548</td>
<td>47.1</td>
<td>121</td>
</tr>
<tr>
<td>ABC/C2/D/E</td>
<td>299</td>
<td>25.3</td>
<td>111</td>
</tr>
<tr>
<td>ABC/C2/D/E</td>
<td>299</td>
<td>25.3</td>
<td>111</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
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to provide lifestyle advice, and fewer than 25% believing it would be "unnecessary", "interfering" or "unimportant" or would imply "blame".

The mean attitude scores were 1.18 (SD = 0.83) for physical activity, 1.24 (SD = 0.83) for healthy eating and 1.16 (SD = 0.87) for weight loss. Attitudes were slightly more positive towards advice on healthy eating than physical activity (P < 0.001) or weight loss (P < 0.001). There were no differences between attitudes to physical activity and weight loss advice (P = 0.288). Differences in attitude scores by demographic characteristics and cancer experience are shown in Table 3. Younger respondents had slightly more positive attitudes to healthy eating advice (P < 0.01), and respondents with a university education had slightly more positive attitudes across all behaviours (P < 0.001). There were no differences between network members and cancer survivors in the adjusted analyses.

**DISCUSSION**

This is the first study to explore attitudes towards lifestyle advice in people who have a more close to them who has had cancer; a group we have termed social network members. The results of this study show that social network members recruited through a population-based survey have positive attitudes towards doctors giving lifestyle advice to patients who have recently completed cancer treatment. The majority of respondents (over 80%) saw lifestyle advice as helpful and believed that doctors had a duty to provide it. Fewer than 10% thought it would be incentivising, although slightly more (14-16%) identified the possibility of appearing to blame the patient. Men and women were equally supportive of lifestyle advice, and the only demographic differences observed were more positive attitudes to advice among younger and more highly educated respondents. In line with the growing use of the term "survivor" rather than "victim" or "sufferer", these results may indicate that public attitudes towards cancer increasingly recognize the opportunities for long-term management of the disease (Mellon, 1985; Tricoli and Callos, 2002; McCorkle et al. 2011).

Given that friends and family members are important sources of information and advice for many people who are diagnosed with cancer (Mastinone et al., 1998; Matthews et al., 2002; Pecorini and Spakos, 2007), it is encouraging that our results indicate such positive attitudes among social network members. Supported
self-management for cancer survivors is a key aim of the National Cancer Survivorship Initiative (Department of Health, 2010), and family and friends are likely to be increasingly involved. For comparison purposes, we included data on individuals who had themselves received a diagnosis of cancer (‘cancer survivors’), although the sample was comparatively small. There were no differences in attitudes to lifestyle advice between social network members and cancer survivors in the multivariable analysis adjusting for demographic factors.

The clinical implication of these results is that health professionals can feel more confident that not only do most cancer patients welcome advice on diet, activity and weight, but that their family and friends are also likely to be supportive. We did not examine reactions to health behaviour advice from other health professionals (the question specifically said ‘doctor’). It is possible that patient and those close to them would feel that the medical teams dealing with their cancer care are particularly well placed to provide safe and appropriate advice.

The strengths of this study included the novel approach of identifying members of the social networks of individuals with cancer through a population survey. This reduced the bias associated with patients nominating member of their social network and probably achieved a broader range of respondents. By recruiting through a survey that included a range of topics, it is less likely that agreement to participate was biased by attitudes to cancer. The study also had a number of limitations. The questions were hypothetical and general, and social network members were not asked to think about a specific individual with cancer, so it is possible that their responses were more stereotyped. The group identified as cancer survivors was small, as would be expected in a population sample of this size, and we lacked any of the clinical detail that would be available if recruitment had been through a clinical setting. For example, the type of cancer diagnosis was not established, and attitudes for both patients and their social networks towards lifestyle advice may be dependent on both type of cancer and prognosis. However, it allowed us to ascertain whether the patients and network members had strikingly different attitudes, and given the small numbers that would likely have been available for each cancer type, sub-group analysis may have been limited. The attitude items were based statements about advice on physical activity, diet and weight loss and they did not ask about specific recommendations. Attitudes may vary for some types and forms of lifestyle advice. We did not include a question on smoking as it was felt that the public are more aware of the potential benefits of smoking cessation relative to the other health behaviours. However, it is possible that attitudes to advice on smoking may have been different.

While these caveats, the results of this study show that lifestyle advice in the context of cancer treatment is generally regarded as beneficial by social network members of individuals with cancer, as well as by survivors themselves. These findings should help counter health professionals’ doubts about the acceptability of diet and activity advice for their patients.
Appendix 8.2 TNS Omnibus Random Location Sampling Method

Note: the information below was written and provided by TNS

The TNS CAPI Omnibus employs a random location methodology, using sampling points which are sub samples of those determined in a sampling system developed by TNS for its internal use.

Sampling frame

2001 Census small area statistics and the Postal Address File (PAF) were used to define sample points. These are areas of similar population sizes formed by the combination of wards, with the constraint that each point must be contained within a single Government Office Region (GOR). In addition, geographic systems were employed to minimise the drive time required to cover each area as optimally as possible.

600 points were defined south of the Caledonian Canal in Great Britain (GB), and, for UK samples, another 25 points were defined in a similar fashion in Northern Ireland. A further 5 points were defined north of the Caledonian Canal. These differ in size from the other points and each other to meet the need to separately cover the different parts of the Highlands and Islands.

Stratification and sample point selection

285 points were selected south of the Caledonian Canal for use by the Omnibus after stratification by Government Office Region and Social Grade. They were also checked to ensure they are representative by an urban and rural classification. Those points are divided into two replicates. Each set is used in alternate weeks. A further point north of the Caledonian Canal is issued every other week.

16 of the points in Northern Ireland were selected and divided into four replicates. Those replicates are used in rotation to give a wide spread across the Province over time in the UK samples. Similarly the statistical accuracy of the GB sampling is maximised by issuing sequential waves of fieldwork systematically across the sampling frame to provide maximum geographical dispersion. This ensures that the sample point selection remains representative for any specific fieldwork wave.

Selection of clusters within sampling points

All the sample points in the sampling frame have been divided into two geographically distinct segments each containing, as far as possible, equal populations. The segments comprise aggregations of complete wards. For the Omnibus alternate A and B halves are worked each wave of fieldwork. Each week different wards are selected in each required half and Census Output Areas selected within those wards. Then, groups of
Output Areas containing a minimum of 125 addresses are sampled in those areas from the PAF.

**Interviewing and quota controls**

Assignments are conducted over two days of fieldwork and are carried out on weekdays from 2 p.m. – 8 p.m. and at the weekend. Quotas are set by sex (male, female housewife, female non-housewife); within female housewife, presence of children and working status, and within men, working status, to ensure a balanced sample of adults within effective contacted addresses. Interviewers are instructed to leave 3 doors between each successful interview.
Appendix 8.3 Full questionnaire for Study 5

I want to ask you first about doctors giving cancer patients advice on how to increase their physical activity. How much do you agree with the following statements about doctors giving advice to cancer patients who have recently finished treatment?

Q.1 Doctors giving cancer patients advice on increasing their physical activity would be beneficial
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on how to increase their physical activity to cancer patients who have recently finished treatment?

- 3  □  Strongly agree
- 1  □  Agree
- 3  □  Strongly disagree

Q.2 Doctors giving advice on increasing physical activity would be insensitive
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on how to increase their physical activity to cancer patients who have recently finished treatment?

- 3  □  Strongly agree
- 1  □  Agree
- 3  □  Strongly disagree

Q.3 It would be placing the blame on the patient
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on how to increase their physical activity to cancer patients who have recently finished treatment?

- 3  □  Strongly agree
- 1  □  Agree
- 3  □  Strongly disagree

Q.4 It would be interfering
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on how to increase their physical activity to cancer patients who have recently finished treatment?

- 3  □  Strongly agree
- 1  □  Agree
- 3  □  Strongly disagree
Q.5 It would be **the doctor's duty**
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on how to increase their physical activity to cancer patients who have recently finished treatment?

- 3  □  Strongly agree
- 1  □  Agree
- -1 □  Disagree
- -3 □  Strongly disagree

Q.6 It would be **helpful**
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on how to increase their physical activity to cancer patients who have recently finished treatment?

- 3  □  Strongly agree
- 1  □  Agree
- -1 □  Disagree
- -3 □  Strongly disagree

Q.7 It would be **encouraging**
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on how to increase their physical activity to cancer patients who have recently finished treatment?

- 3  □  Strongly agree
- 1  □  Agree
- -1 □  Disagree
- -3 □  Strongly disagree

Q.8 It would be **unnecessary**
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on how to increase their physical activity to cancer patients who have recently finished treatment?

- 3  □  Strongly agree
- 1  □  Agree
- -1 □  Disagree
- -3 □  Strongly disagree
Now I would like to ask you about doctors giving cancer patients advice on healthy eating. How much do you agree with the following statements about doctors giving advice to cancer patients who have recently finished treatment?

Q.9 Doctors giving cancer patients advice on healthy eating would be beneficial
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on healthy eating to cancer patients who have recently finished treatment?
   3  □  Strongly agree
   1  □  Agree
  -1  □  Disagree
 -3  □  Strongly disagree

Q.10 Doctors giving advice on healthy eating would be insensitive
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on healthy eating to cancer patients who have recently finished treatment?
   3  □  Strongly agree
   1  □  Agree
  -1  □  Disagree
 -3  □  Strongly disagree

Q.11 It would be placing the blame on the patient
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on healthy eating to cancer patients who have recently finished treatment?
   3  □  Strongly agree
   1  □  Agree
  -1  □  Disagree
 -3  □  Strongly disagree

Q.12 It would be interfering
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on healthy eating to cancer patients who have recently finished treatment?
   3  □  Strongly agree
   1  □  Agree
  -1  □  Disagree
 -3  □  Strongly disagree
Q.13 It would be the doctor's duty
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on healthy eating to cancer patients who have recently finished treatment?

- 3  □  Strongly agree
- 1  □  Agree
- -1 □  Disagree
- -3 □  Strongly disagree

Q.14 It would be helpful
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on healthy eating to cancer patients who have recently finished treatment?

- 3  □  Strongly agree
- 1  □  Agree
- -1 □  Disagree
- -3 □  Strongly disagree

Q.15 It would be encouraging
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on healthy eating to cancer patients who have recently finished treatment?

- 3  □  Strongly agree
- 1  □  Agree
- -1 □  Disagree
- -3 □  Strongly disagree

Q.16 It would be unnecessary
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on healthy eating to cancer patients who have recently finished treatment?

- 3  □  Strongly agree
- 1  □  Agree
- -1 □  Disagree
- -3 □  Strongly disagree
Finally, I would like to ask you about doctors giving advice on weight-loss to cancer patients who are overweight. How much do you agree with the following statements about doctors giving advice to cancer patients who have recently finished treatment?

Q.17 Doctors giving overweight cancer patients advice on weight-loss would be beneficial
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on weight loss to cancer patients who have recently finished treatment?
   3 ☐  Strongly agree
   1 ☐  Agree
  -1 ☐  Disagree
  -3 ☐  Strongly disagree

Q.18 Doctors giving overweight cancer patients advice on weight-loss would be insensitive
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on weight loss to cancer patients who have recently finished treatment?
   3 ☐  Strongly agree
   1 ☐  Agree
  -1 ☐  Disagree
  -3 ☐  Strongly disagree

Q.19 It would be placing the blame on the patient
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on weight loss to cancer patients who have recently finished treatment?
   3 ☐  Strongly agree
   1 ☐  Agree
  -1 ☐  Disagree
  -3 ☐  Strongly disagree

Q.20 It would be interfering
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on weight loss to cancer patients who have recently finished treatment?
   3 ☐  Strongly agree
   1 ☐  Agree
  -1 ☐  Disagree
  -3 ☐  Strongly disagree
Q. 21. It would be the doctor’s duty
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on weight loss to cancer patients who have recently finished treatment?

- 3 □ Strongly agree
- 1 □ Agree
- -1 □ Disagree
- -3 □ Strongly disagree

Q. 22. It would be helpful
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on weight loss to cancer patients who have recently finished treatment?

- 3 □ Strongly agree
- 1 □ Agree
- -1 □ Disagree
- -3 □ Strongly disagree

Q. 23. It would be encouraging
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on weight loss to cancer patients who have recently finished treatment?

- 3 □ Strongly agree
- 1 □ Agree
- -1 □ Disagree
- -3 □ Strongly disagree

Q. 24. It would be unnecessary
INTERVIEWER: IF NECESSARY SAY: How much do you agree or disagree with this statement about doctors giving advice on weight loss to cancer patients who have recently finished treatment?

- 3 □ Strongly agree
- 1 □ Agree
- -1 □ Disagree
- -3 □ Strongly disagree
Appendix 9.1 Ethical approval letter for Study 6

NHS

Health Research Authority

NRES Committee South Central - Oxford B
Whitley
Level 3, Block B
Littlemore
Oxford
OX3 7JX

05 December 2014

Professor Jane Warde
1-19 Torrington Place
London
WC1E 6BT

Dear Professor Warde

Study title: Advancing Survivorship after Cancer: Outcomes Trial (ASCOT)
REC reference: 14/SC/1369
Protocol number: 14/0499
EuropaCT number: N/A
IRAS project ID: 146604

Thank you for your letter of 6 June 2014 regarding the above study.

The Committee considered your letter and supporting information and has requested the following additional information:

1. To whom should correspondence be directed?
2. Where will the data be held?
3. How will you obtain informed consent?
4. How will data be protected?
5. How will you handle any data breaches?
6. How will you deal with data requests?

We would be grateful if you could provide the above information as soon as possible, as this will enable the Committee to make a more informed decision about the ethical suitability of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above study, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study:

- A Research Ethics Committee established by the Health Research Authority
study.

Additional Conditions:

Invitation Letter

The Letter from the Clinician should be made more personal as they have met the individual. This could be achieved with the removal of the phrase "your records show..." and replacement with "Following on from your consultation..."

Letter for patients not eligible for ASCOT pilot trial

- Remove the phrase 'has not spread'
- Correct "feel get in touch" needs correcting to "feel free to get in touch".
Telephonic script for ASCOT intervention

- Correct page 5, paragraph 3 in Walk your way, sentence starting "It's a pedometer..." by removing "It's;"

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at [http://www.irisforum.nhs.uk](http://www.irisforum.nhs.uk).

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

A Research Ethics Committee established by the Health Research Authority
There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blowett (catherine.blowett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

Clinical trial autorisation must be obtained from the Medicines and Healthcare products Regulatory Agency (MHRA).

The sponsor is asked to provide the Committee with a copy of the notice from the MHRA, either confirming clinical trial autorisation or giving grounds for non-acceptance, as soon as this is available.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites listed in the application, subject to management permission being obtained from the NHS/HBC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

The Committee has not yet completed any site specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

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A Research Ethics Committee established by the Health Research Authority
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.
After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at
http://www.hra.nhs.uk/hra-training/

14/SC/1369 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

[Signature]

Mr Chris Foy
Chair

Email: researchcommittee.southcentral-oxford@nhs.net

A Research Ethics Committee established by the Health Research Authority
Appendix 9.2 R&D approval letters for Study 6

Basildon and Thurrock University Hospitals
NHS Foundation Trust

Natasha Bruce-Jones
Palliative Occupational Therapist
Basildon & Thurrock University Hospital NHS Foundation Trust

Dear Natasha,

RE: ASCOT: Lifestyle study for cancer survivors

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This letter is issued on behalf of Basildon & Thurrock University Hospital NHS FT, and I am pleased to confirm that the above study (defined by those documents listed in Appendix 1) now has permission to proceed at the above site.

As the Principal Investigator for the Basildon site, recruitment of Basildon & Thurrock University Hospital NHS Foundation Trust patients can now commence.

As always within the NHS, approval for this study is granted on the understanding that you will abide by the requirements of the Research Governance Framework issued by the Department of Health and all other relevant legislation. As Principal Investigator it is your responsibility to ensure that this project is conducted in accordance with the agreed protocol and that all storage and transfer of data complies with the Data Protection Act 1998.

Once the study is underway you will need to keep us informed of its progress, and your prompt assistance in completing quarterly progress reports issued by the Basildon R&D department would be much appreciated. Additionally you should be aware that you might be required to participate in the audit of compliance to the Research Governance Framework, which is undertaken in a proportion of projects each year.

You will also need to inform the Basildon R&D department if there are any changes to personnel, the protocol or any other documentation involved in the study. Additionally any adverse events should be reported to the Basildon R&D department and also via the Basildon & Thurrock University Hospital NHS Foundation Trust's Incident Reporting system.

Furthermore please note that any individual or members of a team intending to conduct research within Basildon and Thurrock University Hospitals, in accordance with Trust policy and Department of Health Research Governance Framework, must have undertaken Good Clinical Practice (GCP) training.

You are reminded that failure to comply with any of the specifics detailed within this formal R&D approval letter could result in withdrawal of R&D approval.

Chairman: Ian Liddle
Chief Executive: Clare Pardue

406
If you have any queries about any of the arrangements for this study, then please do not hesitate to contact me for any assistance.

Yours sincerely,

Mrs Ashley Sollari
Associate Director Research & Development
Basildon & Thurrock University Hospital NHS Foundation Trust

Cc (by e-mail):
APPENDIX 1 – List of Approved Documents

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TRUST APPROVAL LETTER

Tracey Camburn
Lead Research Nurse
Broomfield Hospital
Court Road
Chelmsford
Essex
CM1 7ET

Letter prepared on 20th January 2015
Effective from date of signature

Dear Mrs Camburn

ASCOT Study – Advancing Survivorship after Cancer Outcomes Trial.
Re: R&D 1049
IRAS: 146804

We are writing on behalf of Mid Essex Hospital Services NHS Trust (MEHT) to advise that the above study was given R&D approval. MEHT has NOT agreed to act as sponsor. The following documents were reviewed by the R&D Department:

<table>
<thead>
<tr>
<th>Description</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protocol</td>
<td>7</td>
<td>19th November 2014</td>
</tr>
<tr>
<td>Ethics approval letter</td>
<td>1</td>
<td>19th November 2014</td>
</tr>
<tr>
<td>ASCOT Poster</td>
<td>1</td>
<td>19th November 2014</td>
</tr>
<tr>
<td>Health and Life Questionnaire</td>
<td>3</td>
<td>19th November 2014</td>
</tr>
<tr>
<td>Insurance Certificate</td>
<td></td>
<td>14th July 2014</td>
</tr>
<tr>
<td>Cancer Grant Award Letter</td>
<td></td>
<td>5th December 2011</td>
</tr>
<tr>
<td>Response to REC letter</td>
<td></td>
<td>21st November 2014</td>
</tr>
<tr>
<td>IRAS Form</td>
<td></td>
<td>29th October 2014</td>
</tr>
<tr>
<td>Peer Review Comments</td>
<td>1</td>
<td>23rd September 2014</td>
</tr>
<tr>
<td>CV Tracey Camburn</td>
<td>2</td>
<td>24th March 2014</td>
</tr>
<tr>
<td>GCP Tracey Camburn</td>
<td>3</td>
<td>5th April 2013</td>
</tr>
<tr>
<td>CV Lauren Fergoy</td>
<td>4</td>
<td>4th March 2014</td>
</tr>
<tr>
<td>GCP Lauren Fergoy</td>
<td>1</td>
<td>24th February 2014</td>
</tr>
<tr>
<td>CV Mark Kibey</td>
<td>19th January 2015</td>
<td></td>
</tr>
<tr>
<td>GCP Mark Kibey</td>
<td>29th October 2014</td>
<td></td>
</tr>
<tr>
<td>CV Jackie Gunn</td>
<td>18th September 2013</td>
<td></td>
</tr>
<tr>
<td>GCP Jackie Gunn</td>
<td>12th May 2014</td>
<td></td>
</tr>
<tr>
<td>CV Liz Davey</td>
<td>11th July 2011</td>
<td></td>
</tr>
<tr>
<td>GCP Liz Davey</td>
<td>19th June 2013</td>
<td></td>
</tr>
</tbody>
</table>

We are pleased to confirm that site recruitment at MEHT can commence after a Site Initiation Visit. You will need to ensure that the patient is recruited after the instructions detailed on the bottom of the Consent Form are adhered to. The patient should sign the Consent Form, with a copy returned to the patient. A further copy should be placed in the patients notes and the original placed in the Site File. A Site File should be prepared for each study.

Chairman: Professor Sheila Salmon
Chief Executive: Paul Forden

Version 6 June 2013

409
Approval for this study is granted on the understanding that you will abide by the requirements of the Research Governance Framework issued by the Department of Health and all other relevant legislation. It is your responsibility to ensure that this project is conducted in accordance with the agreed protocol and that all storage and transfer of data complies with the Data Protection Act 1998. We would be grateful if you would ensure compliance with these instructions and the Trust R&D Operational Policy, which can be found on the Intranet.

For trials involving patients you need to be aware of Trust R&D Policy and the importance of placing a copy of the signed consent form and associated Patient Information Sheet in the patient's main NHS hospital notes. This is to ensure that other clinicians are informed about the patient's participation in the research project, together with documenting any details in the patient's main NHS hospital notes regarding specific research visits, treatments or interventions what are undertaken.

Once the study is underway you will need to keep us informed of its progress. You will be required to complete a Project Annual Status Form issued by the MEHT R&D Department. Additionally, you should be aware that you might be required to participate in the audit of compliance to the Research Governance Framework, which is undertaken in a proportion of the projects each year. Finally when your project has reached completion you will be expected to complete an R&D Project Closure Form.

You will also need to inform the MEHT R&D Department if there are any changes to personnel, the protocol or any other documentation involved in the study. If the Principal Investigator (PI) retires, leaves the Trust or abdicates responsibility for this trial there must be a clear handover to the new PI which must be communicated in writing to the R&D Department. Additionally any adverse events or unexpected serious adverse reactions should be reported to the MEHT R&D Department and also via the MEHT electronic Datix system.

Furthermore, please note that any individual or members of a team intending to conduct research within MEHT, in accordance with Trust Policy and Department of Health Research Governance Framework, must have undertaken Good Clinical Practice (GCP) training. This is valid for two years.

You are reminded that failure to comply with any of the specifics detailed within this formal R&D approval letter could result in withdrawal of R&D approval. If you have any queries about any of the arrangements for this study please contact Mandy Austin, R&D Coordinator on Ext 5136, who will be happy to assist you.

This letter has been sent via email, with a read receipt requested. This will act as acceptance to the conditions outlined above, unless the R&D Department is informed of any issues within 48 hours of receipt of this document.

We wish you every success with the project.

Yours sincerely

Bruce Philp
R&D Co Director

Cc
Laween Al-Atroshi, Chief Research Officer
Christian Barnett, Clinical Trials Support Manager
Lyndsay Johnson, Clinical Trial Administrator
Kate Williams, Sponsor Contact,

Chairman : Professor Sheila Salmon
Chief Executive : Paul Forden
Version 6 June 2013

20 JAN 2015
Mid Essex Hospital Service NHS Trust
Broomfield Hospital
Broomfield, Chelmsford, CM1 7ET

410
Southend University Hospital NHS Foundation Trust

R&D Department
Ground Floor X-ray
Southend University Hospital NHS Foundation Trust
Prittlewell Chase
Westcliff on Sea
SS0 ORY

Tel: 01702 436555
Fax: 01702 221300

Mrs Anne McPherson
Research Nurse
Department of Oncology & Radiotherapy
Southend University Hospital NHS Foundation Trust

Dear Mrs McPherson

Re: Southend University Hospital NHS Foundation Trust R&D approval to undertake a research study

Study: ASCOT / Advancing Survivorship after Cancer: Outcomes Trial / Patient Survey

R&D Ref: P0832  MREC ref: 14/SC/1369  Date of favourable opinion: 07/01/2015

IRAS: 146804  NIHR (Portfolio): 17783  Research Governance Report issued: 03/02/2015

I am writing to provide you with Trust R&D approval to undertake the above study.

You must inform the Clinical Director - Research and Audit immediately of any adverse event which might result in a claim. You must inform the R&D Office of any changes to the trial protocol or any other study documentation, and forward to them copies of the new documentation. You must also copy in the R&D Office on any reports or publications you make to regulatory bodies and respond to the R&D Office, when reasonably requested, for a study progress report.

Southend University Hospital NHS Foundation Trust manages all research in accordance with the requirements of the Research Governance Framework and as the holder of this NHS Permission letter you must comply with the responsibilities of Principal Investigator as laid down in the Research Governance Framework for Health and Social Care (2nd Ed. 2005).

Yours sincerely

[Signature]

Professor Bhaskar Dasgupta
Consultant Rheumatologist, Clinical Director Research & Audit
Honorary Professor Health & Human Sciences Essex University

Dated 3/2/15
### Documents approved for use in this Trust:

<table>
<thead>
<tr>
<th>Description</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protocol</td>
<td>7</td>
<td>19/11/2014</td>
</tr>
<tr>
<td>Letter of Invitation (Patient Survey)</td>
<td>3.0</td>
<td>15/12/2014</td>
</tr>
<tr>
<td>Health and lifestyle questionnaire</td>
<td>3.0</td>
<td>19/11/2014</td>
</tr>
</tbody>
</table>
Appendix 9.3 Patient invitation letter for Study 6

[HEADER FOR NHS TRUST]

Dear [PARTICIPANT NAME]

I am contacting you because following on from your consultation at [NAME OF NHS TRUST] you were diagnosed with cancer in 2012 or 2013. I would like to invite you to participate in some voluntary research about lifestyle for people who have been diagnosed with cancer. This research is being funded by Cancer Research UK and involves researchers from University College London and London Cancer.

What will it involve?
I have enclosed a ‘Health and Lifestyle Questionnaire’ for you to complete. It asks questions about your current health and lifestyle and about the advice you received when you were diagnosed with cancer. This information is very important to us as it will help us improve the care of people diagnosed with cancer.

What am I being asked to do?
We would be very grateful if you could complete this questionnaire and return it to the researchers using the freepost envelope provided (you do not need a stamp). If you prefer you can also complete the questionnaire online at: [web address]

Do I have to take part?
No. Taking part is voluntary, if you choose not to do so it will not affect your medical care in any way.

Do I need to leave my contact details?
On the last page of the questionnaire, there is an invitation to take part in a trial. If you would like more information about this trial, please leave your contact details and a researcher will post you some more information. Your details will remain strictly confidential and will not be shared with anyone outside the research team. If you do not want to leave your contact details, you can return the ‘Health and Lifestyle Questionnaire’ anonymously.

Thank you for your consideration. We look forward to hearing from you.

With kind regards,

[Signature]  
[Name of clinician who treated patient]
Appendix 9.4 Full questionnaire for Study 6
HEALTH AND LIFESTYLE QUESTIONNAIRE

This is a survey about health and lifestyle among people who have been diagnosed with breast, prostate or bowel (colorectal) cancer.

The study is being carried out by researchers at University College London in collaboration with London Cancer. It is funded by Cancer Research UK.

There are no right or wrong answers to any of the questions. Please be as honest as possible when answering. Your answers will be confidential and will not be shared with anyone other than the research team.

Once you have filled in the questionnaire, please can you return it in the freepost envelope provided – there is no need for a stamp.

By completing this questionnaire you are consenting to your anonymous information being used for research on lifestyle in people diagnosed with cancer.

If you have any questions please contact:
Dr Abigail Fisher or Dr Maggie Heinrich
Health Behaviour Research Centre
Department of Epidemiology and Public Health
University College London

Dr Abigail Fisher:
T 020 7679 1722
E abigail.fisher@ucl.ac.uk

Dr Magzie Heinrich:
T 020 7679 1809
E malgorzata.heinrich@ucl.ac.uk
### SECTION 1: ABOUT YOU

This section contains some questions about you to give us some background information.

1. How old are you? ____ years

2. What is your sex?  [ ] Male  [ ] Female

3. At what age did you first leave education? ____ years

4. Which educational or professional qualifications do you have? Please tick all that apply.
   - [ ] GCSE/School certificate/O-level/GCE
   - [ ] Vocational qualifications (e.g. NVQ1+2)
   - [ ] A-level/Higher school certificate or equivalent (e.g. NVQ3)
   - [ ] Bachelor Degree or equivalent (e.g. NVQ4)
   - [ ] Masters/PhD/PGCE or equivalent
   - [ ] Still studying
   - [ ] No formal qualifications
   - [ ] Other (please specify) __________________________

5. What was your employment situation before you were diagnosed with cancer? Please tick one option.
   - [ ] Employed full-time
   - [ ] Employed part-time
   - [ ] Self-employed
   - [ ] Unemployed and looking for work
   - [ ] Full-time education
   - [ ] Retired
   - [ ] Unable or too ill to work
   - [ ] Voluntary work
   - [ ] Other (please specify) __________________________

6. What is your current employment situation? Please tick one option.
   - [ ] Employed full-time
   - [ ] Employed part-time
   - [ ] Self-employed
   - [ ] Unemployed and looking for work
   - [ ] Full-time education
   - [ ] Retired
   - [ ] Unable or too ill to work
   - [ ] Voluntary work
   - [ ] Other (please specify) __________________________

7. What is your current marital status?
   - [ ] Married/living with partner
   - [ ] Single
   - [ ] Separated
   - [ ] Widowed
   - [ ] Divorced

8. Please tick the box which best describes your living arrangement:
   - [ ] Alone
   - [ ] With partner only
   - [ ] With immediate family (including children)
   - [ ] With other family
   - [ ] With friends
   - [ ] In residential care/nursing home

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**HEALTH AND LIFESTYLE QUESTIONNAIRE**

Page 3
9. Which of these best describes your ethnic group?

- White British
- White Irish
- Any other White (please specify)
- Indian
- Bangladeshi
- Pakistani
- Chinese
- Any other Asian (please specify)
- Black African
- Black Caribbean
- Any other Black (please specify)
- Mixed White and Black African
- Mixed White and Black Caribbean
- Mixed White and Asian
- Any other mixed (please specify)
- Any other (please specify)

10. Do you use email?  
- Yes  
- No

11. Do you use the internet? (e.g., for health information)  
- Yes  
- No

12. What is your height?  
- ft  
- inches  
- or  
- cm

13. What is your weight?  
- St  
- lbs  
- or  
- kg

14. Is your weight nowadays…

- More than before you were diagnosed with cancer
- About the same as before you were diagnosed with cancer
- Less than before you were diagnosed with cancer

15. Which of the following best describes you at the present time?

- I think I should be trying to lose weight
- I think I should be trying to gain weight
- I don’t think I need to change my weight
- Don’t know
SECTION 2: YOUR HEALTH

These questions are about your cancer and your general health. This is to help us understand what you have been through and how you are now.

1 Which of these types of cancer have you been diagnosed with? Please tick all that apply.

- [ ] Breast
- [ ] Prostate
- [ ] Bowel (colorectal)
- [ ] Other (please specify)

Approximate date of diagnosis

- [ ] month
- [ ] day
- [ ] year

Please answer the following thinking about your most recent cancer:

2 At the time of your diagnosis, what stage was this cancer?

- [ ] 1
- [ ] 2
- [ ] 3
- [ ] 4
- [ ] Don't know

3 Has this cancer spread to any other parts of your body?  

- [ ] Yes
- [ ] No
- [ ] Don't know

4 What treatment(s) have you had for this cancer? Please tick all that apply.

- [ ] Surgery
- [ ] Radiotherapy
- [ ] Chemotherapy
- [ ] Hormone therapy
- [ ] Active surveillance
- [ ] Not sure
- [ ] None
- [ ] Other (please give details)

5 How long is it since you completed your main treatment for this cancer?

- [ ] I am still having my main treatment
- [ ] It is less than 3 months since my main treatment
- [ ] It is between 3 and 12 months since my main treatment
- [ ] It is between 1 and 5 years since my main treatment
- [ ] On active surveillance
- [ ] Don't know/can't remember

6 Have you ever had any of the following health problems? Please tick all that apply.

- [ ] Osteoporosis
- [ ] Diabetes
- [ ] Asthma
- [ ] Emotional or psychiatric illness
- [ ] Stroke
- [ ] Parkinson's disease
- [ ] Alzheimer's disease or dementia
- [ ] Lung disease
- [ ] Other (please give details)

- [ ] Arthritis
- [ ] Angina
- [ ] Heart attack
- [ ] Heart murmur
- [ ] Irregular heart rhythm
- [ ] Any other heart trouble
- [ ] Another cancer

HEALTH AND LIFESTYLE QUESTIONNAIRE
SECTION 3: PHYSICAL ACTIVITY

These questions are about how active you are and how this might have changed since you were diagnosed with cancer.

1. Over the past month, how many times a week on average did you do the following kinds of exercise for more than 15 minutes during your free time?
   a. Strenuous exercise (heart beats rapidly) e.g. running, jogging, vigorous swimming, cycling
      Times per week: ___  Duration of each session: ___ hours ___ minutes
   b. Moderate exercise (not exhausting) e.g. fast walking, easy cycling, easy swimming
      Times per week: ___  Duration of each session: ___ hours ___ minutes
   c. Mild exercise (minimal effort) e.g. easy walking, fishing, bowling
      Times per week: ___  Duration of each session: ___ hours ___ minutes
   d. During a typical 7-day period (a week), in your leisure time, how often do you engage in any regular activity long enough to work up a sweat (heart beats rapidly)?
      [ ] Often  [ ] Sometimes  [ ] Rarely/Never

2. Is the amount of physical activity you do nowadays...
   [ ] More than before you were diagnosed with cancer
   [ ] About the same as before you were diagnosed with cancer
   [ ] Less than before you were diagnosed with cancer

3. Which of the following best describes you at the present time?
   [ ] I think I should be doing more physical activity
   [ ] I think I should be doing less physical activity
   [ ] I don’t think I need to change my physical activity
   [ ] Don’t know

4. Think about time you spent sitting on weekdays during the last 7 days. Include time spent at work, home, while doing course work, and during leisure. During the last 7 days how much time did you usually spend sitting on a weekday?
   Hours per weekday: ___  Minutes per weekday: ___  [ ] Don’t know

5. How many hours of television do you watch on an ordinary day or evening, that is, Monday to Friday?
   Hours per weekday: ___  [ ] Don’t know

6. How many hours of television do you normally watch in total over the weekend, that is, Saturday and Sunday?
   Hours per weekend: ___  [ ] Don’t know
### SECTION 4: DIET AND NUTRITION

These questions are about your diet. They do not cover everything you eat, just a few of the types of foods we are interested in. We know some of these questions are difficult but we would be grateful if you could answer them as best you can.

1. **About how many times a week do you eat a serving of the following foods?**

<table>
<thead>
<tr>
<th>Food Description</th>
<th>Less than once a week or never</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pasta, rice, noodles, or couscous</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Potatoes, sweet potatoes, yams, or plantains</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peas</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Beans (including baked), lentils, chickpeas, or other pulses</td>
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<tr>
<td>Any other vegetables</td>
<td></td>
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<td></td>
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<tr>
<td>Fruit (fresh, frozen, canned, dried)</td>
<td></td>
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<td></td>
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<tr>
<td>Cheese (any except cottage cheese)</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Beef (excluding burgers, pork, lamb, or goat)</td>
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<td></td>
<td></td>
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<tr>
<td>Beef burgers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bacon, ham, salami, hot dogs, or sausages</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chicken or turkey (including nuggets/burgers)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fish or shell fish (including tinned and breaded fish but excluding fried/battered fish)</td>
<td></td>
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<tr>
<td>Meat alternatives (e.g. eggs, soya, tofu, Quorn but excluding nuts)</td>
<td></td>
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<tr>
<td>Nuts eaten in a meal as an alternative to meat (e.g. nut roast)</td>
<td></td>
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<tr>
<td>Fried food (e.g. fried/battered fish, chips, fried breakfast, samosas, fried rice, bhajis, puris, fritters)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cakes, pies, puddings, pastries, or Indian sweets</td>
<td></td>
<td></td>
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<tr>
<td>Biscuits, chocolate or savoury snacks (e.g. crisps, sax, Bombay mix, nuts)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Coconut milk or coconut cream</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### 2 How often do you drink the following?

<table>
<thead>
<tr>
<th>Beverage Type</th>
<th>Never/rarely</th>
<th>Once a week</th>
<th>2–3 times/week</th>
<th>4–6 times/week</th>
<th>Once a day</th>
<th>Twice a day</th>
<th>3 or more times/week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular squash, cordials, fizzy drinks and juice drinks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sugar-free squash and diet fizzy drinks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pure fruit juice (including from concentrate)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Water</td>
<td></td>
<td></td>
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<td></td>
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</tr>
</tbody>
</table>

### 3 About how many times a week do you have the following breakfast cereals or porridge?

<table>
<thead>
<tr>
<th>Cereal Type</th>
<th>None</th>
<th>Less than 1 per week</th>
<th>1–2 per week</th>
<th>3–5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sugary, Chocolate, Rice or Corn cereals (e.g. Frosted, Coco Pops, Sugar Puffs, Corn Flakes, Rice Crispies, Special K)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Porridge, Ready Brek, Muesli, Multigrain/Wheat cereals (e.g. Shredded Wheat, Weetabix, Puffed Wheat, Fruit n Fibre, Just Right, Shreddies, Start, Cheerios, Nutri-Grain)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bran cereals (e.g. All-bran, Branflakes, Sultana Bran)</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

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**Please use the following examples to help you answer question 4:**

- Pure vegetable oil or Cooking oil (e.g. olive, sunflower, soya, corn, rapeseed, Flora Cuisine, Lurpak Cooking Liquid)
- Butter (including spreadable), Ghee, Dripping, Solid cooking fats, Lard, Palm oil, Coconut oil (e.g. Cockern, Crisp N Dry solid, Tlox)
- Half fat butter, Hard/baking margarine (e.g. Stork Baking Block, Lurpak Cooks Range Baking, Flora Great For Baking, Clover, Willow)
- Soft margarine (e.g. Stork, I Can’t Believe It’s Not Butter, Clover Light)
- Sunflower margarine, Olive margarine, Low fat spread (e.g. Flora, Vitalite, Flora Light, Bertolli, Bertolli Light, Bнесен, I Can’t Believe It’s Not Butter Light)

### 4 What sort of fat do you most often use for the following? Please tick one option.

- [ ] Pure vegetable oil or Cooking oil
- [ ] Butter/Ghee etc.
- [ ] Half fat butter
- [ ] Soft margarine
- [ ] Sunflower/Olive margarine
- [ ] No fat used or don’t eat these foods
## APPENDICES

### b. For frying?

- Pure vegetable oil or Cooking oil
- Butter/Ghee etc.
- Half fat butter
- Soft margarine
- Sunflower/Olive margarine
- No fat used or don't eat these foods

### c. For baking?

- Pure vegetable oil or Cooking oil
- Butter/Ghee etc.
- Half fat butter
- Soft margarine
- Sunflower/Olive margarine
- No fat used or don't eat these foods

### d. For roasting?

- Pure vegetable oil or Cooking oil
- Butter/Ghee etc.
- Half fat butter
- Soft margarine
- Sunflower/Olive margarine
- No fat used or don't eat these foods

5. About how many rounded teaspoons of margarine, butter or other spread do you usually use in a day (e.g. on bread, sandwiches, toast, potatoes, vegetables)? NB: One rounded teaspoon is roughly the amount used to cover a slice of bread thinly.

<table>
<thead>
<tr>
<th>Spread Type</th>
<th>Amount per Day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Butter (including &quot;Lighter&quot;, &quot;Spreadable&quot; and half-fat), Ghee or Margarine (e.g. Stork, Bortoli, Clover, Clover Lighter, I Can't Believe It's Not Butter, Flora, Flora Butter, Flora Pro-activ, Benecol, Vitalife, supermarket own brand olive/sunflower spread)</td>
<td>---</td>
</tr>
<tr>
<td>Low fat spread (e.g. Flora Light, Flora Lighter Than Light, Flora Pro-activ Olive, Flora Pro-activ Light, I Can't Believe It's Not Butter Light, supermarket own brand olive/sunflower light spread, Bortoli Light, Benecol Light, Clover Lighter Than Light)</td>
<td>---</td>
</tr>
</tbody>
</table>

6. About how many rounded teaspoons of sugar, honey, or syrup do you usually use in a day (e.g. in coffee, tea, milk, bread, cereals, fruit)?

<table>
<thead>
<tr>
<th>Type of Sweetener</th>
<th>Amount per Day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total teaspoons per day</td>
<td>---</td>
</tr>
</tbody>
</table>

7. About how much milk do you use in a day (e.g. on cereal and in tea or coffee)?

<table>
<thead>
<tr>
<th>Milk Type</th>
<th>None</th>
<th>Less than a quarter-pint per day</th>
<th>About a quarter-pint per day</th>
<th>About a half-pint per day</th>
<th>At least 1 pint per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-fat (whole)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Semi-skimmed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1% fat</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skimmed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-dairy (e.g. rice or soya milk)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### APPENDICES

8. About how many pieces of bread, rolls, chapatis etc. do you eat on a usual day?

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>Less than 1 per day</th>
<th>1-2 per day</th>
<th>3-4 per day</th>
<th>5 or more per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brown, granary, half and half, seeded, wheatgerm, or oat</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wholemeal (including wholemeal seeded and wholemeal granary) or wholegrain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

9. Over the past month, how many portions of fruit did you usually eat? Include fruit eaten at meal times or as a snack. Examples of a serving are 1 apple or banana, a large slice of melon, 2 plums or satsumas, a small bowl of grapes, 2 tablespoons of dried fruit or 1/2 tablespoon of dried fruit.

- Less than 1 per week
- 1 per week
- 2–3 per week
- 4–6 per week
- 1 per day
- 2 per day
- 3 or more per day

10. Over the past month, how many portions of vegetables did you usually eat? Include vegetables eaten at meal times or as a snack. Examples of a serving are 2 heaped tablespoons of broccoli or carrots, 3 tablespoons of sweetcorn or peas or a bowl of salad. Please do not include potatoes, sweet potatoes or plantains as a vegetable serving.

- Less than 1 per week
- 1 per week
- 2–3 per week
- 4–6 per week
- 1 per day
- 2 per day
- 3 or more per day

11. Would you say your diet now is...:

- Healthier than before you were diagnosed with cancer
- About the same as before you were diagnosed with cancer
- Less healthy than before you were diagnosed with cancer

12. Which of the following best describes you at the present time?

- I think I should have a healthier diet
- I don't think I need to change my diet
- Don't know
SECTION 5: ALCOHOL

These questions are about how much alcohol you drink and how this might have changed since you were diagnosed with cancer.

1a. How often do you have a drink containing alcohol?
- Never
- Monthly or less
- 2–4 times per month
- 2–3 times per week
- 4–5 times per week
- Every day

This is one unit of alcohol...

Half pint of regular beer, lager or cider
1 small glass of wine
1 single measure of spirits
1 small glass of sherry
1 single measure of aperitifs

…and each of these is more than one unit

Pint of regular beer/lager/cider
Pint of premium beer/lager/cider
Alcopop or can/bottle of regular lager
Can of premium lager or strong beer
Can of super strength lager
Glass of wine (175ml)
Bottle of wine

1b. How many units of alcohol do you drink on a typical day when you are drinking?
- I never drink alcohol
- 1–2
- 3–4
- 5–6
- 7–9
- 10+

1c. How often have you had 6 or more units (for women), or 8 or more (for men), on a single occasion in the last year?
- Never
- Less than monthly
- Monthly
- Weekly
- Daily or almost daily

2. Is the amount of alcohol you drink nowadays...
- More than before you were diagnosed with cancer
- About the same as before you were diagnosed with cancer
- Less than before you were diagnosed with cancer

3. Which of the following best describes you at the present time?
- I think I should drink less alcohol
- I don’t think I need to change my alcohol consumption
- Don’t know
SECTION 6: TOBACCO

1. Do you smoke/chew tobacco at all nowadays?  □ Yes □ No

   If yes...
   Did you ever try to quit before you were diagnosed with cancer?  □ Yes □ No
   Have you tried to quit since you were diagnosed with cancer?  □ Yes □ No

   If no...
   Did you ever smoke/chew tobacco regularly? (at least once a day)  □ Yes □ No
   When did you quit smoking/chewing tobacco? ____________ month ____________ year

2. If you currently smoke/chew tobacco, which of the following best describes you at the present time?
   □ I think I should quit smoking/chewing tobacco
   □ I don't think I need to change my smoking/tobacco habits
   □ Don't know
SECTION 7: LIFESTYLE ADVICE

These questions are about the lifestyle advice you received since you were diagnosed with cancer. We are not able to ask about all aspects of lifestyle so we have just focused on a few areas. These questions will help us see what support you are getting and whether anything was missing.

1. In the time since you were first diagnosed with cancer, did a health professional (e.g. doctor/nurse/physiotherapist/dietitian) ever recommend any of the following?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doing more exercise</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating more fruit and vegetables</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoiding foods or drinks high in fat, sugar or salt</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating less red or processed meat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Losing weight</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gaining weight</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keeping your weight the same</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reducing the amount of alcohol you drink</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stopping smoking</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If yes, do you remember what was suggested? Please provide any details you can in the space below.

If yes, do you remember who gave you the information? Please tick all that apply.

- [ ] Oncologist
- [ ] Nurse
- [ ] Dietitian
- [ ] Surgeon
- [ ] GP
- [ ] Physiotherapist
- [ ] Other (please specify)

If yes, please tick the option which best describes the amount of information you received

- [ ] Too much
- [ ] About right
- [ ] Not enough

2. If you had been given the opportunity to have more information/advice/support on making lifestyle changes at the end of your main treatment, would you have taken up the offer?

- [ ] Yes definitely
- [ ] Yes probably
- [ ] Probably not
- [ ] Definitely not
- [ ] Not sure
- [ ] Not applicable
3. If we gave you the opportunity to have more information/advice/support on making lifestyle changes now, would you take up the offer?

- Yes definitely
- Yes probably
- Probably not
- Definitely not
- Not sure

4. How interested would you be in any information/advice to...

<table>
<thead>
<tr>
<th>Topic</th>
<th>Not at all interested</th>
<th>A little interested</th>
<th>Somewhat interested</th>
<th>Very interested</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help you have a healthy diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you maintain a healthy weight</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you increase your physical activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you stop smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you reduce your alcohol consumption</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you adopt an overall healthy lifestyle</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5. When do you think would be the best time to offer information about lifestyle (e.g. diet, physical activity) to people diagnosed with cancer? Please tick one option.

- Before treatment starts
- During treatment
- Immediately after treatment
- 3–6 months after treatment
- 6–12 months after treatment
- More than 1 year after treatment

6. Would you be interested in any of the following formats of information/advice about making lifestyle changes?

<table>
<thead>
<tr>
<th>Format</th>
<th>Not at all interested</th>
<th>A little interested</th>
<th>Somewhat interested</th>
<th>Very interested</th>
<th>Extremely interested</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short leaflet (up to 5 pages)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Longer leaflet/booklet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internet information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>An app for mobile or tablet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DVD/Video information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telephone call from a health professional</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One individual session</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multiple individual sessions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One group session</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multiple group sessions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
2. Please rate how important each of the following are to you in reducing the chance that your cancer will come back (recur):

<table>
<thead>
<tr>
<th></th>
<th>Not at all important</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eating a low fat diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical check-ups/screening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reducing stress in your life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking dietary supplements (e.g. vitamins)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Luck/chance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being physically active</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoiding alcohol</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using complementary therapies (e.g., herbs, acupuncture)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating plenty of fruit and vegetables</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having a positive attitude</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trying to maintain a healthy weight</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>God’s will</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoiding red or processed meat</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other (please specify) __________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________

Page 16
SECTION 9: YOUR WELLBEING

These questions are about your general wellbeing. We know that cancer can often affect lots of areas of wellbeing. Unfortunately we do not have space to ask about all of these in this questionnaire so we have just focused on a few areas.

1 In general, I consider myself...
Not a very happy person  1  2  3  4  5  6  7 A very happy person

2 Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>Some-what</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel fatigued</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel weak all over</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel listless ('washed out')</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel tired</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have trouble starting things because I am tired</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have trouble finishing things because I am tired</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am able to do my usual activities</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I need to sleep during the day</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am too tired to eat</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I need help doing my usual activities</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am frustrated by being too tired to do the things I want to do</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have to limit my social activity because I am tired</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

3 During the past month, when have you usually gone to bed?
Bed time                      

4 During the past month, how long (in minutes) has it taken you to fall asleep each night?
Number of minutes              

5 During the past month, when have you usually gotten up in the morning?
Getting up time                

HEALTH AND LIFESTYLE QUESTIONNAIRE
6. During the past month, how many hours of actual sleep did you get a night? (This may be different than the number of hours you spent in bed)
Hours of sleep per night: __________ Hours

7. During the past month, how often have you had trouble sleeping because you...

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cannot get to sleep within 30 minutes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wake up in the middle of the night or early morning</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have to get up to use the bathroom</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cough or snore loudly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feel too cold</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feel too hot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have bad dreams</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other reason(s), please describe, including how often you have had trouble sleeping because of this reason(s): ________________________________

8. During the past month, how often have you taken medicine (prescribed or ‘over the counter’) to help you sleep?
☐ Not during the past month ☐ Less than once a week ☐ Once or twice a week ☐ Three or more times a week

9. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?
☐ Not during the past month ☐ Less than once a week ☐ Once or twice a week ☐ Three or more times a week

10. During the past month, how much of a problem has it been for you to keep up enthusiasm to get things done?
☐ Not during the past month ☐ Less than once a week ☐ Once or twice a week ☐ Three or more times a week

11. During the past month, how would you rate your sleep quality overall?
☐ Very good ☐ Fairly good ☐ Fairly bad ☐ Very bad

12. How often do you feel you lack companionship?
☐ Hardly ever or never ☐ Some of the time ☐ Often

13. How often do you feel left out?
☐ Hardly ever or never ☐ Some of the time ☐ Often
14. How often do you feel isolated from others?
   - [ ] Hardly ever or never
   - [ ] Some of the time
   - [ ] Often

15. Under each heading, please tick the one box that best describes your health today.
   a. MOBILITY
      - [ ] I have no problems in walking about
      - [ ] I have slight problems in walking about
      - [ ] I have moderate problems in walking about
      - [ ] I have severe problems in walking about
      - [ ] I am unable to walk about
   b. SELF CARE
      - [ ] I have no problems washing or dressing myself
      - [ ] I have slight problems washing or dressing myself
      - [ ] I have moderate problems washing or dressing myself
      - [ ] I have severe problems washing or dressing myself
      - [ ] I am unable to wash or dress myself
   c. USUAL ACTIVITIES
      - [ ] I have no problems doing my usual activities
      - [ ] I have slight problems doing my usual activities
      - [ ] I have moderate problems doing my usual activities
      - [ ] I have severe problems doing my usual activities
      - [ ] I am unable to do my usual activities
   d. PAIN/DISCOMFORT
      - [ ] I have no pain or discomfort
      - [ ] I have slight pain or discomfort
      - [ ] I have moderate pain or discomfort
      - [ ] I have severe pain or discomfort
      - [ ] I have extreme pain or discomfort
   e. ANXIETY/DEPRESSION
      - [ ] I am not anxious or depressed
      - [ ] I am slightly anxious or depressed
      - [ ] I am moderately anxious or depressed
      - [ ] I am severely anxious or depressed
      - [ ] I am extremely anxious or depressed

Please turn over to the final page
SECTION 10: A FEW FINAL DETAILS

1. Are you currently enrolled in a formal lifestyle programme or trial (e.g. Weight Watchers, NHS smoking cessation)? [ ] Yes  [ ] No
If yes, please specify: ___________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
2. Please use the space below to give any other comments you might have.
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

OPPORTUNITY TO TAKE PART IN A FUTURE TRIAL

We have developed a lifestyle programme for people who have been diagnosed with cancer. In order to test if it is helpful, we are recruiting people like you to take part in a trial. If you take part, you could help us improve the programme and help other cancer patients in the future.

If you think you might be interested in taking part in this trial, please leave your contact details below and we will send you further information.

You do not need to commit to taking part at this stage. All information you provide is confidential and will not be shared.

Name: ________________________________________________________________
Telephone: ___________________________________________________________
Email: ______________________________________________________________
Address: _____________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

Thank you for taking the time to complete this questionnaire.
Please return it in the freepost envelope provided – there is no need for a stamp.

Page 20
Appendix 9.5 Physical activity items and scoring for Study 6

Over the past month, how many times a week on average did you do the following kinds of exercise for more than 15 minutes during your free time?

<table>
<thead>
<tr>
<th>Strenuous exercise</th>
<th>Duration of each session</th>
</tr>
</thead>
<tbody>
<tr>
<td>Times per week</td>
<td>Hours</td>
</tr>
<tr>
<td>Moderate exercise</td>
<td></td>
</tr>
</tbody>
</table>

Physical activity scoring:

First convert duration of each session to minutes only (e.g. 1 hour 20 minutes = 80)

\[ N_{\text{moderate}} = T_{\text{moderate}} \times D_{\text{moderate}} \]

\[ N_{\text{vigorous}} = T_{\text{vigorous}} \times D_{\text{vigorous}} \]

Physical activity recommendation: 210 minutes moderate or 105 minutes vigorous exercise per week (or a combination of the two). Therefore need to convert number of minutes of vigorous exercise to equivalent number of minutes of moderate exercise:

\[ \text{Total number of minutes per week} = N_{\text{moderate}} + (N_{\text{vigorous}} \times 2) \]

Total minutes \( \geq 210 \) = Meeting recommendation

Total minutes \( < 210 \) = Not meeting recommendation

T: Times per week

D: Duration of each session (minutes)

N: Number of minutes per week
### Appendix 9.6 Fibre intake items and scoring for Study 6

#### About how many times a week do you eat a serving of the following foods?

<table>
<thead>
<tr>
<th>Item</th>
<th>Less than once a week or never</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Pasta, rice, noodles or couscous</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Potatoes, sweet potatoes, yam, or plantains</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>3. Peas</td>
<td>1</td>
<td>3</td>
<td>8</td>
<td>12</td>
</tr>
<tr>
<td>4. Beans (including baked), lentils, chickpeas, or other pulses</td>
<td>1</td>
<td>4</td>
<td>10</td>
<td>15</td>
</tr>
<tr>
<td>5. Any other vegetables</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Fruit (fresh, frozen, canned, dried)</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>

#### About how many times a week do you have the following breakfast cereals or porridge?

<table>
<thead>
<tr>
<th>Item</th>
<th>None</th>
<th>Less than 1 per week</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. Sugary, chocolate, rice or corn cereals</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>8. Porridge, Ready Brek, muesli, multi-grain/wheat cereals</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>9. Bran cereals</td>
<td>0</td>
<td>2</td>
<td>5</td>
<td>12</td>
<td>18</td>
</tr>
</tbody>
</table>

#### About how many pieces of bread, rolls, chapatis etc. do you eat on a usual day?

<table>
<thead>
<tr>
<th>Item</th>
<th>None</th>
<th>Less than 1 per day</th>
<th>1-2 per day</th>
<th>3-4 per day</th>
<th>5 or more per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>10. White</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>9</td>
<td>13</td>
</tr>
<tr>
<td>11. Brown, granary, half and half, seeded, wheatgerm, or oat</td>
<td>0</td>
<td>2</td>
<td>7</td>
<td>15</td>
<td>22</td>
</tr>
<tr>
<td>12. Wholemeal (including wholemeal seeded and wholemeal granary) or wholegrain</td>
<td>0</td>
<td>3</td>
<td>8</td>
<td>18</td>
<td>26</td>
</tr>
</tbody>
</table>
Fibre scoring:

Total fibre score = sum of scores on 12 items

Score of >30 = Meeting recommendation (equivalent to more than 20g per day)

Score of ≤30 = Not meeting recommendation
## Appendix 9.7 Total dietary fat intake items and scoring for Study 6

About how many times a week do you eat a serving of the following foods?

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Less than once a week or never</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Cheese (any except cottage cheese)</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>2.</td>
<td>Beef (excluding burgers), pork, lamb, or goat</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>3.</td>
<td>Beef burgers</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>4.</td>
<td>Bacon, ham, salami, hot dogs, or sausages</td>
<td>1</td>
<td>2</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>5.</td>
<td>Chicken or turkey (including nuggets/burgers)</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>6.</td>
<td>Fish or shell fish (including tinned and breaded fish but excluding fried/battered fish)</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>7.</td>
<td>Meat alternatives (e.g. eggs, soya, tofu, Quorn but excluding nuts)*</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>8.</td>
<td>Nuts eaten in a meal as an alternative to meat (e.g. nut roast)*</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>9.</td>
<td>Fried food (e.g. fried/battered fish, chips, fried breakfast, samosas, fried rice, bhajis, puris, fritters)</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>10.</td>
<td>Cakes, pies, puddings, pastries, or Indian sweets</td>
<td>1</td>
<td>2</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>11.</td>
<td>Biscuits, chocolate or savoury snacks (e.g. crisps, sev, Bombay mix, nuts)</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>12.</td>
<td>Coconut milk or coconut cream*</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>9</td>
</tr>
</tbody>
</table>
About how many rounded teaspoons of margarine, butter or other spread do you usually use in a day (e.g. on bread, sandwiches, toast, potatoes, vegetables)? NB: One rounded teaspoon is roughly the amount used to cover a slice of bread

<table>
<thead>
<tr>
<th>13. Butter (including 'Lighter', 'Spreadable' and half-fat), Ghee or Margarine</th>
<th>E.g. Stork, Bertolli, Clover, Clover Lighter, I Can’t Believe It’s Not Butter, Flora, Flora Buttery, Flora Pro-activ, Benecol, Vitalite, supermarket own brand olive/ sunflower spread</th>
<th>Total teaspoons per day</th>
</tr>
</thead>
</table>
| **Score = No. tsp x 4**

<table>
<thead>
<tr>
<th>14. Low fat spread</th>
<th>E.g. Flora Light, Flora Lighter Than Light, Flora Pro-activ Olive, Flora Pro-activ Light, I Can’t Believe It’s Not Butter Light, own brand olive/sunflower light spread, Bertolli Light, Benecol Light, Clover Lighter Than Light</th>
<th>Total teaspoons per day</th>
</tr>
</thead>
</table>
| **Score = No. tsp x 4**

About how much milk do you yourself use in a day e.g. on cereal or in tea or coffee?

<table>
<thead>
<tr>
<th>15. Full-fat (whole)</th>
<th>None</th>
<th>Less than a quarter-pint per day</th>
<th>About a quarter-pint per day</th>
<th>About a half-pint per day</th>
<th>At least 1 pint per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>3</td>
<td>6</td>
<td>12</td>
<td></td>
</tr>
</tbody>
</table>

| 16. Semi-skimmed | 0 | 0 | 1 | 3 | 6 |

| 17. 1% fat* | 0 | 0 | 0.5 | 1.5 | 3 |

| 18. Skimmed | 0 | 0 | 0 | 0 | 0 |

| 19. Non-dairy (e.g. rice or soya milk)* | 0 | 0 | 1 | 3 | 6 |

*Added to DINE

**Total fat scoring:**

Total fat score = sum of scores on 19 items

Score of <30 = Meeting recommendation (equivalent to 35% total energy intake)

Score of ≥30 = Not meeting recommendation
## Appendix 9.8 Red meat items and scoring for Study 6

About how many times a week do you eat a serving of the following foods?

<table>
<thead>
<tr>
<th></th>
<th>Less than once a week or never</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Beef (excluding burgers), pork, lamb, or goat</td>
<td>0</td>
<td>1.5</td>
<td>4</td>
<td>6.5</td>
</tr>
<tr>
<td>2. Beef burgers</td>
<td>0</td>
<td>1.5</td>
<td>4</td>
<td>6.5</td>
</tr>
</tbody>
</table>

**Red meat scoring:**

Total number of portions per week = sum of scores on 2 items

One portion = 100g (O’Brien et al., 2015)

Number of grams per week = No. portions*100

Less than 500g per week = Meeting recommendation
500g or more per week = Not meeting recommendation
Appendix 9.9 Processed meat item and scoring for Study 6

<table>
<thead>
<tr>
<th></th>
<th>Less than once a week or never</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Bacon, ham, salami, hot dogs, or sausages</td>
<td>0</td>
<td>1.5</td>
<td>4</td>
<td>6.5</td>
</tr>
</tbody>
</table>

**Processed meat scoring:**

Score of 0 = Meeting recommendation

Any other score = Not meeting recommendation
Appendix 9.10 Sugar intake items and scoring for Study 6

### Daily frequency of consumption of sugary foods

About how many times a week do you eat a serving of the following foods?

<table>
<thead>
<tr>
<th></th>
<th>Less than once a week or never</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Biscuits, chocolate or savoury</td>
<td>0.066**</td>
<td>0.214</td>
<td>0.571</td>
<td>0.857</td>
</tr>
<tr>
<td>snacks (e.g. crisps, sev, Bombay</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mix, nuts)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How often do you drink the following?

<table>
<thead>
<tr>
<th></th>
<th>Never/rarely</th>
<th>Once a week</th>
<th>2-3 times a week</th>
<th>4-6 times a week</th>
<th>Once a day</th>
<th>Twice a day</th>
<th>3 or more times a day</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Regular squash, cordials, fizzy</td>
<td>0</td>
<td>0.143</td>
<td>0.357</td>
<td>0.714</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>drinks and juice drinks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Pure fruit juice (including from</td>
<td>0</td>
<td>0.143</td>
<td>0.357</td>
<td>0.714</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>concentrate)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

About how many times a week do you have the following breakfast cereals or porridge?

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>Less than 1 per week</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Sugary, chocolate, rice or corn</td>
<td>0</td>
<td>0.066**</td>
<td>0.214</td>
<td>0.571</td>
<td>0.857</td>
</tr>
<tr>
<td>cereals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Porridge, Ready Brek, muesli,</td>
<td>0</td>
<td>0.066**</td>
<td>0.214</td>
<td>0.571</td>
<td>0.857</td>
</tr>
<tr>
<td>multi-grain/wheat cereals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Bran cereals</td>
<td>0</td>
<td>0.066**</td>
<td>0.214</td>
<td>0.571</td>
<td>0.857</td>
</tr>
</tbody>
</table>

7. About how many rounded teaspoons of sugar, honey, or syrup do you usually use in a day (e.g. in coffee, tea, milk, bread, cereals, fruit)?

   Total teaspoons per day: [Score as reported]

**Calculated as twice a month
<table>
<thead>
<tr>
<th>Average grams of sugar per portion</th>
<th>Estimated average portion size</th>
<th>Estimated average portion size</th>
<th>Total sugars (g) per portion size</th>
<th>Mean total sugars (g) per 100g</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biscuits etc</td>
<td>50g</td>
<td>One small bar of chocolate/a biscuit</td>
<td>15g</td>
<td>30g*</td>
</tr>
<tr>
<td>Regular squash</td>
<td>330ml</td>
<td>One can</td>
<td>33g</td>
<td>10g</td>
</tr>
<tr>
<td>Pure fruit juice</td>
<td>250ml</td>
<td>One glass</td>
<td>25g</td>
<td>10g</td>
</tr>
<tr>
<td>Sugary cereals etc</td>
<td>60g</td>
<td>One bowl</td>
<td>18g</td>
<td>30g</td>
</tr>
<tr>
<td>Porridge etc</td>
<td>60g</td>
<td>One bowl</td>
<td>4.8g</td>
<td>8g</td>
</tr>
<tr>
<td>Bran cereals etc</td>
<td>60g</td>
<td>One bowl</td>
<td>12g</td>
<td>20g</td>
</tr>
<tr>
<td>Total teaspoons</td>
<td>As reported</td>
<td>-</td>
<td>5g</td>
<td>100g</td>
</tr>
</tbody>
</table>

*Given 50g sugar/100g chocolate, 20g sugar/100g biscuit, <10g sugar/100g savoury snacks

Sugar scoring:

Total daily intake of sugar in grams = \(N_{\text{biscuits}} \times SG_{\text{biscuits}} + N_{\text{squash}} \times SG_{\text{squash}} + N_{\text{frjuice}} \times SG_{\text{frjuice}} + N_{\text{sugcereals}} \times SG_{\text{sugcereals}} + N_{\text{porridge}} \times SG_{\text{porridge}} + N_{\text{bran}} \times SG_{\text{bran}} + N_{\text{teaspoon}} \times SG_{\text{teaspoon}}\)

\(N\): daily frequency of consumption of sugary food

\(SG\): Sugar grams per portion
Appendix 9.11 Fruit and vegetable intake items and scoring for Study 6

1. Over the past month, how many portions of fruit did you usually eat? Include fruit eaten at meal times or as a snack. Examples of a serving are 1 apple or banana, a large slice of melon, 2 plums or satsumas, a small bowl of grapes, 2 tablespoons of tinned fruit or ½ tablespoon of dried fruit.

<table>
<thead>
<tr>
<th>Less than 1 per week</th>
<th>1 per week</th>
<th>2-3 per week</th>
<th>4-6 per week</th>
<th>1 per day</th>
<th>2 per day</th>
<th>3 or more per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.07</td>
<td>0.14</td>
<td>0.36</td>
<td>0.71</td>
<td>1</td>
<td>2</td>
<td>3.5</td>
</tr>
</tbody>
</table>

2. Over the past month, how many portions of vegetables did you usually eat? Include vegetables eaten at meal times or as a snack. Examples of a serving are 2 heaped tablespoons of broccoli or carrots, 3 tablespoons of sweetcorn, or peas or a bowl of salad. Please do not include potatoes, sweet potatoes or plantains as a vegetable serving.

<table>
<thead>
<tr>
<th>Less than 1 per week</th>
<th>1 per week</th>
<th>2-3 per week</th>
<th>4-6 per week</th>
<th>1 per day</th>
<th>2 per day</th>
<th>3 or more per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.07</td>
<td>0.14</td>
<td>0.36</td>
<td>0.71</td>
<td>1</td>
<td>2</td>
<td>3.5</td>
</tr>
</tbody>
</table>

**Fruit and vegetable scoring:**

Total number of portions per day = sum of scores on 2 items

Score of ≥5 = Meeting recommendation

Score of <5 = Not meeting recommendation
Appendix 9.12 Alcohol intake items and scoring for Study 6

1. How often do you have a drink containing alcohol?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Monthly or less</th>
<th>2-4 times per month</th>
<th>2-3 times per week</th>
<th>4-5 times per week</th>
<th>Every day</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>0.04</td>
<td>0.11</td>
<td>0.36</td>
<td>0.64</td>
<td>1</td>
</tr>
</tbody>
</table>

2. How many units of alcohol do you drink on a typical day when you are drinking?

<table>
<thead>
<tr>
<th></th>
<th>I never drink alcohol</th>
<th>1-2</th>
<th>3-4</th>
<th>5-6</th>
<th>7-9</th>
<th>10+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>0</td>
<td>1.5</td>
<td>3.5</td>
<td>5.5</td>
<td>8</td>
</tr>
</tbody>
</table>

Alcohol scoring:

Scores above for question 1 show daily frequency of alcohol consumption

Number of units per day =
Appendix 9.13 Body Mass Index (BMI) scoring for Study 6

Convert weight to kilograms (kg): e.g. 8 stone = 50.8kg

Convert height to metres: e.g. 5 foot 4 inches = 1.62 metres

BMI = weight in kg/height in metres
Appendix 9.14 Proportion of patients meeting each of the WCRF lifestyle guidelines in Study 6 (Complete data only, no imputations) (N=731)

Percentages were derived from the total sample so where numbers do not total 100% this is due to missing data.
Appendix 9.15 Multivariable logistic regression models showing socio-demographic factors associated with meeting each of the WCRF recommendations in Study 6 (Complete data only, no imputations – only showing those that were imputed in main results)

<table>
<thead>
<tr>
<th>Age</th>
<th>Physical activity (N=188) OR [95% CI]</th>
<th>Energy density (N=138) OR [95% CI]</th>
<th>Plant foods (N=572) OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤65 years</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>&gt;65 years</td>
<td>0.94 [0.47-1.89]</td>
<td>0.54 [0.22-1.34]</td>
<td>0.91 [0.47-1.77]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th>Physical activity (N=188) OR [95% CI]</th>
<th>Energy density (N=138) OR [95% CI]</th>
<th>Plant foods (N=572) OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Female</td>
<td>0.52 [0.26-1.05]</td>
<td>1.84 [0.67-5.02]</td>
<td>1.88 [0.90-3.92]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Physical activity (N=188) OR [95% CI]</th>
<th>Energy density (N=138) OR [95% CI]</th>
<th>Plant foods (N=572) OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Married</td>
<td>2.93 [1.34-6.38]**</td>
<td>1.23 [0.51-2.96]</td>
<td>0.95 [0.48-1.87]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education</th>
<th>Physical activity (N=188) OR [95% CI]</th>
<th>Energy density (N=138) OR [95% CI]</th>
<th>Plant foods (N=572) OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Some</td>
<td>1.82 [0.71-4.64]</td>
<td>5.90 [1.60-21.82]**</td>
<td>3.12 [1.25-7.78]**</td>
</tr>
</tbody>
</table>

OR=odds ratio, CI=confidence interval, ORs adjusted for diagnosis, cancer stage and number of health problems, *p <.05, **p <.01
Appendix 9.16 Multivariable logistic regression models showing health factors associated with meeting each of the WCRF recommendations in Study 6 (Complete data only, no imputations – only showing those that were imputed in main results)

<table>
<thead>
<tr>
<th></th>
<th>Physical activity (N=123) OR [95% CI]</th>
<th>Energy density (N=84) OR [95% CI]</th>
<th>Plant foods (N=305) OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Prostate</td>
<td>1.75 [0.50-6.21]</td>
<td>0.16 [0.02-1.52]</td>
<td>0.15 [0.02-1.19]</td>
</tr>
<tr>
<td>Colorectal</td>
<td>0.79 [0.31-2.06]</td>
<td>0.87 [0.28-2.69]</td>
<td>0.41 [0.16-1.06]</td>
</tr>
<tr>
<td><strong>Cancer stage</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>II</td>
<td>1.80 [0.62-5.27]</td>
<td>0.79 [0.20-3.08]</td>
<td>0.66 [0.25-1.71]</td>
</tr>
<tr>
<td>III or IV</td>
<td>2.04 [0.75-5.56]</td>
<td>0.76 [0.21-2.83]</td>
<td>0.74 [0.30-1.85]</td>
</tr>
<tr>
<td><strong>Health problems</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>1</td>
<td>0.36 [0.13-0.95]*</td>
<td>0.42 [0.15-1.22]</td>
<td>0.73 [0.31-1.72]</td>
</tr>
<tr>
<td>≥2</td>
<td>0.60 [0.23-1.52]</td>
<td>0.65 [0.18-2.29]</td>
<td>0.61 [0.24-1.58]</td>
</tr>
</tbody>
</table>

OR=odds ratio, CI=confidence interval, ORs adjusted for diagnosis, cancer stage and number of health problems, *p <.05
Appendix 9.17 Associations between meeting the WCRF lifestyle recommendations and thinking they need to change their lifestyle in Study 6 (Complete data only, no imputations – only showing those that were imputed in main results)

Those not meeting the recommendation for physical activity were more likely to think they should do more physical activity (OR 5.04 [95% CI 2.62-9.68], p<.001, N=178).

There were no differences for plant foods or energy density.
Appendix 9.18 Proportion of patients interested in receiving advice about lifestyle in Study 6 (Complete data only, no imputations) (N=731)

Percentages were derived from the total sample so where numbers do not total 100% this is due to missing data or the patient selecting ‘not applicable’.
Appendix 9.19 Associations between meeting the WCRF lifestyle recommendations and wanting advice about lifestyle in Study 6 (Complete data only, no imputations)

Those not meeting the body fatness recommendation were more likely to want advice on weight (OR 2.71 [95% CI 1.70-4.34], p<.001, N=551).

Those not meeting the alcohol recommendation were more likely to want advice on alcohol (OR 3.23 [95% CI 1.63-6.37], p<.01, N=332).

Those not meeting the smoking recommendation were more likely to want advice on smoking (OR 17.05 [95% CI 6.92-42.02], p<.001, N=155).

There were no differences for physical activity, plant foods, energy density or red meat.
Appendix 9.20 Patient interest in different formats of lifestyle information in Study 6 (Complete data only, no imputations) (N=731)

Percentages were derived from the total sample so where numbers do not total 100% this is due to missing data.