Diet, nutrition and pelvic cancers

A mixed-methods study to explore dietary habits, nutritional awareness and experiences of nutritional care

Georgios I. Saltaouras

Oxford Brookes University

Thesis submitted in partial fulfilment of the requirements of the award of Doctor of Philosophy

In collaboration with Oxford University Hospitals NHS Foundation Trust

December 2019

Acknowledgements

I would like to take this opportunity and thank my Co-Directors of studies, Professor Eila Watson and Dr Helen Lightowler and my second supervisor, Dr Shelly Coe, for their continuous support and guidance over the past three and a half years. It has been a wonderful journey and I am very grateful for everything I’ve learned and practiced during the course of my doctoral studies.

This work would have been impossible without the amazing collaboration with the Radiotherapy Department at the Cancer and Haematology Centre, Oxford University Hospitals NHS Foundation Trust. Many thanks to our collaborators Dr Amanda Horne, Ms Sara Matthews and Ms Loryn Caulfield and to all the cancer specialist nurses and radiographers, who spent time out of their very busy schedule to invite cancer patients to take part in the study.

Also, being part of two special groups within the Faculty has been a great experience. Many thanks to colleagues at the Oxford Brookes Centre of Nutrition and Health (OxBCNH) and the Supportive Cancer Care Research Group for the useful guidance when needed. A special mention to Dr Jo Brett, with whom we worked on the study of the assessment of online patient information materials in nutrition and cancer (Chapter 8) and Dr Lauren Matheson, who provided input to the qualitative analysis (Chapter 5).

This piece of work would have been impossible without the love and support of friends and family. Many thanks to my friends Georgina, Anna, Patricia, John, Tyler, Huw, Anthony, Nicole and Fiona who had been very supportive during the past years – the ups and downs.

The past three years have been immensely stressful for my family. However, my mum and sisters have been there for me every time it was needed and I am very grateful.

Last, but certainly not least, thank you Greg, my long-time partner, friend and supporter. I promise you I will be baking more often from now on.

This thesis is dedicated to you, Dad.

(12.05.2018)

Table of contents

Abstract

Background: Nutrition is an important aspect of cancer survivorship care that is not routinely addressed. Patients may benefit from dietary modifications to improve quality of life and future health outcomes. This PhD aimed to explore dietary habits, awareness of nutritional recommendations and experiences of nutritional support in patients who have received radiotherapy to the pelvic area following a cancer diagnosis.

Methods: First, a systematic review regarding diet and nutrition information and support needs after a pelvic cancer diagnosis was conducted (Phase 1). In Phase two, people diagnosed with a pelvic cancer (anal, bladder, rectal and cancers of the reproductive organs), either undergoing [on-treatment (OT): *n*=266] or having completed pelvic radiotherapy 6-24 months previously [post-treatment (PT): *n*=405], were invited to participate in a survey, followed by telephone interviews with a sub-sample of 28 respondents. In Phase three, the availability and quality of online nutrition information for pelvic cancer patients in the UK was assessed.

Results: The survey was completed by 254 (38%) cancer survivors. High overweight and obesity rates (39% and 24% respectively) and presence of treatment side effects (e.g. bowel changes, appetite issues, fatigue) (82%) were observed. Two-thirds of respondents (*n*=170) reported at least one dietary change since diagnosis; most notable changes were reduction of sugary foods (48%) and alcohol (41%). Forty-three percent (n=108) had received dietary support from the healthcare team, of which 67% (n=72) felt their needs were well met. Receipt of support from the healthcare team was significantly associated with dietary change (OR 3.63, 95% CI: 1.82-7.23). The majority of respondents (68%, n=171) would like to receive additional dietary support. Qualitative analysis identified seven themes: “Impact of diagnosis and treatments on dietary choices”, “Personal resources”, “Social resources”, “Comorbidities and disabilities”, “Influence of work”, “Regaining normality” and “Barriers to dietary changes”.. Finally, most online materials about diet and nutrition had comprehensive content and good quality, but they were not widely available.

Conclusion: This thesis identified a lack of routine provision of nutritional care to patients following a cancer diagnosis and highlighted the need for reliable information to support patients in managing diet-related problems and leading a healthy future lifestyle.

Contribution to knowledge: This thesis has developed a detailed understanding of diet and nutrition information and support needs in an under-researched cancer population, with the use of a mixed-methods design. This knowledge will inform the design of future dietary / lifestyle interventions.

Preface

Published work

Saltaouras, G, Lightowler, H, Coe, S, Brett, J, Watson, EK. (2019) Availability and quality assessment of online nutrition information materials for pelvic cancer patients in the UK. *Eur J Cancer Care*. 28:e13039. https://doi.org/10.1111/ecc.13039

Publication is attached at the end of this thesis.

Conference presentations

National Cancer Research Institute Annual Conference, Glasgow, Scotland, November 2019 (poster presentation)

Title of presentation: “Dietary changes and nutritional support after a pelvic cancer diagnosis: a cross-sectional study.”

13th European Nutrition Conference – FENS, Dublin, Republic of Ireland, October 2019 (poster presentation)

Title of presentation: “Dietary changes and nutritional support after a pelvic cancer diagnosis: a cross-sectional study.”

1st Annual Nutrition and Cancer Networking meeting, Sheffield, England, July 2019 (oral presentation)

Title of presentation: “Dietary changes and nutritional support after a pelvic cancer diagnosis: a cross-sectional study.”

British Psycho-Oncology Society (BPOS) Annual Conference, Chester, England, February 2019 (oral presentation)

Saltaouras, G, Lightowler, H, Coe, S, and Watson, EK. (2018) Diet and nutrition support after a pelvic cancer diagnosis: a cross-sectional study in survivors 6-24 months post-treatment. (2019), BPOS Oral Presentations. *Psycho-Oncology*, 28: 3-8. doi:10.1002/pon.4993.

Masterclass in Nutrition and Cancer, Wageningen University, Holland, February 2019 (oral presentation)

Title of presentation: "Diet and nutrition support after a pelvic cancer diagnosis: a cross-sectional study in survivors 6-24 months post-treatment."

"Life After the PhD" conference, Cumberland Lodge, England, August 2018 (oral presentation)

Title of presentation: "Diet, nutrition and pelvic cancer: a mixed-methods study to explore dietary habits, nutritional awareness and experiences of nutritional care"

British Psycho-Oncology Society (BPOS) Annual Conference, Southampton, England, March 2018 (poster presentation)

Saltaouras, G, Lightowler, H, Coe, S, Brett, J, and Watson, EK. (2018). Assessment of quality of nutrition information materials for pelvic cancer patients in the UK, BPOS Poster Presentations. *Psycho-Oncology*, 27: 9-22. doi:10.1002/pon.4639.

Nutrition Society Winter Conference "Diet and nutrition in the changing face of cancer survivorship", London, England, December 2017 (poster presentation)

Saltaouras, G., Lightowler, H., Coe, S., Brett, J. and Watson, E. (2018) "Assessment of quality of nutrition information materials for pelvic cancer patients in the UK," *Proceedings of the Nutrition Society*. Cambridge University Press, 77(OCE1), p. E15. doi: 10.1017/S0029665117004347.

Awards

Student bursary (2019) 13th European Nutrition Conference – FENS

Dublin, Republic of Ireland, £300.

Student bursary (2019) British Psycho-Oncology Society annual conference

Chester, England, £450.

Academy Fellowship (2019) Masterclass in Nutrition and Cancer

Wageningen University, Holland, €450.

Student bursary (2018) “Life after the PhD” conference

Cumberland Lodge, England, £500.

List of figures

List of tables

List of abbreviations

(includes the abbreviations used most often in this thesis)

BMI	Body Mass Index
CI	Confidence Interval
DoH	Department of Health
ESPEN	European Society for Parenteral and Enteral Nutrition / European Society for Clinical Nutrition and Metabolism
FREC	Faculty Research Ethics Committee
GI	Gastrointestinal (used for lower GI cancer)
HRA	Health Research Authority
NHS	National Health Service
NIHR	National Institute for Health Research
NRES	National Research Ethics Committee
OBU	Oxford Brookes University
OR	Odds Ratio
OUH	Oxford University Hospitals
PI	Principal Investigator
PIS	Patient Information Sheet
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
R&D	Research & Development
RCT	Randomised Controlled Trial
QoL	Quality of Life
WCRF	World Cancer Research Fund
WCRF/AIRC	World Cancer Research Fund/American Institute for Cancer Research

Preamble

So, why was I interested in this topic?

I am an Associate Registered Nutritionist, with an education background in nutrition and dietetics (Bachelor's degree in Dietetics and Nutrition, Harokopio University, Athens, Greece; Master's degree in Human Nutrition and Metabolism, University of Aberdeen, Scotland). Though I cannot practice dietetics in the UK (not registered), I have always been very keen on working with clinical populations, from a research perspective. Therefore, I found this PhD project a unique opportunity to conduct a research project in a clinical population.

I was made aware of the work of the National Institute of Health Research (NIHR) Nutrition and Cancer Collaboration by my supervisory team, and considering the work undertaken / underway by the Collaborative coupled with an awareness of the amount of (mis)information on diet, lifestyle and cancer widely available on the Internet, I was inspired to explore supportive care needs in diet and nutrition. As the Collaboration suggested in the Phase I report (2015), it is essential to understand patient experiences in order to improve patient care in the clinical setting.

The Patient experience survey reported in the Phase I report from the Collaborative was a brief exploration of nutritional support and was completed primarily from survivors of breast cancer. Despite the small sample, the results indicated lack of communication of nutritional advice and limited support. I was particularly interested in these findings and I wanted to explore patient experiences of people undergoing treatment which is known to have a significant burden in diet and nutrition, such as pelvic radiotherapy. This is how this PhD project was "born". People undergoing pelvic radiotherapy for cancer are a group who may present unique needs in diet and nutrition because of the long-lasting treatment side effects of the treatment; therefore, a patient group worth further exploring in relation to diet and nutrition.

Chapter 1. Literature review

1.1. Definition of cancer

Cancer is defined as a “term for diseases in which abnormal cells divide without control and can invade nearby tissues” (National Cancer Institute, 2019). Cancer can start anywhere in the body and is categorised into four main types. Carcinomas are the most common cancers and begin in the skin or in tissues that line or cover internal organs. Sarcoma is a cancer that forms in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue. Leukaemia is a cancer that starts in blood-forming tissue, such as the bone marrow, and does not form solid tumours; instead, it causes large numbers of abnormal blood cells to be produced and enter the blood. Lymphoma and multiple myeloma are cancers that begin in the cells of the immune system (Pelengaris and Khan, 2013).

1.2. Cancer incidence and mortality

Cancer is a significant public health problem worldwide and a leading cause of death in the 21st century. According to the GLOBOCAN 2018 database produced by the International Agency for Research on Cancer (IARC), more than 18 million new cancer cases were estimated to have occurred in 2018 (Bray et al., 2018). Lung and breast cancers had the highest incidence rates (11.6% for both cancers; approximately 2.1 million new cases), followed by colorectal (10.2% or 1.8 million new cases) and prostate cancer (7.1% or 1.3 million new cases). Cancer incidence has increased by approximately 4 million since 2012 (Torre et al., 2015) and is projected to further increase in both developed and developing countries (Bray et al., 2018).

According to the GLOBOCAN database, approximately 9.6 million people died due to cancer. Lung cancer had by far the highest mortality rate with 1.8 million deaths in 2018 (18.4% of all cancer-related deaths), followed by colorectal (8.9% or 0.88 million), stomach (8.2% or 0.78 million deaths) and liver (8.2% or 0.78 million deaths) (Bray et al., 2018). According to the World Health Organisation (WHO), cancer is the first or second leading cause of death in most countries (WHO, 2018).

In the UK, 446,942 new cancer cases were estimated to have occurred in 2018 according to the IARC. Prostate and breast cancer were the most common diagnoses, with 56,401 and 55,439 new diagnoses, respectively (Bray et al., 2018). The Office for National Statistics reported that in 2017, a total of 305,683 new cancers (excluding non-melanoma skin cancers) were registered in England, with breast (15.1%), prostate (13.5%), lung (12.7%) and colorectal (11.4%) cancers accounting for over half of the cancer registrations in England for all ages combined (Office for National Statistics, 2019). It was also highlighted that cancer incidence continued to rise, up from 303,135 cases in 2016 (Office for National Statistics, 2018) and 299,923 in 2015 (Office for National Statistics, 2017).

1.3. Cancer survival

As well as increasing incidence rates, increased survival rates (or decreased mortality rates) are observed worldwide, although there are marked differences according to cancer type and between developed and developing countries (Allemani et al., 2018). According to the CONCORD programme's third update, which collected data on cancer survival up to 2014 (Allemani et al., 2018), western countries, such as the USA, Australia, New Zealand, Japan and the Scandinavian countries (Finland, Norway, Sweden) had the highest 5-year net survival rates for most cancers, whereas South-American and South-Asian countries had lower 5-year net survival rates. Nevertheless, rising survival trends have been observed for all cancers in all countries included in the CONCORD-3 update (Allemani et al., 2018).

In England, although the number of people dying from cancer has remained stable between 2016 and 2017 (135,775 people died from cancer in 2016 and 135,885 in 2017), the age-standardised mortality rate from cancer has decreased from 275.2 deaths per 100,000 in 2016 to 270.1 in 2017 (Office for National Statistics, 2019). A study by Quaresma et al. (2015) showed that 1-year, 5-year and 10-year net survival rates have radically improved for most cancers during the past 40 years in England and Wales. For all cancers combined, 1-year, 5-year and 10-year net survival rates in the 1970's were 50.1%, 29.8% and 24.0% respectively, whereas the projected 1-year, 5-year and 10-year net survival rates in 2010-2011 were 70.5%, 54.3% and 49.8%, respectively. This means that almost half of adults diagnosed with a cancer will survive their disease for ten years or longer, in contrast to almost a quarter, 40 years ago (Quaresma et al., 2015).

Increasing cancer incidence and survival act together to increase cancer prevalence, as more people are diagnosed but at the same time more people live longer after or with cancer. It is estimated that there are currently more than 2.5 million people in the UK living with a cancer diagnosis and this number is expected to rise to over 5 million by 2040 (Maddams et al., 2012).

1.4. Definition of a "cancer survivor"

According to the National Cancer Institute, a person is considered to be a cancer survivor from "the time of cancer diagnosis until the end of life", although definitions vary. (Denlinger et al., 2014). In the UK the term "Living With and Beyond Cancer (LWBC)" is preferred to describe any time since diagnosis (Le Boutillier et al., 2019, Department of Health et al., 2013). There is currently no agreed universal definition. Throughout this thesis, people who have been diagnosed with a cancer will be referred to as cancer survivors.

1.5. Supporting cancer survivors

Advances in early detection and management of cancer, in combination with the ageing population, have increased 10-year life expectancy rates (Quaresma et al., 2015). Allemani et al. (2018) note that although prevention is essential in reducing cancer incidence, not all cancers can be prevented and therefore cancer mortality can be reduced by improving cancer survival.

A cancer diagnosis is often viewed as a life-changing experience. Diagnosis and treatment have significant effects on people's physical, psychological, social and spiritual wellbeing (Palesh et al., 2018, Cleeland et al., 2012, Duska and Dizon, 2014). Different treatments can cause different adverse effects that affect every part of the body. Chemotherapy and radiotherapy destroy healthy cells as well as cancerous cells, leading to symptoms such as gastrointestinal dysfunction, pain and fatigue (Cleeland et al., 2012, Mitsuzuka and Arai, 2018), as well as increasing the risk for cardiovascular disease and cardiac-related mortality (Bouillon et al., 2011). The prevalence of taste and smell changes is up to 70% in people receiving chemotherapy or radiotherapy, contributing to appetite loss, reduced food consumption and weight loss (Spotten et al., 2017). Hormone treatment disrupts the endocrine system, leading to bone loss, sexual dysfunction and weight gain (Cleeland et al., 2012). According to the Institute of Medicine report *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt et al., 2005), the effects of treatments have been known for years; however, survivorship has only relatively recently been recognised as a distinct phase of the cancer trajectory, due to increasing survival rates worldwide. Although the incidence, the severity and the duration of side effects depends on the type of treatment and the combination of treatments and dose, treatment side effects have been reported to affect pelvic cancer survivors long after the end of treatments (Adams et al., 2014).

1.5.1. National initiatives and cancer outcome strategies

With the increasing number of cancer survivors, the Department of Health (DoH) has highlighted the importance of investigating their needs in order to enhance recovery and health after cancer treatment (Department of Health et al., 2013). Many survivors have experienced inadequate care support (Faller et al., 2016, Harrison et al., 2009). As there is now more evidence that cancer survivors have unmet needs and struggle with consequences of treatment, the National Health Service (NHS) considers this to be a major target for improvement.

The DoH, Macmillan Cancer Support and NHS Improvement released a report in 2013 in which actions to improve outcomes of a cancer diagnosis were suggested (Department of Health et al., 2013). A framework for survivorship has been suggested, highlighting five areas of support in cancer survivorship:

1. Information and support from diagnosis – offering survivors support from an early stage so that they make decisions that best reflect their individual needs, including work, and using Patient Reported Outcome Measures to collect information for symptoms, concerns and quality of life to identify individual unmet needs.
2. Promoting recovery – use of a “recovery package” that includes education and support, treatment summary and a Holistic Needs Assessment, as well as offering advice on rehabilitation and lifestyle and access to relevant support services.
3. Sustaining recovery – offering follow-up as a means to further address unmet needs and enhance self-management.
4. Managing the consequences of treatment – assessing short- and long-term consequences and offering relevant information for self-management and recommended surveillance tests.

5. Supporting people with active or advanced disease – offering a full assessment plan in recurrence, relevant care plans smooth transition between cancer support, palliative care and end of life services.

Understanding the need to address the new priorities in cancer care, the Independent Cancer Taskforce, which was established by NHS England on behalf of the Care Quality Commission, Health Education England, Monitor, Public Health England and the Trust Development Authority in 2015, developed a 5-year strategic plan to improve cancer outcomes in England (2015-2020), with a focus on six priorities: prevention; early diagnosis; communication, information provision and patient experience; supporting people living with and beyond cancer; investing on high-quality services and setting clear expectations (Independent Cancer Taskforce, 2015).

Patient experience is set as a central aspect of care, from the point of diagnosis, through to treatment and beyond. Survivors require holistic support to address physical, psychosocial and financial issues as a result of their diagnosis. Patient experience will be improved through effective patient-provider communication, provision of information and promotion of shared decision-making. The varying needs of people living with and beyond cancer highlights the complexity and the challenges of the development of future services; however, it is essential to have a good understanding of the varied needs to shape appropriate services and pathways of care in order to address these needs. Services that have been recommended to improve quality of life will be part of a recovery package and include: a Holistic Needs Assessment; information on management of long-term treatment side-effects; information about actions in case of secondary or recurrent cancers; treatment summaries; wellbeing events on healthy lifestyle and physical activity; and access to rehabilitation, work and financial support services (Independent Cancer Taskforce, 2015).

The NHS supports the move towards a more patient-centred approach in relation to management and support after a cancer diagnosis, through personalisation of approaches and patient empowerment to take share of responsibility to stay healthy. To achieve this, appropriate support and education should be provided so that people live well outside hospitals and return to their lives (Independent Cancer Taskforce, 2015). As a significant proportion of costs relate to survivors' needs after the end of treatment (survivorship phase) (Laudicella et al., 2016), tailored patient-centred care has the potential to reduce these costs through improvement of survivors' Quality of Life (QoL).

1.6. The “teachable moment” of a cancer diagnosis

A cancer diagnosis is often perceived as a “teachable moment” in people's lives. The term “teachable moment” is used to describe life or health events where a patient is receptive to counselling and education and to adopt risk-reducing health behaviours (McBride et al., 2003). Following a diagnosis of cancer, people may be more focussed on their health and recovery and may be more receptive to health-related messages, such as lifestyle and symptom management. Therefore, it is perceived as an opportunity for health services to communicate health messages to cancer survivors that will help them recover fast and improve their QoL. A study by Hawkins et al. (2017) showed that cancer survivors may practice healthier lifestyle habits such as smoking cessation and maintenance of a healthy weight as a result of their diagnosis.

1.7. Diet, nutrition and cancer

Lifestyle has been implicated in cancer development for several decades and recently in survivorship outcomes. This PhD project focusses on one aspect of lifestyle: diet and nutrition. According to the Oxford Dictionary, a diet is defined as “the kinds of food that a person, animal, or community habitually eats”. Nutrition is defined as “the process of providing or obtaining the food necessary for health and growth”. In this thesis, both terms will be used together to describe a person's food consumption.

1.7.1. Diet, cancer development and cancer risk

Over the past decades, there has been extensive research on the role of diet and nutrition in the development and progression of cancer. The most recent summary of evidence was published by the World Cancer Research Fund and the American Institute for Cancer Research (WCRF/AICR) in 2018, as part of the Continuous Update Project programme running from 2007 (World Cancer Research Fund/American Institute for Cancer Research, 2018). The Third Expert Report highlights that overweight and obesity has been linked with the development of 12 different cancers and there is “convincing evidence” for seven of these [oesophageal (adenocarcinoma), pancreatic, liver, colorectal, breast postmenopause, endometrial and kidney]. Evidence also exists for the role of alcohol in increasing the risk of seven different cancers (“convincing evidence” for five of them) and decreasing the risk of developing one cancer (kidney). “Convincing evidence” also exists for the consumption of processed meats and increased colorectal cancer risk, aflatoxins and increased liver cancer risk, high dose beta-carotene and increased lung cancer risk and arsenic in water and increased lung cancer risk. Despite the continuous research in this field, there is insufficient evidence to draw conclusions in numerous combinations of dietary components and different cancers.

1.7.2. Diet, nutrition and cancer survivorship

The role of diet and nutrition after a cancer diagnosis may be different depending on cancer site, cancer stage and treatment stage. After diagnosis and during treatment, cancer survivors are at risk of malnutrition due to the metabolic effects of the cancer and also due to the side effects from anticancer treatment (Arends et al., 2017b). After the end of treatment, survivors may still struggle with long-term and late side effects (Adams et al., 2014), as well as high overweight and obesity rates (Shoemaker et al., 2016) and increased risk for the development of metabolic diseases (Weaver et al., 2013).

1.7.2.1. Diet and nutrition during cancer treatment

Inadequate nutritional intake, muscle protein depletion and systemic inflammation which affect metabolic processes, lead to weight loss and impaired physical function. Between 20% and 70% of on-treatment survivors have been estimated to be malnourished according to a number of studies summarised by Arends et al. (2017b). Weight loss, cachexia (involuntary weight and muscle mass loss) and sarcopenia (low lean body mass) are associated with poorer treatment outcomes (Gangadharan et al., 2017), poorer quality of life (Gellrich et al., 2015), increased risk of mortality (Gangadharan et al., 2017, Ryan et al., 2016) and increased length of hospital stay (Ryan et al., 2016).

Treatment side effects, such as appetite problems (appetite loss, anorexia, early satiety or increased appetite), gastrointestinal disturbances (diarrhoea, constipation, bloating), taste and smell changes, dysphagia, xerostomia, nausea and vomiting, all can have a negative effect on weight status and further contribute to the risk of malnutrition. Tumour site and stage determine the treatment(s), which means that different people will experience different side effects (Cancer Research UK, 2017).

In order to improve detection and treatment of malnutrition in the cancer setting, the European Society for Clinical Nutrition and Metabolism (ESPEN) has published guidelines which focus on early screening, assessment and intervention (Arends et al., 2017a). From a total of 37 recommendations, only twelve are characterised as “strong” and even fewer (four) are based on high or moderate quality evidence, highlighting the need for further research to create stronger evidence (Arends et al., 2017a). There are strong recommendations about screening and assessment, energy and protein requirements, physical activity, use of vitamins and minerals and use of oral and artificial (enteral/parenteral) nutrition based on individual assessment while on treatment (Table 1.1).

Table 1.1: ESPEN recommendations in nutrition and cancer characterised as "strong", and their level of evidence (Arends et al., 2017a).

Section	"Strong" recommendation	Level of evidence
Screening and assessment	To detect nutritional disturbances at an early stage, regular evaluation of nutritional intake, weight change and BMI is recommended, beginning with cancer diagnosis and repeated depending on the stability of the clinical situation.	Very low
	In patients with abnormal screening, objective and quantitative assessment of nutritional intake, nutrition impact symptoms, muscle mass, physical performance and the degree of systemic inflammation is recommended.	Very low
Energy and substrate requirements	Total energy expenditure of cancer patients, if not measured individually, is recommended to be assumed to be similar to healthy subjects and generally ranging between 25 and 30 kcal/kg/day.	Low
	Protein intake should be above 1 g/kg/day and, if possible up to 1.5 g/kg/day	Moderate
	In weight-losing cancer patients with insulin resistance, increase of the ratio of energy from fat to energy from carbohydrates is recommended. This is intended to increase the energy density of the diet and to reduce the glycaemic load.	Low
	Vitamins and minerals should be supplied in amounts approximately equal to the RDA and the use of high-dose micronutrients in the absence of specific deficiencies is discouraged.	Low
Nutrition interventions	Nutritional intervention to increase oral intake in cancer patients who are able to eat but are malnourished or at risk of malnutrition is recommended. This includes dietary advice, the treatment of symptoms and derangements impairing food intake (nutrition impact symptoms), and offering oral nutritional supplements.	Moderate
	Use dietary provisions that restrict energy intake in patients with or at risk of malnutrition should be avoided.	Low
	If a decision has been made to feed a patient, enteral nutrition is recommended if oral nutrition remains inadequate despite nutritional interventions (counselling, ONS), and parenteral nutrition if enteral nutrition is not sufficient or feasible.	Moderate
	If oral food intake has been decreased severely for a prolonged period of time, it is recommend to increase (oral, enteral or parenteral) nutrition only slowly over several days and to take additional precautions to prevent a refeeding syndrome.	Low
	In patients with chronic insufficient dietary intake and/or uncontrollable malabsorption, home artificial nutrition (either enteral or parenteral) in suitable patients is advised.	Low
Exercise training	We recommend maintenance or an increased level of physical activity in cancer patients to support muscle mass, physical function and metabolic pattern.	High

In cancer groups most prone to malnutrition during treatment, such as ovarian cancer, a recent systematic review of nutritional interventions showed that nutritional support was associated with reduced length of hospital stay and fewer post-operative complications

(Rinninella et al., 2019). Nevertheless, large-scale randomised controlled trials (RCTs) with more homogeneous types of intervention and clinical outcomes are warranted.

1.7.2.2. Diet and nutrition after cancer treatment

The “teachable moment” of a cancer diagnosis and the treatment complications may be drivers for survivors to consider changing dietary habits. A recent study assessed health behaviours of breast, colorectal and prostate cancer survivors and showed that all cancer groups consumed on average about five servings of fruit and vegetables per day (Bluethmann et al., 2015). Also, one third (33%) of the survivors’ daily energy intake was derived from fat (Bluethmann et al., 2015), which is in line with current recommendations for healthy eating (Public Health England, 2016). There were considerable differences according to BMI status, educational status and gender; people with higher BMI and lower educational status, as well as male survivors consumed significantly less fruit and vegetables compared to people with lower BMI, college-educated and female survivors. It should be noted that the response rate in this survey was 56% and no information about non-respondents was provided (Bluethmann et al., 2015).

On the other hand, results from a retrospective, cross-sectional matched case-control study in survivors of breast, colorectal and prostate cancer in the USA (data collected in 2009) showed that only a minority followed the American Cancer Society recommendations for physical activity (30–47%), consumption of five fruit and vegetables daily (20–34%), and healthy weight (25–40%). Women with breast cancer were more likely to meet the 5-a-day recommendation in the short term, compared to cancer-free matched women, but this was not the case in the long term (LeMasters et al., 2014). It was, therefore, shown that healthy lifestyle behaviours may be implemented in the short-term but may not be maintained in the long-term.

Also, survivors may be less likely to make changes in relation to diet and nutrition, compared to other lifestyles changes, such as smoking. A large cross-sectional study conducted in the USA in survivors of six different cancers showed that only 15-19% of them were adhering to the recommendation for fruit and vegetable consumption (consumption of 5 servings of fruit and vegetables per day) (Blanchard et al., 2008). On the other hand, 88-92% of them were non-smokers. Interestingly, only 4-6% of survivors in that study adhered to all three lifestyle recommendations (150 minutes of moderate-to-strenuous physical activity, consumption of five servings of fruit and vegetables per day, no smoking) (Blanchard et al., 2008). The relationship between smoking and cancer development has been well established and there is robust evidence in comparison to the relationship between diet and cancer. Also, smoking cessation promotion campaigns have been shown to be more effective on a population level than campaigns which promote healthy diet or increased physical activity (Mozaffarian et al., 2012, Liu et al., 2012). Although there is limited evidence on the effectiveness of smoking cessation interventions in oncology populations (Nayan et al., 2013), general health promotion messages to avoid or stop smoking may have been better communicated.

1.7.2.2.1. Overweight and obesity in cancer survivors

The World Health Organisation defines overweight and obesity as *"abnormal or excessive fat accumulation that may impair health"* (World Health Organisation, 2018). A simple way to determine overweight and obesity on a population level is the use of Body Mass Index (BMI); an index of weight-for-height. It is calculated by dividing a person's weight in kilograms by the square of his height in metres (kg/m^2) (World Health Organisation, 2018).

It has been documented that cancer survivors have high overweight and obesity rates. A study on breast, prostate, colorectal and gynaecological cancer survivors showed that 62% were classified as overweight or obese (BMI>25 kg/m^2) (Weaver et al., 2013). In other studies, obesity (BMI>30 kg/m^2) was prevalent in about three out of ten survivors (Shoemaker et al., 2016, Greenlee et al., 2016).

With regards to cancer survivorship, there have been several observational studies and systematic reviews that have assessed survivors' weight status and evaluated the effect of overweight/obesity in overall survival, cancer-specific or non-cancer specific deaths and QoL in cancer populations. A systematic review and meta-analysis of 82 follow-up studies has shown that obesity (as defined by BMI status) was associated with poorer breast cancer survival, both in pre-menopausal and post-menopausal women (Chan et al., 2014). More specifically, for every 5kg/m^2 increase in BMI after diagnosis the risk of cancer-specific mortality was increased by up to 29%, although the authors suggested statistical power may have influenced the results. Women who were classified as obese 12 months after diagnosis had a 21% increased risk for total mortality, compared to normal weight breast cancer survivors (Chan et al., 2014).

Other cancer diagnoses are less studied but there are available systematic reviews to summarise the existing evidence. Secord et al. (2016) explored the association between post-diagnosis BMI and overall mortality in survivors of an endometrial cancer. Compared to women with a BMI<25 kg/m^2, women with BMI over 40kg/m^2 had a 66% increased risk for all-cause mortality [Odds Ratio (OR):1.66, 95% Confidence Interval (CI): 1.10-2.51, *P*=0.02]. The authors also estimated that for every 10% increase in BMI, there was a 9% increase in the odds of all-cause mortality; however, a more recent study from the Women's Health Initiative does not support the findings of the systematic review (Arem et al., 2017).

With regards to prostate cancer, an earlier systematic review showed a 5kg/m^2 increase in BMI led to 20% higher, prostate cancer-specific mortality; however this was not statistically significant [Relative Ratio (RR) 1.20, 95% CI 0.99–1.46, *P*=0.06] (Cao and Ma, 2011). A more recent, retrospective study conducted in the USA showed that overweight and obesity were associated with increased prostate cancer-specific mortality in people treated with radical prostatectomy (Vidal et al., 2017). However, Schiffman et al. (2018) demonstrated that prostate cancer survivors with obesity were less likely to exhibit metastases after radical prostatectomy, highlighting an “obesity paradox”, as it was anticipated by the authors that excess adiposity would be associated with increased risk of development of metastasis. It was also shown that obesity was associated with increased metastases-free survival. Authors highlighted that these findings may not be related to prostate cancer patients in active surveillance or treated with radiation. A previous meta-analysis of cohort studies has demonstrated a positive association between obesity and prostate cancer-specific mortality (Zhang et al., 2015). The above indicate that the link between obesity and mortality/survival after cancer diagnosis may be more complex than initially assumed, and highlights that different methodological approaches can yield conflicting evidence.

Obesity is also implicated in survival of people diagnosed with colorectal cancer. A retrospective observational study showed that BMI was associated with all-cause and cancer specific mortality in a non-linear way (Kroenke et al., 2016). People classified as underweight (BMI<18.5 kg/m^2) and class II obese (>35 kg/m^2) had an increased risk of mortality (all-cause or cancer-specific). Interestingly, those classified as overweight had the best prognosis and those classified as class I obese (30 kg/m^2<BMI<35 kg/m^2) had no different mortality risk compared to those in the “normal weight” (18.5 kg/m^2<BMI<30 kg/m^2) category (Kroenke et al., 2016). Moreover, results from the Cancer Prevention Study-II Nutrition Cohort conducted in colorectal cancer survivors showed that post-diagnosis BMI was not associated with all-cause or cause-specific mortality (Campbell et al., 2012).

Apart from its impact on survival, overweight and obesity have been associated with lower QoL. Vissers et al. (2017) demonstrated that colorectal cancer survivors with increased BMI and/or waist circumference had worse QoL indexes (physical, emotional, cognitive and social functioning) and symptoms of fatigue, compared to survivors with normal BMI

(18.5kg/m^2<BMI<25 kg/m^2). Similarly, a systematic review and meta-analysis that included a total of 1,363 endometrial cancer survivors showed that women with obesity had significantly poorer physical, social and role functioning when compared to non-obese women (Smits et al., 2015a). A smaller, cross-sectional study on ovarian cancer survivors showed that increasing BMI was associated with lower physical and emotional functioning (Smits et al., 2015b). Consequently, although findings on the role of obesity on survival may depend on cancer site and study design, evidence on its negative effect on QoL is more consistent.

1.7.2.2.2. Dietary patterns, dietary components and outcomes in cancer survivors

Regardless of weight status, observational studies have evaluated the role of dietary components and dietary patterns in cancer outcomes, such as all-cause mortality, cancer-specific mortality and QoL.

A recent systematic review on the effect of dietary patterns on prognosis following a breast cancer diagnosis showed that better overall dietary intake, as assessed by indexes (health/prudent dietary pattern or the Healthy Eating Index or the Alternative Healthy Eating Index), may independently improve overall and non-breast cancer survival. However, there was very limited and inconsistent evidence regarding breast cancer-specific survival and recurrence. Only seven studies were included in this review, in which dietary intake was taken post-diagnosis and was assessed with Food Frequency Questionnaires (Terranova et al., 2018).

Two studies assessed post-diagnosis diet quality and cancer outcomes in colorectal cancer survivors. The first study used the Alternate Healthy Eating Index-2010 (AHEI-2010), alternate Mediterranean Diet score (aMED) and Dietary Approaches to Stop Hypertension score (DASH), as well as two dietary patterns, Western (unhealthy) and prudent (healthy) to assess diet quality. The authors found that higher AHEI-2010 score (better diet quality) was significantly associated with lower overall mortality, but no other indexes showed any significant associations. Moderate alcohol consumption and lower consumption of sugar-sweetened beverages seemed to drive this association, as significant inverse associations for overall mortality were shown with these two food components when they were examined separately (Fung et al., 2014). The other study assessed two dietary patterns [Modified Mediterranean Diet Score (MMDS) and healthy Nordic Food Index (HNFI)] and found that high scores (better diet quality) in both indexes were associated with lower all-cause mortality (Ratjen et al., 2017).

Two recent reviews on lifestyle factors and their impact on survival and recurrence indicated that evidence on diet and dietary components is currently weak to draw any conclusions (van Zutphen et al., 2017, Jochems et al., 2018). Even for dietary components which are known for their influence (either positive or negative) on cancer development, more research is needed regarding their role on survival and mortality (van Zutphen et al., 2017). For example, a study among colorectal cancer survivors in Germany showed that red and processed meat consumption was not associated with mortality (Carr et al., 2016). Another study found that post-diagnosis total calcium intake and milk intake, but not vitamin D intake, was inversely associated with all-cause mortality in colorectal cancer survivors of the Cancer Prevention Study-II Nutrition Cohort (Yang et al., 2014). Jochems et al. (2018) concluded that there may be some limited evidence to indicate that a low-fat diet, a high-quality diet and a prudent diet are beneficial for breast cancer survivors, but there is insufficient evidence for all other cancer sites that particular behaviours influence cancer-related outcomes.

One study assessed adherence to the WCRF/AICR guidelines for cancer prevention (which are also encouraged to be followed by cancer survivors) and its association with mortality in older female cancer survivors. Results showed that women with the highest versus lowest adherence score had lower all-cause mortality (Hazard Ratio = 0.67; 95% CI: 0.50–0.94). Adherence to physical activity recommendations had greater benefits than adherence to dietary or body weight recommendations, as it was associated with lower all-cause, cancer-specific and CVD-specific mortality (Inoue-Choi et al., 2013).

1.7.2.2.3. Dietary interventions in cancer survivors

There is limited research regarding the impact of dietary or lifestyle modifications in cancer outcomes following a diagnosis. Most of the evidence on diet, nutrition, obesity and cancer outcomes comes from observational studies and have been discussed in the previous sections.

A recent Cochrane review and meta-analysis by Burden et al. (2019)) summarised the evidence of dietary interventions in outcomes in cancer survivors. Included studies provided dietary advice in groups sessions, telephone or face-to-face consultations, or written or web-based form. A total of 25 studies, most of which were conducted in breast cancer populations, showed some favourable results in relation to Body Mass Index (slight decrease), Diet Quality Index (likely improvement) and consumption of fruit and vegetables (slight increase). There was little or no effect of a dietary intervention in overall survival, development of a secondary cancer, energy intake 12 months post-diagnosis and waist-to-hip ratio. QoL results were mixed, due to the variety of tools used from the included studies. Most results were based on low or very low quality evidence, highlighting the need for more rigorous research with standardised methods to gain a better understanding of dietary interventions in cancer outcomes (Burden et al., 2019).

Interventions that implement dietary and physical activity modifications are also available in the literature. The Exercise and Nutrition Routine Improving Cancer Health (ENRICH) intervention was a RCT in which cancer survivors and carers were provided with face-to-face, theory-based sessions on healthy eating and physical activity (intervention group) or routine care (control group). At 20 weeks, the intervention group had increased physical activity and vegetable intake, while achieving greater weight loss than the control group (James et al., 2015). On a 12-month follow-up during which no further intervention was provided, physical activity and weight loss were maintained, but vegetable intake decreased, indicating that not all lifestyle behaviours are maintained in the long-term (Stacey et al., 2017).

The FRESH START Trial was a 10-month diet and exercise intervention for breast and prostate cancer survivors in the USA. Tailored printed materials promoting fruit and vegetables, reducing fat intake and increasing exercise were provided to the intervention group, while the control group received generic information. Although both groups improved lifestyle behaviours, participants in the intervention group were more active (+20 minutes, *P*=0.02), ate more fruit and vegetables (+0.5 servings, *P*=0.01) and achieved modest weight loss in comparison to the control group which did not achieve weight loss (Demark-Wahnefried et al., 2007).

Another diet and exercise intervention in breast cancer survivors (Exercise and Nutrition to Enhance Recovery and Good Health for You or ENERGY) aimed to reduce weight to those assigned in the intervention group by 7% within 24 months. Results showed that the intervention group lost more weight at 12 months and 24 months, compared to the control group that received publicly available materials; however, weight loss in the intervention group was less than 7%, both in 12 and 24 months (6% and 3.7%) (Rock et al., 2015).

Dietary or lifestyle interventions are less frequent for other cancer sites. A recent systematic review on lifestyle interventions in gynaecological cancer survivors included only three studies, none of which examined the effect of lifestyle modification in survival or recurrence. Two studies included in the meta-analysis examined the effect of lifestyle modification on QoL and found no significant results (Yeganeh et al., 2018).

In view of limited intervention studies producing inconclusive evidence about the role of diet or lifestyle (diet and physical activity) on cancer related outcomes following a cancer diagnosis, there is a strong scientific interest in this area of research. Several protocols have been published with ongoing studies that have developed dietary or lifestyle interventions with the aim to explore cancer outcomes: management of treatment side effects (Sun et al., 2018), disease-free and overall survival (Henriksen et al., 2017, Thomson et al., 2016), risk of recurrence (Ramirez et al., 2017) and QoL (Thomson et al., 2016).

1.8. Dietary support post-cancer treatment

At present, nutritional guidelines for post-treatment cancer survivors in the UK are available from two sources: the ESPEN guidelines (Arends et al., 2017a) and the WCRF 3rd expert report (World Cancer Research Fund/American Institute for Cancer Research, 2018). The WCRF guidelines were developed for cancer prevention but are also recommended for post-treatment cancer survivors, due to the weak evidence base, as indicated in the previous sections. It also highlights that post-treatment cancer survivors should follow these recommendations "*if possible*", indicating that potential detrimental effects of treatments may affect survivors' life and subsequent dietary habits (World Cancer Research Fund/American Institute for Cancer Research, 2018). The two ESPEN recommendations are also based on low level of evidence, as most of the available studies are observational. Recommendations are summarised in Tables 1.2 and 1.3.

Following the Department of Health's initiative towards supporting patients throughout the cancer trajectory, it is important to investigate whether and how successfully dietary and nutritional information is communicated to cancer patients. Previously published scoping and systematic reviews have highlighted a number of unmet needs in cancer patients and information on diet and nutrition is one of them (Fletcher et al., 2017, Puts et al., 2012, Van Mossel et al., 2012, Kotronoulas et al., 2017). Dietary information is needed in different phases of the cancer trajectory, including treatment, rehabilitation/recovery and end of life (Fletcher et al., 2017).

Table 1.2: ESPEN recommendations for cancer survivors (Arends et al., 2017a).

Section	Recommendation	Strength of recommendation	Level of evidence
Cancer survivors	We recommend that cancer survivors engage in regular physical activity.	Strong	Low
	In cancer survivors we recommend to maintain a healthy weight (BMI 18.5 – 25 kg/m^2) and to maintain a healthy lifestyle, which includes being physically active and a diet based on vegetables, fruits and whole grains and low in saturated fat, red meat and alcohol.	Strong	Low

Table 1.3: WCRF guidelines for cancer prevention and cancer survivors (World Cancer Research Fund/American Institute for Cancer Research, 2018).

Recommendations
Be a healthy weight – Keep your weight within the healthy range and avoid weight gain in later life
Move more – Be physically active as part of everyday life – walk more and sit less
Enjoy more grains, veg, fruit & beans – Eat a wide variety of wholegrains, vegetables, fruit and pulses such as beans
Avoid high-calorie foods – Limit consumption of fast foods and other processed foods high in fat or sugar
Limit consumption of red and processed meat – Eat no more than three portions of red meat a week and eat little, if any, processed meat
Limit consumption of sugar-sweetened drinks – Drink mostly water and unsweetened drinks
For cancer prevention, don’t drink alcohol – If you do, limit alcoholic drinks and follow national guidelines
Don’t rely on supplements – Eat a healthy diet rather than relying on supplements to protect against cancer
Breastfeed your baby – If you can, breastfeed your baby for six months before adding other liquids and foods

Recognising patients’ unmet needs in this area and the lack of consistent evidence, the National Institute of Health Research (NIHR) created the NIHR Nutrition and Cancer Infrastructure Collaboration, with the aim of bringing nutrition research and cancer research together, to shape future research pathways and support cancer survivors. According to the Phase I report from collaboration (2015), research knowledge about diet and nutrition is not currently being translated to improve care, suggesting that many patients with cancer do not receive dietary advice from their healthcare professionals (Cancer and Nutrition NIHR infrastructure collaboration, 2015). The survey was predominantly completed by breast cancer survivors and there was insufficient information for other cancer groups (Cancer and Nutrition NIHR infrastructure collaboration, 2015).

1.9. Pelvic cancers

The focus of this PhD will be on people who were treated with radiotherapy for a cancer diagnosis in the pelvic area. Pelvic cancer refers to a variety of cancers involving the structures and the organs in the pelvis. Pelvic cancers include cancers of the anus, bladder, rectum, gynaecological cancers (cervix, uterus, ovaries, vulva and vagina) and male cancers (prostate, penis and testes) (Paramasivam et al., 2006). Prostate cancer is the most common cancer in males in England (26% of registered male cancers), while gynaecological cancer accounted for almost 12% of registered cancer cases in women in 2014 (Office for National Statistics, 2019). Survival rates are higher than average in most pelvic cancers; it is expected that 84% prostate, 77% endometrial, 63% cervical, 57% rectal and 50% bladder cancer survivors will live for more than ten years (Quaresma et al., 2015). Only patients with an ovarian cancer diagnosis still have a poor 10-year life expectancy (35%) (Quaresma et al., 2015).

Apart from increasing incidence and survival, people diagnosed with a pelvic cancer share a number of common characteristics that may affect future wellbeing and quality of life, such as persistent treatment side effects (Adams et al., 2014) and high obesity rates (Weaver et al., 2013). Pelvic radiotherapy (external beam radiation or brachytherapy) is often an integral part of the multidisciplinary approach used to treat pelvic tumours. Although radiotherapy is directed to a specific part of the body there is also often damage to normal tissues in the surrounding area and patients can experience a range of side effects as a result. Although technological advances have led to improvement of techniques, toxicity still affects the gastrointestinal tract and can lead to functional damage, including malabsorption and change in motility of the intestinal tract (Teo et al., 2015). These adverse effects can have a significant impact on a patient's diet, subsequent nutritional status and quality of life (Andreyev et al., 2011) and these effects can persist for many years (Adams et al., 2014).

Obesity rates in pelvic cancer populations are higher than in the general population, especially for prostate, colorectal and gynaecological cancers (Weaver et al., 2013). Systematic reviews of observational studies have demonstrated increased mortality in obese ovarian (Protani et al., 2012), prostate (Zhang et al., 2015) and endometrial cancer survivors (Secord et al., 2016) in comparison to non-obese cancer survivors, although the evidence on obesity and prostate cancer specific mortality is still inconclusive (Vidal et al., 2017, Schiffmann et al., 2018). Obesity has also been associated with lower physical and functional well-being and poorer quality of life among endometrial cancer (Koutoukidis et al., 2015), prostate cancer (Dieperink et al., 2012) and colorectal cancer survivors (Adams et al., 2016) in observational studies. It is also documented that cancer survivors are at increased risk of developing comorbidities, such as type II diabetes, cardiovascular disease, osteoporosis (Edgington and Morgan, 2011) as well as a secondary primary cancer (Travis et al., 2013). It is evident that individuals diagnosed with cancers that typically have high survival rates, such as pelvic cancers, are more likely to die of a cardiovascular disease rather than cancer progression or recurrence (Weaver et al., 2013).

Common characteristics in pelvic cancer populations (increased incidence and survival, pelvic radiotherapy side effects, obesity) provide the opportunity for a researcher to explore experiences in diet and nutrition in these cancers as one whole group. However, it should be acknowledged that there are also distinct differences in relation to dietary management following diagnosis, which are particularly attributed to receipt of treatments other than pelvic radiotherapy. People diagnosed with prostate cancer often follow additional hormone therapy, which may lead to muscle wasting, fat accumulation and weight gain. On the contrary, receipt of chemotherapy is common in rectal and gynaecological cancers, and is linked with loss of appetite, weight loss and increased risk for malnutrition. Irrespective of other treatment regimens, patients diagnosed with pelvic cancers face a range of issues in relation to diet and nutrition that affect nutritional status and body weight.

Treatment side-effects and the increased risk of developing a secondary cancer or comorbidity are likely to influence patients' sense of well-being (Koch et al., 2013). Pelvic cancer patients often express concerns about their diet and are likely to be interested in receiving information about healthy eating (Coa et al., 2014, Bours et al., 2015). In recognition of the importance of translational research and the need to deliver quality, standardised nutritional care tailored to the needs of pelvic cancer patients, it is essential to understand their experiences, perceptions and knowledge in relation to their diet and nutrition.

1.10. Aim and objectives

The overall aim of the PhD project is to explore dietary habits, nutritional awareness and experiences of nutritional care of cancer survivors with a pelvic cancer and treated with radical pelvic radiotherapy.

An initial search during the early stages of the PhD to explore "what has been done up to now", identified relevant past research published in journals, as well as written materials that included practical information on diet and nutrition relevant to pelvic cancer survivors. After discussions with the supervisory team, it was decided that the initial search identified two potential topics worth further exploring:

1. A search of the published, peer-reviewed research, which would be organised in a systematic literature review (Phase 1; Chapter 2) to identify research gaps and inform the mixed-methods study (Phase 2) and

2. Original research to evaluate the quality of the written materials (Phase 3; Chapter 8).

Based on the initial scoping exercise, the specific objectives of the project are to

- Review the literature regarding information and support needs in diet and nutrition in cancer patients receiving pelvic radiotherapy.
- Explore survivors' current dietary habits, including dietary changes as a result of the cancer diagnosis
- Assess survivors' awareness of and attitudes towards current dietary recommendations
- Explore survivors' experiences of nutrition support received during or after pelvic radiotherapy treatment and highlight unmet needs
- Identify the availability of online information in diet and nutrition suitable for pelvic cancer patients

Therefore, answers to the following questions are sought:

- Do pelvic cancer patients change their diet as a result of diagnosis and treatment and why?
- How familiar are pelvic cancer patients with the current nutritional recommendations published by the WCRF?
- Do pelvic cancer patients receive support and information with regards to diet and nutrition from their healthcare team or any other source?
- What information on diet and nutrition is available online for pelvic cancer patients?

In order to address the aim and objectives, this PhD is divided in three sections.

<u>Phase 1 (Chapter 2):</u> A systematic review of the literature regarding diet and nutrition information and support needs of cancer patients receiving pelvic radiotherapy.

Phase 2 (Chapters 3-7): A mixed-methods study to explore dietary changes, nutritional awareness and patient experiences in people diagnosed with a pelvic cancer either undergoing or having completed pelvic radiotherapy 6-24 months before.

Phase 3 (Chapter 8): An original study of the availability and quality assessment of online nutrition information for pelvic cancer patients in the UK.

The long-term goal is to optimise support in diet and nutrition in order to address nutritional problems and to improve wellbeing in cancer survivors. In order to achieve the long-term goal, gaps in care and unmet needs should be highlighted. The identification of unmet needs, along with research relating to the role of diet in cancer survivorship outcomes, is expected to improve the level of support in this field.

The aim and objectives of this PhD will lead to the identification of unmet needs of pelvic cancer survivors in diet and nutrition. In order to obtain this information, a mixed-methods approach (detailed in Chapter 3) will be implemented to explore aspects of patients' nutritional behaviour, such as dietary changes following diagnosis, supplement use and nutritional awareness of current recommendations. Also, it is essential to explore current level of support from the healthcare environment, as well as external sources, such as the internet. An additional original study will be implemented to identify and evaluate nutritional information available online suitable for pelvic cancer survivors (Chapter 8).

Unmet needs are expected to be vary within a group of patients with a diagnosis of pelvic cancer. For example, treatment stage (currently undertaking radiotherapy or having completed radiotherapy) could unveil different needs in diet and nutrition. As highlighted earlier, on-treatment patients may be more prone to undernutrition and suffer more side effects, compared to survivors who have completed treatment and recovered their disease. Similarly, expected outcomes may be different according to cancer diagnosis, socioeconomic and health factors (e.g. Body Mass Index, additional comorbidities) and should be explored in more depth. Fig. 1.1. summarises the link between the study aim and objectives, and long-term goal.

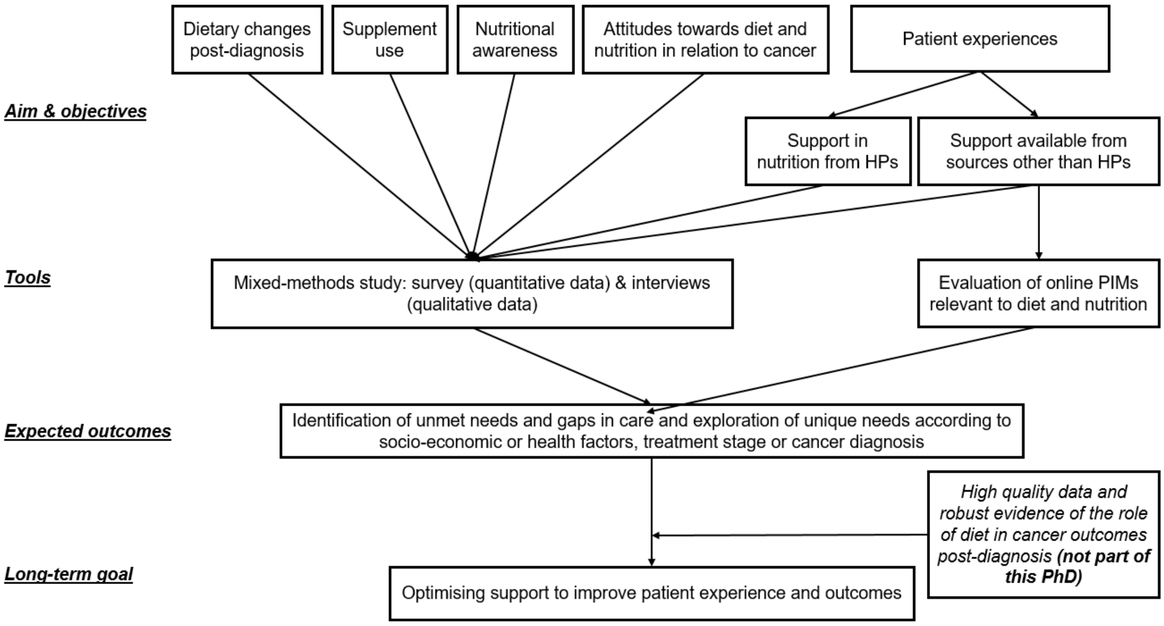


Figure 1.1: Summary of aim/objectives, expected outcomes and long-term goal. *HPs: Health Professionals.*

Chapter 2. Systematic review

Diet and nutrition information and support needs after a pelvic cancer diagnosis: a systematic, mixed-methods review.

2.1. Summary

The first phase of this PhD aimed to review information and support needs in relation to diet and nutrition following a pelvic cancer diagnosis. A systematic review of the literature was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Peer-reviewed studies of any design that assessed diet and nutrition needs after a pelvic cancer diagnosis were included. Narrative synthesis was used to integrate findings. Thirty-one studies (12 quantitative, 16 qualitative, 3 mixed-methods) were included in the analysis. Nutritional guidance was not routinely provided after a cancer diagnosis or treatment. Pelvic cancer patients expressed nutritional information and support needs following diagnosis and sought tailored, evidence-based and practical nutritional advice in relation to their disease.

2.2. Introduction

Improving the quality of nutritional care provided to people with cancer requires gaining a better understanding of their needs and identifying ways to offer solutions to these needs. To date, there has been no review of the literature regarding information and support needs in relation to diet and nutrition in cancer patients. This PhD focuses on cancers receiving pelvic radiotherapy (bladder, lower GI, male and female reproductive organs); therefore this review aims to provide answers to the following questions:

- What dietary information do patients with a pelvic cancer receive in relation to their diagnosis?
- What are pelvic cancer patients' perceived information and support needs regarding diet and nutrition?
- Are there differences in information and support needs in different survivorship stages (during treatment and post-treatment)?

2.3. Methods

This systematic review was conducted according to the PRISMA guidelines, where applicable. The review protocol has been registered at the International Prospective Register of Systematic Reviews (PROSPERO CRD42018115832).

2.3.1. Search strategy

A systematic search of six databases (MEDLINE, EMBASE, CINAHL, Web of Science, AMED: Allied and Complementary Medicine and PsycINFO) was performed in April 2018 and was updated in February 2019. There were no restrictions in publication date. The following keyword topics were used:

1. Cancer (cancer OR oncology OR neoplasm OR carcinoma OR tumour)
2. AND pelvic (pelvic OR bladder OR ovarian OR endometrial OR cervical OR uterine OR vaginal OR vulvar OR rectal OR colorectal OR testicular OR prostate OR anal OR reproductive organs OR bowel). Although colon cancer is not routinely treated with radiotherapy, it was decided to include in the search, as research papers usually refer to ‘colorectal cancer’ or ‘bowel cancer’.
3. AND patients (patients OR survivors OR diagnosis OR survivorship)
4. AND information needs (information OR advice OR education OR support OR guidance OR needs OR views OR concerns)
5. AND diet (diet OR nutrition OR food OR lifestyle OR nourishment OR supplement

Subject headings were used, where applicable. Appendix 1a shows the detailed search strategy in Web of Science. Initial database searches revealed a number of studies published in specific journals: Supportive Care in Cancer; Journal of Cancer Survivorship; and European Journal of Cancer Care. In addition to the search of databases, all volumes and issues of these journals were searched from 2000 to February 2019 using the words “diet and cancer” or “nutrition and cancer”. Also, reference lists of two scoping (Van

Mossel et al., 2012, Fletcher et al., 2017) and two systematic reviews (Kotronoulas et al., 2017, Puts et al., 2012) of unmet needs of cancer patients were also thoroughly searched for relevant publications. Finally, the reference lists of all full-text articles were examined for any studies that may have been overlooked.

2.3.2. Eligibility criteria

Studies were considered for inclusion if:

- They investigated supportive care needs or information needs in relation to diet and nutrition of people diagnosed with a cancer in the pelvic area, irrespective of disease stage, time-point after diagnosis or treatment.
- The study design was cross-sectional, prospective, retrospective, a randomised trial or qualitative. All quantitative and qualitative research designs were considered as the aim was to provide a complete picture, deduce maximum information and get a better understanding of the phenomenon (Hong et al., 2017).
- They were conducted with adult individuals (i.e. aged >=18 years)
- They were original research published in peer reviewed journals
- They were published in English (a translation service was not possible)

Studies were excluded if:

- They did not highlight diet and nutrition support needs of the target population (i.e. if they discussed lifestyle in general)
- They were an audit of a current hospital service, editorials, case studies, reviews, opinion papers or conference proceedings.
- The sample was a mix of pelvic and other cancer diagnoses except when separate sub-groups analyses were reported for pelvic cancers.
- Patients were in receipt of palliative care for advanced cancer.

2.3.3. Study selection

The studies were selected in two stages. First, a title and abstract screening was performed by the Principal Investigator (PI) for all identified studies. A randomly selected subsample (10%) of the studies was also screened by the supervisory team to ensure consistency. Any disagreements were discussed until a mutual decision was reached. After title and abstract exclusion, all remaining studies were considered for full-text review. Eligibility criteria were applied to full-text articles by the PI. In case of uncertainty or any disagreements, discussions took place in supervisory meetings until a mutual decision was reached.

2.3.4. Data extraction and synthesis

Relevant features and results were extracted for each included study. Data were extracted by the PI and were confirmed by the supervisory team (Table 2.1). Location of study, study design, study duration, aim(s), inclusion criteria, sample size, percentage of women in sample, mean/median age and age range of participants, response rate and sample cancer diagnosis were extracted, where possible, for all included studies. Studies in the data extraction table (Table 2.1) have been grouped according to the research design (qualitative, quantitative) and cancer diagnosis (prostate, colorectal, gynaecological cancer).

Findings from all studies were integrated and collated under the three research questions. First, thematic analysis was performed to identify common themes and concepts related to diet and nutrition information and support needs from qualitative studies. Thematic analysis was conducted according to Braun and Clarke (2006) which involves six steps: familiarisation with the data; coding; searching for themes; reviewing the themes; defining and naming the themes; and producing the report. Then, findings from the quantitative studies were integrated with the findings of the thematic analysis of qualitative studies.

Thematic synthesis, which is a type of synthesis commonly used in qualitative research, is also used as a means of organising and summarising the findings from large, diverse bodies of research (Lucas et al., 2007). Quantitative data fitted well with the themes developed in thematic analysis of qualitative data; hence results are presented according to these themes.

2.3.5. Quality assessment

For the assessment of cross-sectional studies, the Appraisal Tool for Cross-Sectional studies (AXIS) was used (Downes et al., 2016). The tool comprises 20 questions, seven of which relate to the quality of reporting, seven to study design and six to study biases. For the assessment of qualitative studies, a previously adapted appraisal tool for qualitative studies (Cesario et al., 2002, Hannes, 2011) was used. The tool comprises five categories: descriptive vividness (credibility); methodological congruence (dependability and confirmability); analytical preciseness; theoretical connectedness (transferability); and heuristic relevance (Collaco et al., 2018). A score range of 1-24 was given to each qualitative study based on the scores for each of the five categories. The quality of a study was considered good for a score of 18-24 (75-100% of the total criteria met), fair for a score of 12-17 (50-74% of the total criteria met) and poor for a score lower than 12 (less than 50% of the total criteria met). The quantitative and qualitative arm of the mixed-methods studies was assessed separately.

2.4. Results

The initial search yielded 4,529 results. After removal of duplicates (1,407), 3,048 articles were excluded following review of title and abstract and a further 44 were excluded after full-text read. Thirty articles are included in this review (Figure 2.1).

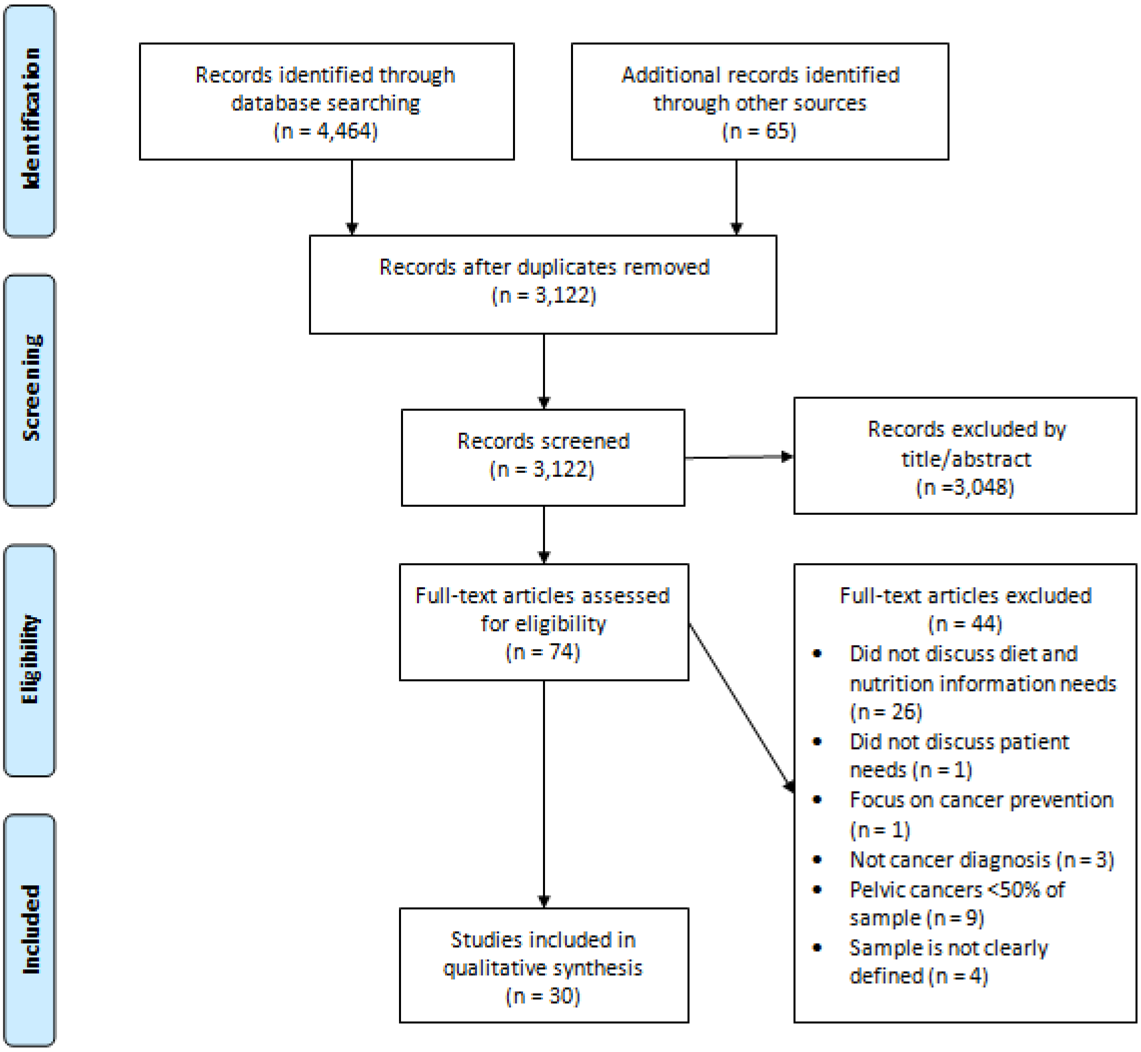


Figure 2.1: Article selection PRISMA flow chart (Moher et al., 2009)

2.4.1. Characteristics of selected studies

Of the 30 included studies, eleven studies were conducted in the UK (Anderson et al., 2013, Avery et al., 2014, Beaver et al., 2010, Beaver et al., 2011, Brown et al., 2016, Er et al., 2017, Evans et al., 2007, Kassianos et al., 2015, Koutoukidis et al., 2017, Rozmovits et al., 2004, Sutton et al., 2017), five in the USA (Clark et al., 2016, Demark-Wahnefried et al., 2000, des Bordes et al., 2016, Tseng et al., 2015, Zaleta et al., 2017), four in Australia (Dunn et al., 2006, Hardcastle et al., 2017, Hardcastle et al., 2018, Nikoletti et al., 2008), two in Canada (Fitch et al., 2000, Fitch et al., 2001), two in New Zealand (Cha et al., 2012, Pullar et al., 2012), two in South Korea (Lee et al., 2016, Jang et al., 2018) and one each in Israel (Perl et al., 2016), the Netherlands (Hoedjes et al., 2017), Sweden (Samuelsson et al., 2018) and Malaysia (Lee et al., 2017). Twelve studies employed a quantitative design (Beaver et al., 2011, Cha et al., 2012, Clark et al., 2016, Demark-Wahnefried et al., 2000, Fitch et al., 2000, Fitch et al., 2001, Lee et al., 2016, Nikoletti et al., 2008, Perl et al., 2016, Pullar et al., 2012, Tseng et al., 2015, Zaleta et al., 2017), fifteen were qualitative (Anderson et al., 2013, Avery et al., 2014, Beaver et al., 2010, Brown et al., 2016, Dunn et al., 2006, Er et al., 2017, Evans et al., 2007, Hardcastle et al., 2017, Hardcastle et al., 2018, Kassianos et al., 2015, Koutoukidis et al., 2017, Rozmovits et al., 2004, Sutton et al., 2017, Lee et al., 2017, Samuelsson et al., 2018) and three were mixed-methods studies (des Bordes et al., 2016, Hoedjes et al., 2017, Jang et al., 2018). Sample size varied according to research design, with the range being 8-58 participants in qualitative studies and 20-1198 participants in quantitative studies. Twelve studies (40%) were conducted on colorectal cancer patients (Anderson et al., 2013, Beaver et al., 2010, Beaver et al., 2011, Brown et al., 2016, Cha et al., 2012, Dunn et al., 2006, Hardcastle et al., 2018, Hoedjes et al., 2017, Nikoletti et al., 2008, Pullar et al., 2012, Rozmovits et al., 2004, Samuelsson et al., 2018), nine studies (30%) on gynaecological cancer patients (Zaleta et al., 2017, Tseng et al., 2015, Lee et al., 2016, Koutoukidis et al., 2017, Hardcastle et al., 2017, Fitch et al., 2000, Fitch et al., 2001, Clark et al., 2016, Jang et al., 2018), five studies (17%) on prostate cancer patients (Avery et al., 2014, Er et al., 2017, Sutton et al., 2017, Kassianos et al., 2015, Lee et al., 2017) and four studies (13%) had a sample with mixed cancer diagnoses (Demark-Wahnefried et al., 2000, des Bordes et al., 2016, Evans et al., 2007, Perl et al., 2016). All studies were published after the year 2000 and most (80%) after 2010. Table 2.1 shows the characteristics of the included studies.

Table 2.2 describes the main findings reported across the papers in relation to diet and nutrition information needs, the tool(s) used to collect data and the related themes from the thematic analysis. Ten cross-sectional studies, including one mixed-methods study, used non-validated questionnaires developed by the study authors (Cha et al., 2012, Clark et al., 2016, Demark-Wahnefried et al., 2000, Fitch et al., 2000, Fitch et al., 2001, Hoedjes et al., 2017, Lee et al., 2016, Nikoletti et al., 2008, Pullar et al., 2012, Tseng et al., 2015). Three studies, including one mixed methods, used validated tools for one or more of their research questions (Zaleta et al., 2017, Perl et al., 2016, Jang et al., 2018) and two (including one mixed-methods study) used adapted validated questionnaires (Beaver et al., 2011, des Bordes et al., 2016). Twelve qualitative studies (including two mixed-methods) conducted interviews (Beaver et al., 2010, Brown et al., 2016, des Bordes et al., 2016, Er et al., 2017, Evans et al., 2007, Hardcastle et al., 2017, Hardcastle et al., 2018, Kassianos et al., 2015, Rozmovits et al., 2004, Sutton et al., 2017, Jang et al., 2018, Samuelsson et al., 2018), two (including one mixed-methods) conducted focus groups (Anderson et al., 2013, Hoedjes et al., 2017) and four used a combination of interviews and focus groups (Dunn et al., 2006, Koutoukidis et al., 2017, Avery et al., 2014, Lee et al., 2017). Three main themes were identified: “content of dietary information”; “sustaining dietary change”; and “views on the role of diet in survivorship”.

All studies included participants that had completed treatment and seven of these, all qualitative studies, also included patients undergoing treatment at the time of the study (Avery et al., 2014, des Bordes et al., 2016, Er et al., 2017, Evans et al., 2007, Kassianos et al., 2015, Pullar et al., 2012, Sutton et al., 2017). The studies that included participants in different treatment stages did not present results according to treatment stage (on-treatment/post-treatment), so it was not possible to identify any sub-themes related to differences in information and support needs according to treatment stage. The three themes provided insights in relation to the first two research questions: “What information do pelvic cancer patients receive in relation to their diagnosis?” and “What are their information and support needs?”.

2.4.2. Theme 1: Content of dietary information

A total of 27 studies discussed patients' receipt of information on diet and nutrition. Six of these, all quantitative (Beaver et al., 2011, Clark et al., 2016, Fitch et al., 2000, Fitch et al., 2001, Nikoletti et al., 2008, Tseng et al., 2015), reported that a majority of participants (50-59%) received advice related to their diet and four reported levels of satisfaction with received information (53-59%). Twenty-one studies, most of them qualitative, highlighted diet and nutrition counselling as an unmet need (Anderson et al., 2013, Avery et al., 2014, Beaver et al., 2010, Brown et al., 2016, Cha et al., 2012, Demark-Wahnefried et al., 2000, Dunn et al., 2006, Er et al., 2017, Evans et al., 2007, Hardcastle et al., 2017, Hardcastle et al., 2018, Koutoukidis et al., 2017, Pullar et al., 2012, Rozmovits et al., 2004, Sutton et al., 2017, Samuelsson et al., 2018, Jang et al., 2018, Lee et al., 2017, Kassianos et al., 2015, Hoedjes et al., 2017, des Bordes et al., 2016). Participants reported receipt of vague and often contradictory advice in six studies (Anderson et al., 2013, Er et al., 2017, Hardcastle et al., 2018, Kassianos et al., 2015, Koutoukidis et al., 2017, Lee et al., 2017). Patients also reported being advised or following themselves a "trial and error" approach, particularly in relation to diet adaptation to altered bowel habits (Anderson et al., 2013, Beaver et al., 2010, Hardcastle et al., 2018), which was perceived as "unhelpful" (Anderson et al., 2013). In Avery et al.'s study (2014), lack of reliable information was considered to be a barrier to dietary change for prostate cancer patients. It was highlighted across studies that patients look for simple, clear messages (Anderson et al., 2013, Avery et al., 2014, Hardcastle et al., 2018, Hoedjes et al., 2017, Rozmovits et al., 2004) and reliable, evidence-based information (Avery et al., 2014, Kassianos et al., 2015, Koutoukidis et al., 2017, Sutton et al., 2017) which could influence dietary change. Also, tailored advice was expected and should be provided (Anderson et al., 2013, Avery et al., 2014, Beaver et al., 2010, Hardcastle et al., 2018, Hoedjes et al., 2017, Kassianos et al., 2015, Brown et al., 2016, Koutoukidis et al., 2017, Sutton et al., 2017, Lee et al., 2017, Samuelsson et al., 2018). Hoedjes et al. (2017) reported that not only content, but also format, intensity and timing of counselling should be individualised.

Patients frequently asked about dietary support in relation to physical symptoms, such as management of bowel problems and weight changes. Queries about management of bowel problems were reported in ten studies with colorectal cancer patients (Anderson et al., 2013, Beaver et al., 2010, Brown et al., 2016, Dunn et al., 2006, Hardcastle et al., 2018, Hoedjes et al., 2017, Nikoletti et al., 2008, Pullar et al., 2012, Rozmovits et al., 2004, Samuelsson et al., 2018) and two studies with gynaecological cancer patients (Koutoukidis et al., 2017, Lee et al., 2016). In particular, patients expressed concerns on which specific diet would be appropriate after removal of part of the bowel (Beaver et al., 2010, Rozmovits et al., 2004). In the Rozmovits et al. study (2004), patients reported difficulties adjusting their dietary habits to the altered bowel function but could not find the information they wanted. Anderson et al. (2013) reported that colorectal cancer patients sought practical dietary advice on which foods to avoid for controlling diarrhoea and flatulence, which affected them on a daily basis. According to two studies, dietary support was more frequently provided to colorectal cancer patients with a stoma, in comparison to those who did not have a stoma (Rozmovits et al., 2004, Hardcastle et al., 2018).

Regarding weight changes, a study showed that colorectal cancer patients experienced both weight loss and weight gain during their treatment and attributed these changes to a lack of guidance (Anderson et al., 2013). In Samuelsson et al. study (2018), older patients lost weight during treatment and were experiencing difficulties regaining weight; yet only a few of them reported dietetic support. Studies in overweight and obese gynaecological cancer survivors showed that weight management counselling was not routinely provided as part of the follow up consultations (Tseng et al., 2015, Zaleta et al., 2017). Most gynaecological cancer survivors were largely receptive to weight management counselling, which would reinforce the importance of attempting weight loss (Clark et al., 2016, Tseng et al., 2015, Zaleta et al., 2017).

Apart from dietary information in relation to physical symptoms, a number of other education needs were highlighted across several studies. Patients requested advice in relation to recipes (des Bordes et al., 2016, Hardcastle et al., 2018, Lee et al., 2016), shopping practices (des Bordes et al., 2016), classification of foods (Hardcastle et al., 2018), portion sizes (Hardcastle et al., 2018), energy intake (Hardcastle et al., 2018), food labels (Hardcastle et al., 2018), supplements (Evans et al., 2007, des Bordes et al., 2016, Hoedjes et al., 2017), general healthy eating (Anderson et al., 2013, Hardcastle et al., 2017) and healthy lifestyle (Koutoukidis et al., 2017).

Healthcare professionals, such as oncologists, consultants, cancer specialist nurses, primary care physicians and dietitians were considered the most reliable sources of information (Avery et al., 2014, Brown et al., 2016, Clark et al., 2016, Er et al., 2017, Hardcastle et al., 2017, Koutoukidis et al., 2017, Sutton et al., 2017, Hoedjes et al., 2017); however, in few studies patients noted that health professionals were lacking adequate knowledge in this topic (Kassianos et al., 2015, Koutoukidis et al., 2017, Rozmovits et al., 2004) or were uncertain about the role of diet in survivorship (Er et al., 2017). It was not possible to compare experiences of information and support according to different healthcare disciplines (e.g. oncologist Vs dietitian) due to insufficient information from the included studies.

2.4.3. Theme 2: Sustaining dietary change

Several studies reported lack of dietary counselling during follow up (Hardcastle et al., 2017, Hardcastle et al., 2018, Koutoukidis et al., 2017, Samuelsson et al., 2018) and highlighted the need for regular ongoing monitoring as a means of sustaining healthy behaviours, including dietary changes and weight management (Hardcastle et al., 2017, Hoedjes et al., 2017, Kassianos et al., 2015, Zaleta et al., 2017, Samuelsson et al., 2018). Also, patients expressed an interest in having their current dietary habits assessed and receive feedback on what could improve in their diets (Hoedjes et al., 2017, Kassianos et al., 2015, Sutton et al., 2017). Patients perceived health professionals to have an important role in engaging them in regular conversations that could help them sustain healthy dietary habits (Hardcastle et al., 2017, Zaleta et al., 2017). In a study conducted in endometrial cancer survivors, participants expressed a need for accountability and external support to commit to lifestyle behaviour change (Hardcastle et al., 2017). On the other hand, a study in cancer survivors showed that self-management was another important aspect of keeping a healthy diet (Hoedjes et al., 2017).

2.4.4. Theme 3: Views on the role of diet post-treatment

Although dietary support is valued as an important topic of discussion with health professionals across most included studies, a few qualitative studies conducted on prostate and colorectal cancer patients showed that diet was not always perceived as an important aspect of survivorship, particularly after curative surgery (Anderson et al., 2013, Avery et al., 2014, Er et al., 2017, Sutton et al., 2017, Kassianos et al., 2015). Anderson et al. (2013) reported that some colorectal cancer survivors did not believe that a healthy diet would reduce the risk of recurrence, since it had not prevented its development. In another study, prostate cancer patients who underwent radical treatment were less likely to consider dietary changes than those on active surveillance (Avery et al., 2014). In the Er et al. (2017) pilot study of assessing prostate cancer survivors’ interest in a dietary intervention program, participants perceived their current diet to be healthy and questioned which further changes could be made to improve it. For others, implementation of dietary changes following counselling was viewed as returning control and allowing patients “to do something after diagnosis” or as adjunct therapy by some studies in prostate and colorectal patients (Anderson et al., 2013, Avery et al., 2014, Kassianos et al., 2015). Three studies also highlighted the need for a holistic package of survivorship care, including diet alongside physical activity, and mental, sexual and psychological wellbeing (Anderson et al., 2013, Evans et al., 2007, Koutoukidis et al., 2017).

2.4.5. Quality of the included studies

The results of the quality assessment of the included studies are presented in Appendix 1b. Quality of reporting and quality of study design were generally high across the quantitative (cross-sectional) studies. Aims, population, recruitment settings and basic data were presented clearly and study design was appropriate in all quantitative studies. Most studies provided adequate information regarding statistical analysis, conflicts of interest, ethical approval and study limitations; however, no studies justified sample size and only three described the characteristics of non-respondents. Non-response bias may have occurred in 13 studies (including all mixed-methods). Most studies used non-validated questionnaires. Results were internally inconsistent in four studies.

Quality was overall characterised as “fair” (score 12-17) in eleven qualitative studies (including three mixed-methods) and “good” (18-24) in seven studies. No studies scored lower than 12 points and no studies achieved the maximum score of 24. All studies provided an adequate description of the methods and ethical procedures and most referred to policy and research recommendations. All studies had enough information to ensure transferability (fair or good scores) and most of them to ensure confirmability. On the other hand, several studies scored “poor” on assessment of credibility and dependability.

Table 2.1: Characteristics of the selected studies, grouped according to cancer diagnosis (colorectal, prostate, gynaecological) and study design (qualitative, cross sectional, mixed).

First author and country	Design & study duration	Aim of study	Sample, N, sex, age	Response rate	Inclusion criteria	Cancer type
Anderson (UK)	Qualitative, NS	To explore patient needs for advice on diet, activity and lifestyle; patient beliefs about the role of diet, activity and lifestyle for reducing disease risk; and preferred formats, timings and routes of delivery for such guidance	N=40, 50.0% women; mean age (SD) 60 (12.2) years; range 27-84	NS	Diagnosed with and treated for colorectal cancer and not undertaking active cancer treatment	Colorectal
Beaver (UK)	Qualitative, NS	To explore patient perceptions of their experiences of follow-up care after treatment for colorectal cancer	N=27, 48.1% women; mean age 72 years; range 59-86	NS	Patients diagnosed with colorectal cancer who completed active treatment and had no current clinical problems	Colorectal
Brown (UK)	Qualitative, 3 months	To explore awareness of long-term and late treatment consequences of colorectal cancer survivors when they are nearing discharge from oncology	N=19, 42.1% women; mean age 67.1 years; range 37-84	NS	Participants with a colorectal cancer diagnosis, at least 12 months post treatment, over 18 years old, able to communicate in English and without a terminal diagnosis or dementia	Colorectal
Dunn (Australia)	Qualitative, NS	To examine quality of life and psychosocial variables most salient to colorectal cancer patients	N=20, 60% women; mean age and range not reported	28%	Diagnosed with colorectal cancer within the past 18 months, under 80 years old, spoke English, and had no mental or intellectual impairment	Colorectal
Evans (UK)	Qualitative, NS	To investigate why men choose to use Complementary and Alternative Medicine (CAM), and the extent to which CAM is used to fill 'gaps' in conventional care provision	Total sample N=34. Prostate cancer survivors: N=10; colorectal cancer survivors N=10; Mean age and range not reported for the subsamples	NS	Men with a cancer diagnosis and Complementary and Alternative Medicine (CAM) users	Prostate and colorectal
Hardcastle (Australia)	Qualitative, 3 months	To explore colorectal cancer survivors' information and support needs in relation to health concerns and the promotion of healthy eating and physical activity	N=24, 45.8% women; mean age 69.4 years; range 63-77	19%	Colorectal cancer diagnosis within the past two years and presence of comorbidities which put them at high risk for cardiovascular disease	Colorectal

First author and country	Design & duration	Aim of study	Sample, N, sex, age	Response rate	Inclusion criteria	Cancer type
Rozmovits (UK)	Qualitative, 12 months	To describe current hospital follow-up policy and to explore patients' needs and preferences for follow-up	N=39; 48.7% women; mean age 60.1 years; range 33-87	NS	People with a colorectal cancer diagnosis	Colorectal
Samuelsson (Sweden)	Qualitative, NS	To describe older patients' experiences from diagnosis of colorectal cancer, to recovery and aftercare and evaluate how information provision was perceived by patients	N=16, 50% women, median age 82.5 years; range 76-89 years	84%	People aged 75 years and above who had undergone elective CRC surgery with curative intent at least 3 months prior to the interview	Colorectal
Beaver (UK)	Cross sectional survey, NS	To explore patient satisfaction on different aspects of follow-up service provision following treatment for colorectal cancer	N=187, 43.3% women; mean age (SD) 72.8 (8.5) years; range 46-90	63%	Adults (>18 years) who had received resection with curative intent for either cancer of the colon or rectum	Colorectal
Cha (New Zealand)	Cross sectional survey, NS	To describe dietary intakes and dietary patterns of colorectal cancer patients in the Auckland region, and to investigate what the current information resources are, and patient satisfaction with these resources	N=29, 31% women; Age band most frequently selected 70+ years	73%	Participants with a diagnosis of colorectal cancer who had received surgical resection (with curative intent) of their tumour in the last 1-4 months	Colorectal
Nikoletti (Australia)	Cross sectional survey, NS	To explore long-term information needs and self-care practices relating to bowel management after sphincter-saving colorectal surgery	N=101, 29.7% women; mean age 66.2 years; range 40-88	56-86% across different settings	Adults (>18 years of age), diagnosed with a colorectal cancer, undergoing sphincter-saving surgery in the past 6-24 months and able to speak and understand English	Colorectal
Perl (Israel)	Cross sectional survey, NS	To characterize gastrointestinal cancer patients' specific physical and psychosocial needs and quality of life concerns	Total sample N=50. Colorectal cancer N=40, 50% women. Mean age and range not reported for the subsample	94%	Young adults (18-40 years old) diagnosed with cancer of the GI tract (oesophagus, gastric, colon, rectum, anal) between 6 months and two years prior to enrolment; had a Karnofsky Performance Status of 80 or above or an Eastern Cooperative Oncology Group (ECOG) score of 0 or 1	Colorectal

First author and country	Design & duration	Aim of study	Sample, N, sex, age	Response rate	Inclusion criteria	Cancer type
Pullar (New Zealand)	Cross sectional survey, 2 months	To establish the dietary patterns of colorectal cancer patients, the level of dietary advice they currently received and its impact on their behaviour	N=40, 47.5% women; 70% were 60 years or older	NS	Adults (>18 years of age), diagnosed with colorectal cancer (stages II, III or IV), with sufficient literacy to comprehend the survey	Colorectal
Hoedjes (the Netherlands)	Mixed, NS	To explore needs and preferences for dietary support among colorectal cancer survivors	Survey: N=1198; 40.0% women; mean age (SD) 69.1 (9.5). Focus groups: N=16; 37.5% women; mean age and range not reported for the qualitative arm	Survey: 68%; focus groups: 27%	Survey: a colorectal cancer diagnosis between 2000-2009 and no cognitive impairments. Focus groups: at least one year after a colorectal cancer diagnosis and a Body Mass Index >27 kg/m^2	Colorectal
Avery (UK)	Qualitative, 4 years	To explore views about diet and motivations for and barriers to dietary change in men at elevated risk and those diagnosed with PC	At elevated risk: N=21, all men; mean age 65.4 years; range 52.5-72.3. Diagnosed with cancer: N=37, all men; mean age 66.5 years; range 54.4-75.4)	95% (58/61 in phase 1), 56% (5/9 in phase 2)	At elevated risk: prostate specific antigen (PSA) level of 2.0-2.9 ng/ml or ≥3.0 ng/ml with a negative biopsy. Diagnosed with cancer: diagnosis (PSA ≥3.0 ng/ml) and either treatment of prostate cancer, active monitoring or active surveillance	Prostate
Er (UK)	Qualitative, 12 months	To explore the facilitators and barriers to dietary and lifestyle changes and the acceptability of a lifestyle intervention among African Caribbean prostate cancer survivors	N=14, all men; mean age 69.6 years; range 52-80.	NS	Men aged 18 and above who self-identified as African Caribbean and had a clinically confirmed prostate cancer diagnosis	Prostate
Kassianos (UK)	Qualitative, NS	To identify factors that are believed to be associated with changes in diet following diagnosis	N=8, all men; mean age 64.9 years; range 55-76	NS	A prostate cancer diagnosis and resident in the UK	Prostate
Lee P. (Malaysia)	Qualitative, 3 months	To explore the post-treatment impact and related needs of prostate cancer survivors in Malaysia	N=24, all men; mean age not reported, range 58-79 years	NS	Diagnosis of prostate cancer	Prostate
Sutton (UK)	Qualitative, 6 months	To explore the experiences of men with prostate cancer and their partners on the provision of dietary and physical activity advice following diagnosis of, and treatment for, prostate cancer	N=16, all men; age range 53-79 years	NS	Men diagnosed with prostate cancer, who had recently undergone radical prostatectomy or were undergoing radiotherapy for localised prostate cancer	Prostate

First author and country	Design & duration	Aim of study	Sample, N, sex, age	Response rate	Inclusion criteria	Cancer type
Demark-Wahnefried (USA)	Cross sectional survey, 5 weeks	To assess health behaviours among cancer survivors; readiness to make changes and interest in lifestyle interventions	Total sample N=978. Prostate cancer survivors N=447, all men; mean age and range not reported for the prostate cancer subsample	60%	Patients with early stage (in situ or localized) prostate carcinoma diagnosed between January 1, 1992 and December 31, 1997	Prostate
Des Bordes (USA)	Mixed, 7 months	To assess information needs on bone health in survivors of prostate and breast cancer and identify the preferred method to deliver health information	Survey: Total sample N=20; prostate cancer survivors N=10, all men. Interviews: Total sample N=20; prostate cancer survivors N=10, all men. Mean age and range not reported for the prostate cancer subsample	31%	Diagnosed with prostate cancer, adults and no cognitive deficit, English speaking and access to telephone	Prostate
Hardcastle (Australia)	Qualitative, NS	To investigate survivors' recollections regarding the content of lifestyle advice received following cessation of their active treatment and explore the factors that impact on lifestyle behaviour change	N=22, all women; mean age 62.6 years; range 49-72	20%	Adult (25-80 years old) participants who had completed active treatment of endometrial cancer within the preceding 3 years and were deemed to be in remission; had at least one risk factor for CVD (i.e. body mass index [BMI] of 30 or more; hypertension; hypercholesterolemia; and diabetes mellitus); and were able to speak and comprehend English	Endometrial
Koutoukidis (UK)	Qualitative, 3 months	(1) To examine the perceived importance of health behaviours after endometrial cancer treatment, and the factors influencing adherence to a healthy lifestyle after treatment and (2) to explore the information that endometrial cancer survivors obtain after treatment, and their preferred method of information delivery	N=16, all women; median age 57 years; range 33-84	47%	Endometrial cancer survivors within 5 years post-active treatment	Endometrial

First author and country	Design & duration	Aim of study	Sample, N, sex, age	Response rate	Inclusion criteria	Cancer type
Clark (USA)	Cross sectional survey, 2 months	(1) To assess patient's knowledge of the role of obesity in endometrial cancer and to determine patient perceptions of provider's counselling with regard to obesity, weight loss and health improvement and (2) to characterize lifestyle changes made by patients after diagnosis and barriers to change	N=108, all women; mean age 66.0 years; range 41-91	46%	Any patient with a diagnosis of endometrial cancer between June 2011 and June 2012 and without evidence of active disease	Endometrial
Fitch (Canada)	Cross sectional survey, 6 weeks	To investigate the experiences of younger women with ovarian cancer	N=39, all women; mean age 38 years; range 21-45	NS	Women under 45 years old with a diagnosis of ovarian cancer and ability to read either English or French	Ovarian
Fitch (Canada)	Cross sectional survey, 6 weeks	To investigate the experiences of older women with ovarian cancer	N=146, all women; mean age 70 years; range 61-93	NS	Women over 61 years old with a diagnosis of ovarian cancer and ability to read either English or French	Ovarian
Lee (South Korea)	Cross sectional survey, 2 months	To investigate diet-related problems and nutritional care needs according to the survival stage among female cancer survivors in South Korea	Total sample N=186; gynaecological cancer survivors N=82. Extended stage (2-5 years since diagnosis) mean age (SD) 49.7 (8.0) years; long-term stage (>5 years since diagnosis) mean age (SD) 51.2 (7.3) years	NS	Adult women (18-65 years old) at least 2 years after a gynaecological cancer diagnosis who have finished active treatment (Except for hormone treatment)	Uterine, endometrial, in situ of uterine, uterine cervical, or ovarian cancer
Tseng (USA)	Cross sectional survey, 2 months	(1) To describe the experiences, attitudes, and perceived barriers of uterine cancer survivors related to weight loss and lifestyle counselling and (2) to characterize survivor preferences for physician intervention in this regard	N=180, all women; median age 58 years; range 29-76	28.3%	Women diagnosed with uterine cancer	Uterine

First author and country	Design & duration	Aim of study	Sample, N, sex, age	Response rate	Inclusion criteria	Cancer type
Zaleta (USA)	Cross sectional survey, 3 months	To examine perceptions of weight management counselling among gynaecologic cancer survivors	N=244, all women; mean age (SD) 57.1 (12.4) years	NS	All women diagnosed with a gynaecological cancer diagnosis presenting at the clinic for a follow up visit	Endometrial, ovarian, cervical, vulvar
Jang (South Korea)	Mixed, 10 weeks	To evaluate the information requirements for knowledge and self-management health behaviours related to metabolic syndrome	Survey: N=70, all women, mean age (SD) 58.7 (9.2) years, range 36-81. Interviews: N=27, all women, mean age (SD) 58.3 (10.1) years, range 36-75	36% (survey), 39% (interviews)	Women older than 18years with a diagnosis of ovarian or endometrial cancer, and diagnosis of MetS according to the NCEP-ATP III criteria, capacity to communicate and understand the questionnaire and ability to provide informed consent with no cognitive deficits	Ovarian and endometrial

NS: Not stated; SD: Standard Deviation.

Table 2.2: Summary of diet and nutrition information and support needs.

Study first author	Tool used	Description of provision (or lack of) of information and identification of needs	Themes
Anderson	Focus groups	Diarrhoea and flatulence were daily problems for which patients sought simple practical dietary advice on foods to avoid. Participants reported mixed messages which created anxiety and confusion, such as messages opposite to general healthy eating (e.g. counter intuitive to 5-a-day) and eating high fat, low quality foods. Participants were advised to adopt a "trial and error" approach while they were looking for solid advice/parameters to work with. Some participants also expressed the need for dietary advice to reduce disease recurrence or progression; however, others were sceptical about how diet could reduce the risk of disease in the future, since it did not prevent the development.	Content of dietary information Views on the role of diet in survivorship
Beaver	Face-to-face interviews	A commonly expressed concern was related to diet and what specific type of diet would be appropriate following removal of part of the bowel.. There was an expectation that specific dietary advice was important and should be provided. Support and advice are not mentioned by participants.	Content of dietary information
Brown	Face-to-face interviews	Respondents highlighted gaps in information provision and support services, the biggest of which was related to changes in bowel habit and diet adaptation. Bowel changes and their associations with diet had the biggest impact in patients' life. Input from a dietitian was regarded as helpful.	Content of dietary information
Dunn	Face-to face interviews and focus groups	A difficulty reported by participants was about obtaining information about what they could expect in the long term. The most frequent concern expressed was that they did not receive any information on diet. Most found that they had difficulty digesting a number of foods after their treatment, yet they had not been advised about what they should and should not be eating. Although a nutritionist visited some of them in hospital, there was no follow up.	Content of dietary information
Evans	Face-to-face interviews	As part of a more holistic approach, participants wanted advice on diet and lifestyle, so that they could keep themselves as fit as possible and reduce the chance of disease recurrence. Emphasis was also given to mental wellbeing. These topics were rarely discussed in their conventional consultation.	Content of dietary information Views on the role of diet in survivorship
Hardcastle	Face-to-face interviews	Participants felt unsupported regarding bowel changes and management of bowel movements, especially the ones without stoma. They didn’t know what kinds of foods they should or should not be eating, so they had to use trial and error to work out which foods are appropriate. Some participants mentioned receiving conflicting and inconsistent information after discharge in relation to bowel management. They also reported lack of knowledge as to what constitutes a healthy diet (classification of foods and portion sizes). Some participants wanted to know why some foods are not very healthy. Participants needed knowledge of nutrition and calorie intake in order to understand food labels. Monitoring would be beneficial to sustain a healthy behaviour.	Content of dietary information Sustaining dietary change

Study first author	Tool used	Description of provision (or lack of) of information and identification of needs	Themes
Rozmovits	Face-to-face interviews	Respondents reported being given little or no advice after surgery. Some had severe difficulties readjusting their eating and bowel habits. Patients described needs for realistic and non-contradictory information about diet, as they reported receiving contradictory and even inappropriate advice to eat "a high fibre diet". There is confusion on what constitutes an appropriate diet post-surgery to manage bowel function and no one had such knowledge.	Content of dietary information
Samuelsson	Face-to-face interviews	Older patients expressed concerns related to diet and nutrition during recovery and follow up. Most of them perceived nutritional support during recovery from surgery as inadequate to match their individual requirements. They also reported not being given guidance on how to manage side effects. On follow up, a lot of participants experienced difficulty regaining weight after surgery but very few received dietetic support. Older people ask for individually tailored information throughout the entire process (diagnosis to follow up).	Content of dietary information Sustaining dietary change
Beaver	Questionnaire	Most (59%) respondents stated they received all information they needed about diet in relation to their disease and 56% were satisfied. Those who didn't receive information expressed a need of getting advice on the role of diet and how diet could help from now on.	Content of dietary information
Cha	Questionnaire	43% of the participants reported that they had received dietary information after surgery. 50% of participants suggested that they would like to have had more information provided to them.	Content of dietary information
Nikoletti	Questionnaire	53% of respondents expressed a need to receive dietary information to manage bowel function and this was rated as important. Most participants who did receive advice perceived it as inadequate. Respondents expressed a need for information on what foods to eat when they dine out to avoid bowel problems (28%).	Content of dietary information
Perl	Questionnaire	As part of an overall needs assessment, 70% respondents expressed a need for nutritional counselling after diagnosis and it was highlighted significantly more by women rather than men.	Content of dietary information
Pullar	Questionnaire	33% of respondents received advice on dietary change. Most of them felt they had not received enough information in relation to their condition. Half of the respondents received advice in relation to survivorship (reducing red/processed meat and increasing fruit and vegetables) and half in relation to their treatment (formation of a stoma, future weight gain and managing low appetite). No participant classified as obese reported any discussions around diet and nutrition. They would be interested in getting more information and would more likely consider changing habits, particularly people with a higher Body Mass Index.	Content of dietary information

Study first author	Tool used	Description of provision (or lack of) of information and identification of needs	Themes
Hoedjes	Questionnaire and focus groups	17% reported the need for dietary support, which was significantly higher in participants classified as overweight or obese. Focus groups highlighted that individuals with treatment-related complaints expressed a need for advice for appropriate nutrition to reduce side effects, such as lack of strength and energy, stoma-related problems and bowel changes. Some participants needed information and individually-tailored advice on lifestyle-related issues, such as appropriate nutrition and use of dietary supplements, in order to make an informed, autonomous decision on adapting their lifestyle or not. Some wanted feedback on their lifestyle and how healthy or unhealthy it is and what areas may need improvement. A gastrointestinal oncology nurse, an oncology dietitian and a stoma nurse specialist were regarded the most appropriate providers for dietary advice and support.	Content of dietary information Sustaining dietary change
Avery	Face-to-face & telephone interviews and a focus group	Irrespective of whether they made changes, most men expressed confusion and dissatisfaction with available dietary information and/or its contradictory nature. Some men described unreliable information as a barrier to making dietary changes. Men said they would welcome scientific and evidence-based dietary advice from authoritative sources (primary care physician, consultant or nurse) but information needs varied according to treatment success and disease status.	Content of dietary information Views on the role of diet in survivorship
Er	Face-to-face interviews	Participants reported mistrust of dietary messages from media, because they were conflicting. They preferred receiving information from HPs who they regarded as experts and a trusted source of health information and that had a positive influence on their health behaviour. Some of men were sceptical about the role of diet in cancer progression, especially if treatment was effective.	Content of dietary information Views on the role of diet in survivorship
Kassianos	Telephone interview	Participants had high expectations but felt health professionals' did not have sufficient knowledge on diet and nutrition support for future health. They felt that lack of/conflicting information could lead them to get wrong messages and inappropriate action. Credible, evidence-based information was considered important for the management of their condition and for reducing the risk of recurrence. Some participants expressed uncertainty about the nature of the relationship between dietary change and recurrence. The health professionals' advice was an important trigger for dietary change and health action.	Content of dietary information Sustaining dietary change Views on the role of diet in survivorship
Lee P	Focus groups and one interview	Patients wanted information on diet and supplements tailored to their disease, in order to prevent recurrence and improve overall health. The advice they got about healthy eating was perceived as generic and therefore not helpful to prevent recurrence.	Content of dietary information
Sutton	Face-to-face and telephone interviews	Men (who did not participate in a Lifestyle coaching program) did not recall any discussions about diet with health professionals. They would have valued an assessment of their diet or evidence-based advice that could be beneficial long term. Few patients believed that dietary changes would not be necessary successful removal of the prostate. A trusted healthcare professional, regardless of the role, was viewed as a credible source of information. Some men were given leaflets which were hard to read.	Content of dietary information Sustaining dietary change Views on the role of diet in survivorship

Study first author	Tool used	Description of provision (or lack of) of information and identification of needs	Themes
Demark-Wahnefried	Questionnaire	Few respondents reported discussions with HPs regarding increasing F&V or reducing fat. 48% of respondents were very or extremely interested for diet-related programs, particularly the younger ones.	Content of dietary information
Des Bordes	Questionnaire and interviews	Patients expressed a need for information on nutrition, particularly nutritional supplements, to maintain or improve bone health. Most of them didn't know the negative effects of salt and alcohol on bone health while few prostate cancer survivors knew the optimal calcium requirement in diet.	Content of dietary information
Hardcastle	Face-to-face interviews	Most participants do not recall receiving lifestyle advice, including dietary information. Oncologists are viewed as an authoritative and trustworthy source of information and they would feel obliged to follow their advice on healthy eating and weight loss. Apart from advice, regular monitoring was expressed as a need, because it motivates patients to stick to a healthier diet and a lower weight.	Content of dietary information Sustaining dietary change
Koutoukidis	Telephone interviews and focus groups	None of the participants received any lifestyle advice from a health professional post-treatment. Those who underwent radiotherapy received dietary advice for bowel symptom management during treatment, but there was no follow up. Participants prompted discussions with health professionals but received unsatisfactory advice. Health professionals were unaware of support groups or just advised to eat healthy. Participants searched for information on their own e.g. online, but it was difficult to find reliable information. They would welcome tailored advice regarding recovery, symptom management and healthy lifestyle overall.	Content of dietary information Sustaining dietary change Views on the role of diet in survivorship
Clark	Questionnaire	52% reported weight loss counselling from a primary care physician and 35% from a gynae-oncologist. 47% reported dietary advice from a primary care physician and 25% from a gynae-oncologist. Receipt of weight loss counselling was significantly associated with attempting weight loss. Provider counselling and encouragement can help overcome motivation barriers.	Content of dietary information
Fitch	Questionnaire	Several respondents reported changes in diet (eating healthy foods and taking supplements, especially vitamins C & E). 79% of women rated diet and nutrition as important discussions in the survivorship phase. However, not all were satisfied with the information they received.	Content of dietary information
Fitch	Questionnaire	66% of women rated diet and nutrition as important discussions in the survivorship phase. However, not all were satisfied with the information they received.	Content of dietary information
Lee	Questionnaire	Most respondents demanded nutritional care and education in a variety of topics; mainly foods to avoid, appropriate nutrition to prevent recurrence, information on how to improve nutritional status, healthy recipes, and nutritional guidance for the patient's family.	Content of dietary information

Study first author	Tool used	Description of provision (or lack of) of information and identification of needs	Themes
Tseng	Questionnaire	50% of respondents reported weight management or lifestyle counselling, primarily from a gynaecologic oncologist or a primary cancer provider. Providers discussed the need for weight loss but did not make specific recommendations regarding how to achieve this. However, most found the counselling motivating to make a change. Of those who did not receive counselling, most believe would have been motivated to set goals and make positive lifestyle changes. Several of them expressed a desire to discuss weight and lifestyle during most clinic visits. Oncologists and nutritionists were the most preferable sources of information.	Content of dietary information Sustaining dietary change
Zaleta	Questionnaire	Most women have attempted weight loss thought diet restriction but only few under guidance and even fewer routinely. Although most agree that oncologists should discuss weight loss with the patients, only very few reported this sort of counselling, in contrast with counselling for smoking cessation. Most respondents believe that weight management counselling would prompt them to attempt weight loss. The oncologist was viewed the most reliable source for information.	Content of dietary information Sustaining dietary change
Jang	Survey and face-to-face interviews	As part of the information needs assessment, 27% of participants requested information/education on diet in relation to metabolic syndrome and 14% information on weight management (survey data). Requests on dietary information were also expressed in interviews. Participants consider diet management as an important self-management tool for controlling metabolic syndrome.	Content of dietary information

2.5. Discussion

This review collected evidence on information and support needs in relation to diet and nutrition after a pelvic cancer diagnosis. To our knowledge, this is the first systematic review to focus on survivors' support needs in diet and nutrition after a cancer diagnosis. Provision of information and support in relation to diet and nutrition will help survivors lead a healthier lifestyle and improve quality of life.

Results showed that provision of information and support in relation to diet and nutrition was not routinely provided to survivors of a pelvic cancer. In most qualitative studies, most survivors reported a lack of information and support from their healthcare team and for those who did receive this, it frequently did not meet their individual needs. Survivors wanted information related to future wellbeing, management of gastrointestinal side effects and weight changes. The content of the requested information was different across cancer diagnoses, with advice in relation to the management of bowel symptoms being sought mostly from colorectal cancer patients and advice regarding weight management and future wellbeing from gynaecological and prostate cancer patients.

Survivors sought evidence-based information that would prompt them to change their current dietary behaviours and improve their quality of life. Some expressed concerns about the lack of comprehensive research in this area and therefore a lack of consistent evidence about the role of diet or weight loss in outcomes following a cancer diagnosis. This lack of evidence may, in part, account for the reported lack of information provision or provision of generic advice about a healthy diet. Coa et al. (2015) noted that healthcare providers also hold varied beliefs about lifestyle changes in the survivorship phase because of the lack of evidence base and therefore are hesitant in engaging in conversations about diet. Irrespective of their beliefs, health professionals are perceived by survivors as the most suitable sources to provide dietary support. In some of the included studies there was patient dissatisfaction with health professional's knowledge or attitude towards diet and nutrition, indicating that health professionals may not be adequately trained on nutritional care of cancer patients (Dempsey et al., 2011, Koutoukidis et al., 2018). To date, dietary recommendations for cancer survivors that have been developed by the WCRF/AICR (2018) and the European Society for Parenteral and Enteral Nutrition (ESPEN) (Arends et al., 2017a) are based on limited evidence. Also, to date, no recommendations tailored to a specific cancer diagnosis have been published. Lack of strong evidence further contributes to the differing views about the role of diet in the survivorship phase for patients and the “trial and error” approach sometimes recommended by health professionals or used by patients independently.

Another important finding in this review was the perception from survivors that they should have their dietary behaviour and weight monitored on a regular basis in order to sustain dietary changes. A recent systematic review and meta-analysis showed that supervision and social support improved adherence to a weight loss program in overweight and obese populations (Lemstra et al., 2016). A qualitative study in breast cancer survivors who followed a 12-month weight loss program showed that regular monitoring by dietitians was viewed as a facilitator for sustaining healthy behaviours (Terranova et al., 2017). This is an important point for future interventions evaluating nutritional education and weight loss in pelvic cancer survivors. It should, however, be noted that regular monitoring may have feasibility and cost implications which need to be taken into consideration.

There was a considerable difference in the amount and type of information extracted from the qualitative and quantitative studies included in this review. Qualitative studies examined issues and concerns around diet and nutrition in more depth and contributed more information to this narrative synthesis compared to quantitative studies. Therefore, it is possible that qualitative design features, such as sampling procedures (purposive sampling) and researcher bias in data collection and interpretation may have influenced the findings. Also, some studies focussed exclusively on diet and nutrition issues whereas some assessed follow-up care needs in general. Consequently, available data extracted from follow-up care studies was limited and, in some quantitative studies, in a form of statement about receipt of dietary information (Beaver et al., 2011, Demark-Wahnefried et al., 2000, Nikoletti et al., 2008), importance of receiving dietary information (Fitch et al., 2000, Fitch et al., 2001, Nikoletti et al., 2008) or need for receiving more dietary information in relation to cancer (Cha et al., 2012, Perl et al., 2016, Jang et al., 2018). Although limited, the data could clearly be extracted and therefore the studies were eligible for inclusion in this review. Due to the large heterogeneity of the studies, it was decided that a narrative synthesis was the best approach of presenting the results in this review.

It was not possible to extract any information from the included studies about dietary support needs for patients currently undergoing treatment. Studies in breast cancer survivors have shown that information needs may vary according to the survivorship stage. A study by Halbach et al. (2016) showed that breast cancer respondents were more interested in information about nutrition shortly after surgery compared to 40 weeks later. Overall, health promotion needs were increased during or shortly after treatment and decreased over time (Halbach et al., 2016). Another study showed that cancer patients are more active in seeking information in the pre-treatment period compared with the post-treatment period (Eheman et al., 2009).

2.5.1. Strengths and limitations

This review has a number of strengths and limitations. A comprehensive systematic search of the literature was conducted according to the PRISMA guidelines. Searching was performed across six big databases, eligibility criteria were applied and the quality of all included studies was assessed. Any unclear abstracts were included for full-text review. Findings were synthesised using thematic analysis, which is an effective way of combining results from quantitative and qualitative studies (Lucas et al., 2007). Synthesis of findings was conducted in an unbiased manner, although it is acknowledged that thematic analysis may induce personal/researcher bias. The researcher's background (degrees in nutrition and dietetics) could be a potential bias in the analysis and interpretation of the data. Reviewing themes with one of the Director of Studies (Prof Eila Watson) who does not have a background in nutrition and has extensive knowledge in qualitative analysis has contributed to reduce potential researcher bias.

It should be acknolwedged that this review included cancer diagnoses that share common characteristics (e.g. obesity rates, pelvic radiotherapy) but can also vary considerably in other outcomes, as described in Chapter 1 (1.8). All three themes in the Results section describe in detail the differing needs per cancer diagnosis, where applicable. Findings are also limited by the scientific quality of the papers. Quality appraisal showed that cross-sectional studies presented high selection and non-response bias. Similarly, most qualitative studies failed to provide adequate evidence of credibility and dependabilty. Therefore, it may be difficult to generalise the results to all pelvic cancer survivors. Furthermore, in most quantitative studies, the measurement tools were developed by the authors and no information on validity and reliability of these tools is reported. Also, there was no attempt to contact any authors for clarification on study findings. The search was not exhaustive, as it was limited in large databases and grey literature was not explored. The search was also limited to English language publications only due to lack of translation options; however, initial screening did not reveal any non-English publications.

2.6. Conclusion

This review has highlighted the need for provision of information and support in diet and nutrition after a pelvic cancer diagnosis. Survivors sought evidence-based, clear information on how to improve their future wellbeing and manage physical symptoms deriving from their diagnosis and treatment. However, there were several issues regarding the methodological quality of the included studies. Future studies that combine collection of quantitative and qualitative data could provide in-depth insights on patient support and information needs and reduce the impact of methodological limitations.

Future interventions and future clinical practice should take into account patients’ needs for quality evidence and tailored advice with the aim of sustaining healthy behaviours and overcoming disease problems in the long term. Stronger evidence from prospective studies on the role of diet in outcomes related to cancer survivorship is also needed, in order to support the quality of information provided to pelvic cancer populations.

Chapter 3. Methodology and Methods

3.1. Summary

A concurrent, mixed-methods design was chosen to address the research aim and objectives of this PhD. People who have been diagnosed with cancer and either currently being treated with curative pelvic radiotherapy (on-treatment group) or having completed curative pelvic radiotherapy treatment 6-24 months before (post-treatment group) were invited to fill in a paper-based survey. The survey included questions about current dietary habits and changes since diagnosis; perceptions of the role of diet in managing cancer treatment and for future health, experiences of nutritional support and interest in receiving more information about diet in the future. Recruitment of participants was in collaboration with the Radiotherapy Department, Cancer and Haematology Centre, Oxford University Hospitals (OUH) NHS Foundation Trust.

A sub-sample of the participants who completed the questionnaire was invited to telephone interviews to explore in more depth patient experiences in diet and nutrition after diagnosis. The subsample was selected using maximal variation sampling. Telephone interviews were audio recorded and transcribed verbatim. Interviews took place until “data saturation” was achieved. Thematic analysis using the Framework approach was conducted to identify important themes.

3.2. Methodology

3.2.1. Choosing a mixed-methods design

Mixed methods research combines quantitative and qualitative research within a single study with a view to providing more robust answers to the research questions than each method alone would provide (Bryman, 2012). Quantitative and qualitative research methods each have their own strengths and weaknesses and combining them allows the researcher to offset their weaknesses and draw on the strengths of both. The strengths of quantitative research include accurate measurement of a specific construct and the ability to conduct comparisons, strength of association between variables and test hypotheses. Qualitative research, on the other hand, provides a "whole person" naturalistic approach by evaluating human experiences (views, beliefs and emotions) in a way that no quantitative tool can assess (Castro et al., 2010). In other words, the quantitative arm of a mixed-methods approach investigates *"what the behaviour is"*, whereas the qualitative arm explores *"why people behave the way they do"*.

It is well established in the literature that quantitative and qualitative research are underpinned by distinct philosophical assumptions, which are taken into consideration when deciding data collection methods to answer research questions. These assumptions relate to ontology (i.e. what is there to know?), epistemology (how knowledge can be generated?) and methodology (how should research proceed?) (Bryman, 2012).

Ontology refers to a person's understanding of the world as an entity. Quantitative research usually assumes that social phenomena are stable and cannot be influenced (objectivism). On the contrary, qualitative research assumes that social phenomena are produced through social interaction and they constantly change (constructionism) (Bryman, 2012).

Epistemology refers to the way knowledge can be produced. Positivism is an epistemological position related to objectivity and is a main characteristic of quantitative research. On the other hand, qualitative researchers tend to embrace subjectivity, to accept the role of researcher in data interpretation and to reflect upon it (the term interpretivism is used) (Bryman, 2012).

Quantitative research tends to embrace deductive theory; a hypothesis is developed to examine the research question. Data will either confirm or reject the proposed hypothesis and conclusions are undeniable if data are derived by objective methods. Qualitative research usually works in a different way; collection of data will result in the development of theory (inductive approach) (Bryman, 2012).

Despite the clear differences in ontological and epistemological positions underpinning each research design, Bryman (2012) argues the connections are not settled. Instead, the positions should be regarded as “tendencies and not definite connections”. For example, while hypotheses are frequently developed prior to undertaking a study in quantitative research, this assumption better reflects experimental studies. Survey-based studies are often more exploratory and offer opportunities for the generation of theories and concepts. Also, even if there is clear distinction between the collection of numbers (data) in quantitative research and words (data) in qualitative research, qualitative researchers sometimes quantify a limited amount of their data. It has also been suggested that thematic analysis, which is one of the most common methods for analysis of qualitative data, could sometimes be operated by the frequency of occurrence of certain words or phrases, implying some level of quantification.

Bryman (2012) suggests that research methods are more autonomous in relation to epistemological commitments than is often appreciated. The “technical version” is a position among researcher in which philosophical assumptions between quantitative and qualitative research are recognised but they are not viewed as fixed. Instead, greater value is given to the strengths of data collection and analysis tools from the two methods, as one method can be used in the service of the other.

Considering the aim and objectives of this PhD, it was felt that a mixed methods design was the most suitable, with both methods addressing each research objective to varying degrees, and with the interviews adding depth to the information gathered from the survey and covering any gaps.

Bryman (2012) conducted a content analysis of articles based on mixed-methods research and identified sixteen possible rationales for combining quantitative and quantitative research, some of which apply to this mixed-methods study:

1. Offset: research methods associated with both quantitative and qualitative research have their own strengths and weaknesses so that combining them allows the researcher to offset their weaknesses to draw on the strengths of both.
2. Completeness: the researcher brings together a more comprehensive account of the area of enquiry in which they are interested by employing both quantitative and qualitative research methods.
3. Explanation: one method is used to help explain findings generated by the other.
4. Credibility: employing both approaches enhances the integrity of findings.
5. Illustration: qualitative data are used to illustrate quantitative findings.
6. Utility or improving the usefulness of findings: combining quantitative and qualitative approaches will create findings more useful to practitioners and others.
7. Enhancement or building upon quantitative/qualitative findings: making more of either quantitative or qualitative findings by gathering data using a qualitative or quantitative research approach.

There is increased interest in the use of mixed-methods research in health sciences. Over the past few years, researchers have begun to acknowledge the complexity of health-related research and employ a combination of methods to answer research questions. Moreover, the challenges of conducting patient-centred research in the real world can sometimes be best understood through multiple forms of measurement (Currie and Nunez-Smith, 2017).

3.2.2. Concurrent mixed methods design

According to Bryman (2012), it is important to define the role of the quantitative and the qualitative component in a mixed-methods study according to priority and sequence. In terms of priority, mixed methods studies can have either the quantitative or the qualitative component as the main data collection component or have equal weight components in the data collection process. In terms of sequence, collection and analysis of quantitative data can precede the collection and analysis of qualitative data collection or vice versa (sequential mixed methods design) or data collection can occur more or less concurrently in the quantitative and the qualitative component (concurrent mixed methods design).

Phase two of the PhD consisted of two parts. Part I was a quantitative, cross-sectional survey which was the primary data collection component supplemented with qualitative interviews (Part II) with a sub-sample of the participants from Part I to explore the topics of interest in more depth. The study is considered to have a concurrent mixed-methods design, as quantitative and qualitative data for the whole sample were collected during the same period (November 2017 – February 2019) and analysed after the end of collection. Only on an individual basis quantitative data collection (completion of survey) preceded qualitative data collection (telephone interview). Participants' survey responses were checked prior to an interview to ensure variation in the sampling of the qualitative arm of the study.

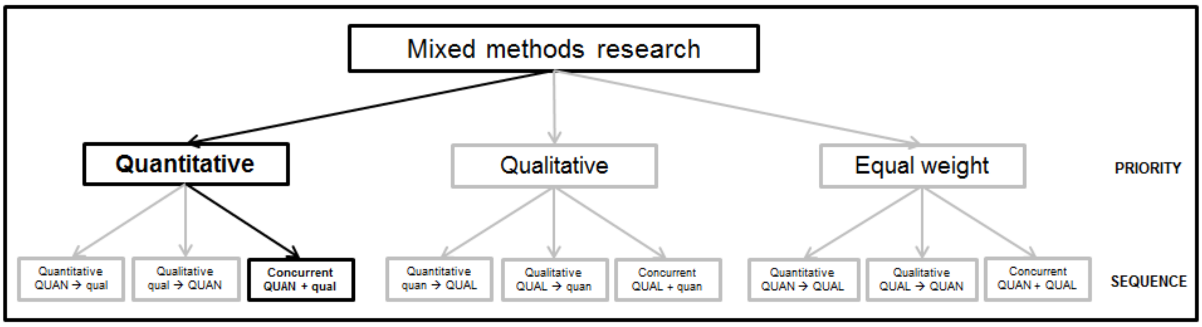


Figure 3.1: Classification of mixed methods research in terms of priority and sequence. Figure adapted from Bryman (2012). Note: Capitals and lower case indicate priority; arrows indicate sequence; + indicates concurrent. Priority and sequence options for this project are highlighted.

3.2.3. Rationale for selection of participants

Different needs in relation to diet and nutrition at different stages after the cancer diagnosis may arise. This was the reason why survivors were recruited at two different stages of the cancer trajectory (on-treatment group and post-treatment group). Whilst the ideal would have been for a prospective, longitudinal study to explore patient experiences over time, this was not feasible within the timeframe of the PhD studies.

It was decided that the post-treatment group would include survivors of a pelvic cancer 6-24 months after the end of curative radiotherapy treatment. Six months was considered a sufficient period in which survivors would have begun to return to their normal lifestyle after treatment and was decided after consultation with the clinical collaborators at Oxford University Hospitals (OUH).

3.2.4. The use of a paper-based survey

For the quantitative arm of the mixed-methods study, a self-report paper-based survey was developed. With the increased use of the internet, there have been suggestions to use web-based surveys instead of paper-based ones as they significantly reduce costs and data collection is easier (Ebert et al., 2018); however, it is not clear if web surveys affect response rates compared to paper surveys (Hohwü et al., 2013, Horevoorts et al., 2015, Ebert et al., 2018). After consultation with the clinical collaborators at OUH NHS Foundation Trust, a paper-based survey was considered the best option, given that the population of interest (survivors of a pelvic cancer diagnosis) are generally older and may be more reluctant in using the internet to complete a survey.

3.2.5. The use of telephone interviews

In this study, telephone interviews were preferred to face-to-face interviews for practical reasons, such as geographically dispersed interviewees around Oxfordshire and other counties, costs and flexibility in scheduling. Telephone interviews are considered a valuable method of interviewing and findings are comparable to those of face-to-face interviews (Drabble et al., 2016, Sturges and Hanrahan, 2004). Although there is no direct contact between the interviewer and the interviewee, telephone interviews have the advantage of providing anonymity and privacy and reducing distraction (Drabble et al., 2016). Telephone interviews have successfully been conducted in previous research projects at the Supportive Cancer Care Research group at Oxford Brookes University (OBU) (Collaco et al., 2019, Wagland et al., 2019).

3.2.6. Sample size estimation

3.2.6.1. Survey

In order to estimate sample size for the survey, the equation as described by Scheaffer (2012) was used. The equation was:

$$n = \frac{Npq}{(N-1)D + pq}$$

and $q = 1 - p$ and $D = \frac{B^2}{4}$

where n=survey sample size, N=population of interest, p=variance of heterogeneity, B=margin of error.

According to the National Cancer Registration and Analysis Service (NCRAS), around 42,000 people were treated with pelvic radiotherapy between 2013 and 2014 in England (bladder cancer n=3,718; cervical cancer n=2,126; prostate cancer n=24,691; rectal cancer n=7,629; endometrial cancer n=3,189). Due to lack of resources with more recent information, the population of interest was estimated at N=42,000 (National Cancer Registration and Analysis Service, 2017).

Assuming a 50% estimated variance of heterogeneity of population (which produces the maximum sample size; p) and a 5% magnitude of error (B=0.05), the estimated survey sample size was:

$$D = \frac{0.05^2}{4} = 0.000625$$

$$n = \frac{42{,}000 \ x \ 0.5 \ x \ 0.5}{(42{,}000 - 1) \ x \ 0.000625 + 0.5 \ x \ 0.5} = 396$$

The clinical team at OUH advised on the number of patients treated with radiotherapy each year. Based on their feedback, the timeframe of the PhD studies and a minimum response rate of 30-40%, it was decided it would be feasible to recruit a sample of 100-150 participants on treatment within 12-18 months. The estimated response rate was based on the results from the 2010 English Cancer Patient Experience Survey, in which response rate varied across NHS organisations and was as low as 39% (Saunders et al., 2016). The recruitment period was also determined by the time constraints of the PhD. As the incidence of prostate cancer is higher than other pelvic cancer types and in order to avoid surveys being completed predominantly by prostate cancer survivors, it was decided that recruitment of prostate cancer patients would stop when 50 completed questionnaires were received.

The sample size for the post-treatment group was determined based on the number of patients that were treated with curative radiotherapy 6-24 months before the administration of the survey and an expected minimum response rate of 30-40%. To avoid saturation of the sample with prostate cancer patients, a randomly selected subsample of prostate cancer survivors was invited to take part. A sample size of 120-160 participants was expected for the post-treatment group.

The sample size of n=396, as estimated by the equation, could not be achieved for pragmatic reasons. Instead, a sample size between 200 and 300 was expected and the two groups (on treatment and post-treatment) would have a comparable sample size. In order to identify the potential impact of a smaller sample size on the results, the maximum margin of error (the value B in the equation) was calculated again assuming survey sample n=200 and n=300. The margin of error was B=0.070 (or 7%) for n=200 and B=0.057 (or 5.7%) for n=300.

3.2.6.2. Interviews

Onwuegbuzie and Collins (2007) noted that sample size in qualitative research can be estimated based on the research design (e.g. case study, ethnography, phenomenology or grounded theory), sampling design (subgroup sampling or nested sampling design) or data collection procedure (interview or focus group). Adequate sample size was determined in this study by achieving “data saturation”. Data saturation is a term deriving from grounded theory but is commonly used in other qualitative research designs, and refers to the number of interviews needed to “get a reliable sense of thematic exhaustion and variability within [their] data set” (Bryman, 2012). Charmaz (2014) suggested that 25 interviews may be adequate to reach theoretical saturation in small projects, although more may be needed when information is contradictory to established research. The systematic review (Chapter 2) included qualitative studies with a sample size between 8 and 58 participants but most of them were conducted with participants of a particular cancer diagnosis.

3.2.7. Integration of quantitative and qualitative data

The integration of the quantitative and qualitative findings is an essential aspect of a mixed-methods study, as it increases the amount of knowledge deriving from the two components of the study. Effective data integration can produce a more robust set of insights. Without integration, it is perceived that findings come from two studies undertaken independently (Barbour, 1999).

A data analysis plan was developed a priori for each component of the study. Curry and Nunez-Smith (2015) highlighted three key considerations regarding the data analysis plan in mixed-methods studies; aim/objectives, research design and analysis need to be aligned; priority of components needs to be determined; and the point of integration has to be defined. As described in Section 3.2.2, quantitative and qualitative data were collected concurrently. Also, the quantitative arm was the primary data collection component, supplemented by the collection of qualitative data. Analysis of the quantitative and the qualitative component was performed independently (Fig. 3.2). Regarding integration, the interpretation stage is considered the most common point of integration in mixed-methods studies and determines the conclusions that result from analysing findings across components (Curry and Nunez-Smith, 2015). In this mixed-methods study, integration took place in the interpretation stage (after presentation of results in Chapters 4 and 5; before discussion in Chapter 7.

Integration followed the triangulation protocol, as described by O'Cathain et al. (2010). The process of triangulation usually takes place at the interpretation stage of a study when quantitative and qualitative data have been analysed separately (O'Cathain et al., 2010). Therefore, it was considered the most appropriate method of integrating the findings in this project. As O'Cathain et al. (2010) suggest, findings from each component were listed and the researcher considered where findings from each method agreed (convergence), contradicted each other (divergence) or offered additional information on a topic (complementarity). This method also offered the opportunity to detect whether unique information on a topic emerges from one component, when the other component offered no information at all (silence).

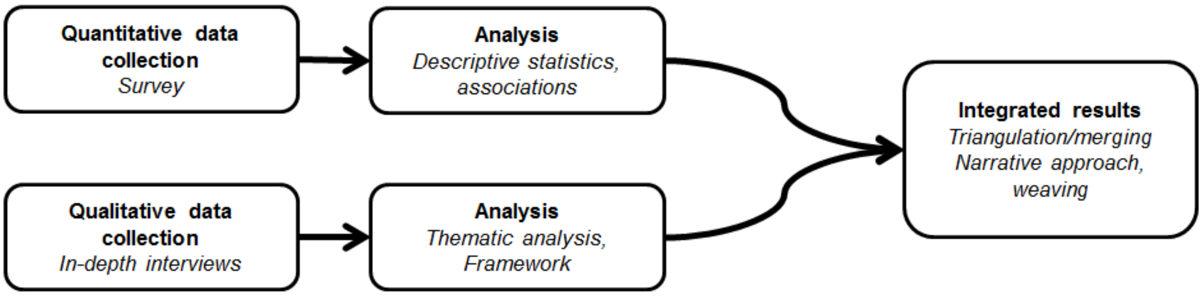


Figure 3.2: Integration in Data analysis through triangulation/merging.

A narrative approach is the most common approach for the interpretation and presentation of findings in health sciences and it was selected for the presentation of the integrated findings in this study (Currie and Nunez-Smith, 2015). Weaving is a narrative approach technique in which quantitative and qualitative data are presented within specific themes or concepts (Currie and Nunez-Smith, 2015). Chapter 6 provides details of the concepts used for the integration of findings.

3.3. Methods

3.3.1. Part I: The cross-sectional survey

3.3.1.1. Sample

The population of interest was people diagnosed with cancer and who received pelvic radiotherapy as part of the treatment regimen. A cancer diagnosis that is frequently treated with pelvic radiotherapy includes cancer of the lower gastrointestinal tract (rectal and anal cancer), bladder, female reproductive organs (endometrial, cervical, ovarian, vaginal and vulval cancer) and male reproductive organs (prostate and testicular cancer) (West and Davidson, 2009). Recruitment of cancer patients from the Radiotherapy Department, Cancer and Haematology Centre, OUH NHS Foundation Trust, was deemed practical and feasible within the timeframe of the PhD studies. OUH was the Patient Identification Centre for this project.

3.3.1.2. Inclusion/exclusion criteria

Inclusion and exclusion criteria were applied for the eligibility of participants in both groups (on-treatment and post-treatment groups). Inclusion criteria were as follows:

1. Diagnosis with a cancer in the pelvis; anus, bladder, rectum, endometrium/uterus, cervix, ovaries, vulva, vagina, prostate and testes
2. Current receipt of radiotherapy with curative intent (on-treatment group) or having received radiotherapy with curative intent 6-24 months before (post-treatment

group). As indicated by the clinical team, radical radiotherapy involved ionising radiation doses of >20 gray (Gy).

3. Ability to read and write in English

Exclusion criteria were as follows:

1. Diagnosis of cancer in any other part of the body
2. Receipt of palliative radiotherapy treatment or short courses of radiotherapy treatment
3. Patients unable to make informed decisions for themselves
4. Patients less than 6 months or more than 24 months from the end of their treatment (for the administration of survey in post-treatment participants only)
5. Patients unable to read or write.

3.3.1.3. Procedure

3.3.1.3.1. Recruitment of on-treatment survivors

Survivors attending a routine clinical treatment review appointment mid-way during their radiotherapy treatment (week 3) were asked by either their therapeutic radiographer or clinical nurse specialist if they would be interested to hear about a research being conducted by Oxford Brookes University. If the participant agreed to hear more about the study, the member of the clinical team informed them about the study and its main aim and, if still interested, the clinical team gave them a survey pack which contained:

- A Study Invitation Letter (SIL), signed by Dr Amanda Horne, consultant oncologist and clinical collaborator (Appendix 2a)
- A Participant Information Sheet (PIS), which provided details of the project and the involvement of the participant (Appendix 2b)
- A copy of the survey (Appendix 2c)
- A paid and stamped reply envelope (for return of completed questionnaire)

Potential participants were encouraged to fill in the survey within a week of receipt of the pack. It was expected that one week would allow plenty of time to process all information provided and make a decision to take part. Informed consent was implied by completion and return of questionnaires, as was acceptable to the National Research Ethics Service (NRES) at the time of this study. Recruitment took place from November 2017 to February 2019 (16 months).

Health professionals who were responsible for recruitment were provided with training on the study, so that they were aware of the inclusion/exclusion criteria. They were also provided with a predetermined script (Appendix 2d) which included all necessary information they needed to communicate with the patients and invite them to participate. It was made explicit, by the recruiting clinical staff member and in the SIL and PIS, that participation was voluntary.

Between November 2017 to February 2019, a total of 266 patients were considered eligible to participate and therefore invited to take part: 119 with a prostate cancer diagnosis, 70 rectal or anal (lower gastrointestinal cancers), 70 gynaecological, 4 bladder and 3 other pelvic cancer diagnoses. Consent was implied by completion and return of the questionnaire.

3.3.1.3.2. Recruitment of participants post-treatment

People who had completed radical pelvic radiotherapy (ionising radiation of >20 gray) 6-24 months (1st April 2016 – 30th September 2017) before the administration of the survey (April 2018), were identified through the Cancer and Haematology Centre, Radiotherapy Services Team database. An administrative member of the Radiotherapy Department then checked for deaths using the hospital Electronic Patient Records system.

All eligible survivors treated for a rectal, bladder, gynaecological, testicular or other pelvic cancers between April 2016 and September 2017 were sent the survey pack. Participants were posted the same survey pack as the one given to on-treatment participants, with a modified SIL (Appendix 2e). To avoid saturation of the sample with prostate cancer survivors, a randomly selected subsample of prostate cancer survivors was sent a survey pack. Patients who received pelvic radiotherapy for a prostate cancer diagnosis between April 2016 and September 2017 were divided in three groups (completion of treatment between April – September 2016, October 2016 – March 2017, April – September 2017) and the first 50 patients on the list within each group were sent the survey (total of 150). Similarly to the invitation of on-treatment patients to take part, it was made explicit in the SIL and PIS that participation was voluntary.

In total, 405 survivors were sent a survey pack: 151 with a prostate cancer diagnosis, 126 colorectal (120 rectal and 6 colon/bowel), 40 anal, 30 bladder, 26 endometrial, 23 cervical, 4 testicular, 3 vulvar and 2 vaginal. Consent was implied by completion and return of the questionnaire.

3.3.1.4. Survey Development

Initially, a literature search was performed to identify previously validated questionnaires that would address the aim and objectives of this PhD project. In the absence of validated questionnaires for any of the objectives, the survey incorporated modified versions of previously used, non-validated questionnaires (Demark-Wahnefried et al., 2000, Bours et al., 2015, NIHR, 2015) and used information from the WCRF/AICR Second Expert Report (2007). A number of additional questions were developed, with input from the clinical team at OUH.

Most survey questions required binary (Yes/No) or Likert scale responses. Free text boxes were added to give the opportunity to expand and capture the respondents' views on diet and nutrition perceptions, needs and experiences in relation to their cancer diagnosis. In order to ensure acceptability, the survey was initially reviewed by clinical colleagues and twelve members of the NIHR Cancer and Nutrition infrastructure collaboration Public and Patient Involvement (PPI) Group. Feedback was used to optimise both the content and the appearance of the survey. In relation to content, for example, one PPI member suggested adding a question about weight changes, which is common in cancer patients. A few PPI members suggested adding more open-comment boxes in a number of questions, in order to get more detailed information. Also, PPI contributors advised on the acceptable length of the survey, which should take up to a maximum of thirty minutes to complete.

The final version of the questionnaire consisted of five sections and included questions regarding demographic, clinical and health characteristics; dietary habits and changes since diagnosis; awareness of current nutritional recommendations for cancer survivors; perceptions of the role of diet and nutrition after a cancer diagnosis; receipt of advice and support; and interest in receiving further support in this area. A copy of the questionnaire is available in Appendix 2c.

3.3.1.4.1. Collection of demographic, clinical and health information

The following demographic, clinical and health information was sought:

- Date of birth (to determine age), height and weight (to determine Body Mass Index), marital and socioeconomic status and ethnic background (demographic characteristics)
- Tumour site and treatment(s) received (clinical characteristics)
- Smoking habits, presence of comorbidities (heart problems, diabetes, hypertension, asthma, osteoporosis, problems with pancreas, stomach, kidney or liver, Alzheimer's disease, epilepsy or other neurological problems) and weight

changes since diagnosis (weight gain, weight loss, no weight changes; health characteristics).

Questions about diagnosis and treatments were taken from the Phase One survey conducted by the NIHR Nutrition and Cancer Infrastructure Collaboration (Patient Experience Survey) (NIHR, 2015).

3.3.1.4.2. Presence of side effects

Participants were asked to indicate whether they were currently experiencing any of the following side effects: loss of appetite, changes in taste or smell, wind/bloating, nausea/vomiting, diarrhoea, constipation, fatigue/lack of energy, dry mouth, incontinence, mouth sores, difficulty swallowing. These side effects are common in patients undergoing treatment for a pelvic cancer (Macmillan Cancer Support, 2017, Macmillan Cancer Support, 2018a, Macmillan Cancer Support, 2018b, Macmillan Cancer Support, 2018c) and can affect dietary intake, as they affect either the individual's sensory perceptions or the function of the gastrointestinal tract.

3.3.1.4.3. Assessment of dietary habits

Participants were asked if they had changed their diet after their diagnosis (Yes/No). For those who had, they were asked if they had increased, decreased or did not change the consumption of the following food groups: whole grains, refined grains, fruit, vegetables, milk and dairy products, meat and poultry, fish, sugary foods, processed meats and alcohol. An open question provided the participants the opportunity to indicate any other changes. Questions were adapted from Bours et al. (2015). Participants were also asked about supplement use [idea also taken from Bours et al. (2015)] and daily water/fluid intake (suggestion from clinical colleagues). Also, consumption of homemade and ready-to-eat meals and social occasions of eating ("Who do you have meals with?" and "Who prepares your meals?”) was assessed. Questions were adapted from the Flexible Consumer Behaviour Survey (FCBS) module used in the National Health And Nutrition Examination Survey (NHANES) 2007-2008 (Variyam and Lin, 2007).

3.3.1.4.4. Nutritional awareness

These questions were incorporated to assess participants’ familiarity (never heard of it/slightly familiar/mostly familiar/very familiar) with the dietary recommendations guidelines published in 2007 by the World Cancer Research Fund for cancer prevention, which also apply to cancer survivors. The idea was taken from a similar project regarding awareness of dietary and alcohol guidelines in colorectal cancer survivors (Hawkins et al. 2015).

3.3.1.4.5. Perceptions of diet and nutrition

Participants were asked to indicate what they considered the importance of diet and nutrition to be (not important at all/a little important/important/very important) in preventing cancer recurrence; improving overall health; supporting recovery; alleviating treatment related side effects (appetite problems, gastrointestinal problems and fatigue). Questions about perceptions of the role of diet and nutrition in current and future health were taken from a similar survey conducted in colorectal survivors in New Zealand (Pullar et al., 2012) and were formed according to the Food and Agriculture Organisation of the United Nations guidelines for assessing nutrition-related Knowledge-Attitudes-Practices (KAP) (Macias and Glasauer, 2014).

3.3.1.4.6. Diet and nutrition support

Questions in this section assessed any support participants may have received from a health professional or another source (online sources, newspaper/magazine, family, friend or other patient). For those that received support, they were asked the type of information they received (general healthy eating/nutritional management of symptoms/weight management/healthy recipes/survivorship courses/supplements), whether it met their needs and whether they were influenced to change their diet. An open question was available for respondents to indicate dietary support they would like to have received. For those who did not receive support, they were asked what support they would like to have received. Questions were all taken from the survey in the NIHR Phase One study (NIHR, 2015).

3.3.1.4.7. Interest in receiving support/information

Participants were asked to convey their general interest (Likert scale: 1=not at all interested, 2 =a little, 3=somewhat, 4=very, and 5=extremely interested) in receiving information on diet and nutrition in relation to their cancer, as well as preferred modes of information delivery (face to face/brochures/internet/DVD/telephone) and optimal time of delivery (at diagnosis/during treatment/at the end of treatment/on a follow up visit/anytime). Questions were adapted from a previous study on health behaviours and readiness to pursue changes in cancer survivors (Demark-Wahnefried et al., 2000).

3.3.1.4.8. Other information

An open question (“Anything we missed?”) was available at the end of the questionnaire for respondents to add any comments around diet and nutrition or anything in relation to their diagnosis.

3.3.1.5. Analysis

Descriptive statistics were used to summarise the data. Mean and frequency tables were used to describe socio-demographic, cancer-related and health-related characteristics. Results in tables are presented as N (%) with the exception of age, which is presented as median (Interquartile Range) and range. Median (IQR) was chosen as the variable “age” did not follow a normal distribution (Shapiro Wilk test of normality, $P<0.001$; Fig. 3.3 and 3.4). Tables present information for the whole sample and per treatment status (on-treatment, post-treatment).

Chi-squared tests for categorical and nominal data were used to identify differences of socio-demographic, cancer-related and health-related characteristics according to treatment status (on-treatment, post-treatment) and cancer diagnosis [urological (prostate and bladder), lower GI (rectal/anal) and gynaecological (cervical, ovarian, endometrial, vaginal, vulval)]. Reduction of the number of cancer diagnosis groups was necessary, as there were very small numbers for several cancer types. For example, there were only 10 participants who reported an endometrial cancer diagnosis (see 4.2.1).

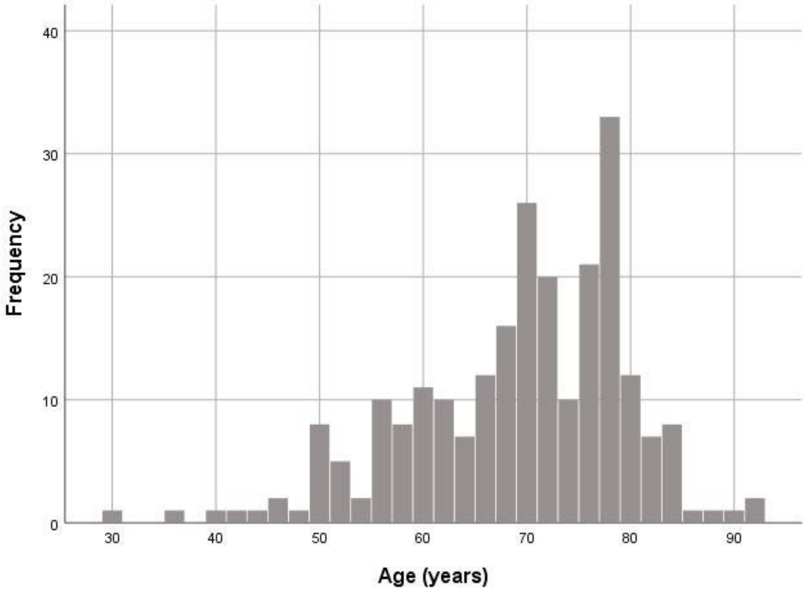


Figure 3.3: Histogram of the variable "age".

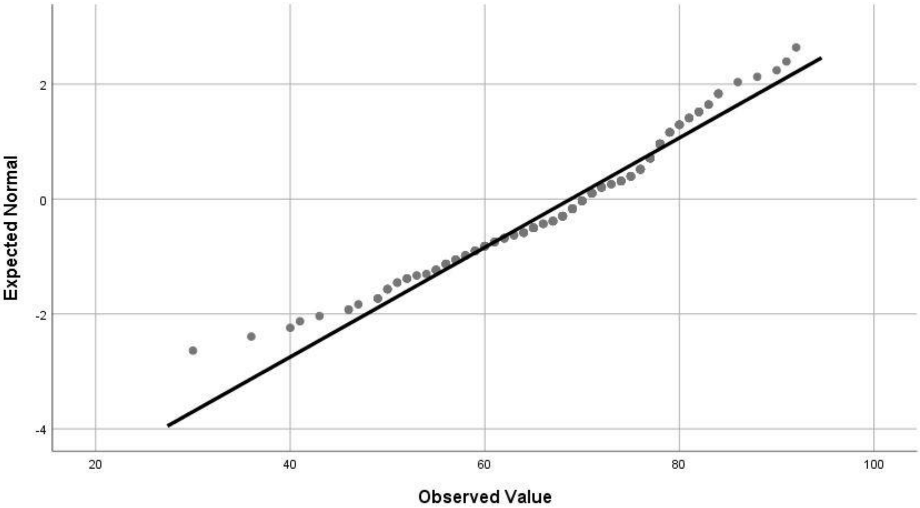


Figure 3.4: Normal Q-Q plot of the variable "age".

It was not possible to carry out analysis for variables that included very small numbers. For example, in the variable “Ethnicity”, the option “White” was chosen by the majority of the sample, therefore all other options had an expected number of <5 and a non-parametric chi-squared test for the variable “Ethnicity” could not be performed. To identify differences between groups with regards to age, the non-parametric Mann-Whitney and Kruskal-Wallis tests were used. As there were multiple comparisons, significance levels were set at 99% for the descriptive analysis (*P*<0.01) (Abdi, 2007).

Binary logistic regression analysis was conducted to identify potential explanatory factors that are associated with the four main outcomes of interest:

- Report of dietary change
- Report of supplement use
- Receipt of dietary support/information from a health professional
- Receipt of dietary support/information from another source

These outcomes of interest are relevant to specific objectives as described in Section 1.10 (Aim and objectives):

- Explore current dietary habits, including dietary changes as a result of diagnosis
- Explore experiences of nutrition support and highlight unmet needs

For the logistic regression analysis, it was necessary to reduce the number of groups for some nominal variables, because one of the response options was selected much more often than others. For example, the variable “marital status” had four options: married or living as married; divorced or separated; widowed; single. The group “married or living as married” was predominantly reported compared to all others (see 4.2.3). Therefore, for the logistic regression analysis, the variable “marital status” was recoded to include two categories: married/other than married. A similar grouping procedure was followed for the variables “cancer diagnosis”, “qualifications”, and “employment”.

Factors that were entered in the model as potential explanatory variables included treatment stage (on-treatment, post-treatment), diagnosis (urological, lower GI, gynaecological), age, Body Mass Index, qualifications (<=high school, > high school), employment (retired/not retired), marital status (married/not married), presence of a comorbidity (yes/no), presence of a side effect (yes/no), report of a dietary change (yes/no; when not a dependent variable/outcome), report of supplement use (yes/no; when not a dependent variable/outcome), support from health professionals (yes/no; when not a dependent variable/outcome). These variables were selected for inclusion in the models based on previous research (Bours et al., 2015, Hoedjes et al., 2017) and expected outcomes, as stated in section 1.10.

First, univariate logistic regression analyses were conducted with each of the outcomes of interest (yes/ no) as dependent variable and one of the above factors as independent variable. Multivariate logistic regression was also conducted using all independent variables in the same model.

In order to determine which multivariate regression analysis method would be used (enter, stepwise forward or stepwise backward), meetings with a statistician (Dr Hoshang Izadi) were conducted. The stepwise backward method (i.e. all variables included in the model and each one is deleted one at a time if they do not contribute to the regression equation) was preferred to the most commonly used “Enter” method (i.e. all variables are “forced” into the model) for two reasons. First, the number of independent variables was considered large, due to the exploratory nature of the study and second, neither the researcher knew, nor the relevant literature supported which independent variables would create the best prediction equation.

The stepwise method has been criticised as an automated procedure that may lead to “overfitting” the model with too many independent variables. For this reason, the analysis in this study was repeated using the “Enter” method and results between the two methods were very similar. Only results from the Stepwise backward method are presented in the Survey Results section (Chapter 4). In the stepwise backward method, a 10% cut-off was used to retain an independent variable in the model (Default in SPSS Software). Multicollinearity of the independent variables was assessed before each logistic regression analysis. There was no multicollinearity between any of the variables (Variance Inflation Factor for all variables lower than 5; Appendices 3a-3d).

Univariate and multivariate logistic regression analyses were conducted for the whole sample, the urological cancer subsample and the lower GI subsample. It was not possible to conduct this analysis for the gynaecological cancer subsample, as it was very small (n=16 for the on-treatment group and n=16 for the post-treatment group). Statistical significance for the logistic regression models was set at $P<0.05$. Results are presented as Odds Ratios (OR) and 95% Confidence Intervals (CI). SPSS (v25.0) was used for the analysis of the survey data.

The survey included a total of five open questions:

1. C4: Is there anything else you changed in your diet since diagnosis?
2. D9: What, if any, additional nutrition support would you like to receive/have received?
3. D8: Did dietary information/advice influence you to change dietary habits (support from health professionals) – please describe how?
4. D18: Did dietary information/advice influence you to change dietary habits (support from other sources) – please describe how?
5. Final question: Anything we missed?

Questions C4, D9, D8 and D18 were very specific to topics of the survey (Section C: Dietary changes; Section D: Support from health professionals or other source) and are, therefore, presented in Chapter 4 (Findings from the survey). Findings from the final, broader question were analysed thematically (see 3.3.2.4) and are presented in Chapter 5 (Findings from the interviews).

3.3.2. Phase II: The interviews

3.3.2.1. Sample

A sub-sample of participants who completed and returned the cross-sectional survey in Part I was invited to participate in Part II. Maximal variation sampling was used to recruit participants for the interviews. Maximal variation sampling is a type of purposeful sampling and is used to identify important characteristics of a phenomenon among cases that vary from each other (Benoot et al., 2016). Maximum variation sampling is commonly used in the qualitative arm of mixed-methods studies (Palinkas et al., 2015). The aim was to recruit survivors with a range in terms of diagnoses (prostate, bladder, gynaecological, rectal, anal cancer), Body Mass Index status (underweight, normal weight, overweight, obese), treatment stage (on- and post-treatment), age (<65 or >65 years of age) and educational status (with or without a University degree). Other particular unique characteristics were also considered when contacting potential interviewees, such as dietary patterns (e.g. being vegetarian), having a stoma after cancer diagnosis and reporting being an ethnicity other than white.

3.3.2.2. Procedure

At the end of the questionnaire, there was a section in which participants filled in their contact details if they wanted to be contacted for a telephone interview. Within 10 days of receipt of the completed questionnaire, participants were contacted and asked whether they would be interested to have a telephone conversation at a time suitable for them. All necessary information for the interview was provided, including the purpose, the content and the expected duration (approx. 30 mins). Telephone interviews were conducted from a private room in Marston Campus, OBU, Oxford UK ensuring that the interview content remained confidential. Verbal consent to each item on the study consent form (Appendix 2f) was sought before the beginning of the interview and a copy of it was provided to participants upon request. Three participants asked for a copy of the consent form, which was sent to them via post.

The first two interviews were used as a pilot to test the content of the questions and the interview format. In the first two interviews, participants were initially invited to provide information about their cancer diagnosis and treatment, but the PI noticed they were hesitant and appeared to be a little uncomfortable. A main adjustment was made to start the conversation by asking participants to give a description of their current dietary habits using the prompt: “Could you give me a description of what you ate yesterday?”. This question was followed by discussion around dietary changes and adjustments as a result of diagnosis. This prompt was found to be a useful introduction to the discussion, as all participants were feeling comfortable answering questions about their current and past diet. Information about treatments and related side effects followed questions about dietary habits. As no other significant changes were made to the topic guide, the first two interviews were included in the analysis. The prompt “Could you please tell me a bit more about that?” was used when the PI wanted the participant to expand on topics related to the research questions or topics dictated by the participants (e.g. comorbidities and diet, weight issues and diet).

At the end of each interview, the PI wrote a summary of the content of the conversation and reflected on issues that may have arisen. Reflexivity is a technique used in qualitative research, in which the researcher addresses how their own positions and attitudes as researchers affect the interpretation of the content of the interviews (Primeau, 2003). Summaries were also useful for comparison and contrast, in order to understand when no new information emerged (data saturation). Interviews were audio-recorded.

3.3.2.3. Topic guide development

A topic guide (Appendix 2g) was developed based on the topics in the survey: dietary changes, beliefs of the role of diet in future health and symptom management and experiences of nutritional support after diagnosis. The topic guide had five sections:

- Introduction: The PI reminded the participant of the scope of the study and obtained verbal consent
- Dietary habits: The PI asked questions about current dietary habits and changes since diagnosis and (where applicable) after the end of treatment. Questions around diet and nutrition included diet quality (macro- and micronutrients), food groups preferences, supplement use and weight changes since diagnosis.

- Attitudes/beliefs about diet in managing side effects and keeping healthy: The initial question was “What does keeping healthy mean to you?”. The interviewer asked questions about the participant’s beliefs on the role of diet and nutrition (diet quality, specific foods or supplements) to alleviate treatment side effects and whether they have done any relevant dietary modifications. Another question was about attitudes towards the role of diet and nutrition in keeping healthy and improving quality of life in the future.
- Experiences of nutritional support: Participants were asked whether they received information and support regarding diet and nutrition from healthcare professionals, online sources, support groups or any other way. They were also asked to describe their experiences and whether there was any other information they wanted.
- Conclusion: The interviewer thanked participants for taking part and also provided information about two online cancer support charities, Macmillan Cancer Support and Cancer Research UK, which have reliable and consistent information on diet and nutrition after a cancer diagnosis.

Although there was a topic guide and questions were formed based on the structure of the cross-sectional survey, the interviews were semi-structured, allowing participants to talk about their experiences in relation to diet and nutrition in as much depth as they desired. Questions were adapted in each interview depending on the participant’s answers. Emphasis was given to participants’ answers that the PI felt was worth exploring in more depth.

3.3.2.4. Analysis

Thematic analysis was used to analyse the data from the telephone interviews. Thematic analysis is a widely-used qualitative method of analysis and includes identifying, analysing and reporting themes deriving from the data (Braun and Clarke, 2006). It is commonly used in qualitative research in nutrition and dietetics and is considered a flexible and practical type of analysis for non-experienced qualitative researchers (Fade and Swift, 2011). Thematic analysis was conducted according to Braun and Clarke (2006) which involves six steps: familiarisation with the data, coding, searching for themes, reviewing the themes, defining and naming the themes and producing the report.

The Framework approach is a method for organising the qualitative data during the process of thematic analysis. The Framework method was originally created by Ritchie and Spencer and applied to policy research; however it has become an increasingly helpful tool for organising data in applied health research (Gale et al., 2013). Framework uses a matrix output in which the data are organised by cases (rows) and codes (columns), providing the researcher an easy way to compare data across cases and within codes. The Framework method is not aligned with a particular epistemological, philosophical, or theoretical approach, making it practical and flexible for non-experienced qualitative researchers (Gale et al., 2013).

Gale et al. (2013) describe the use of the tool in six steps. As expected, the steps are similar to those described by Braun and Clarke (2006), as Framework is a tool for thematic analysis:

1. Transcription: After the end of each interview, the PI wrote a summary of the content of the interview and reflections of the interactions over the phone with the participant. All interviews were transcribed verbatim by the PI and all verbal and some non-verbal (e.g. coughs, pauses, laughs) utterances were transferred in Word documents. Personal data, dates or places mentioned in interviews were not transcribed to preserve anonymity.
2. Familiarisation with the interviews: Transcripts were read repeatedly to obtain a better understanding of the depth and breadth of the content. This was an essential part of the analysis, as it gave the opportunity to create initial ideas of

coding (step 3). Any difficulties in the transcription process were solved after discussion with the supervisory team.

3. Generating initial coding: A list of initial ideas was produced after carefully re-reading five transcripts.
4. Developing a working analytical framework: After coding the first five transcripts, the research team met to discuss and compare codes and agree on a set of codes. An initial working framework with eight themes and 35 sub-themes was created.
5. Applying the analytical framework: The agreed set of codes was applied to all remaining transcripts. New codes deriving from the remaining transcripts were entered to the matrix.
6. Charting data into the framework matrix: The matrix was created on a Microsoft Excel spreadsheet. Each row represented a participant and each column represented a code. Data were summarised by code from each transcript. Where applicable, quote(s) were added under summaries. Care was taken so that data were reduced to a summary while retaining all important information.
7. Interpreting the data: Themes and subthemes were generated from the data set by reviewing the framework matrix and identifying common characteristics among participants and categories. A combination of deductive and inductive analysis was taken; although there was a topic guide informed by topics relevant to the content of the questionnaire (Phase I), analysis also allowed for new topics to emerge.

3.3.2.5. Rigour

Lincoln and Guba use the criteria of credibility, transferability, dependability and confirmability to establish trustworthiness of the qualitative research. The interview topic guide was pilot tested in the first two interviews and any necessary changes were made. There were frequent meetings with the supervisory team to discuss emerging analysis with input from academics with considerable experience conducting thematic analysis using the Framework approach (Dr Jo Brett, Dr Lauren Matheson). Dr Matheson and Dr Brett are not part of the PhD team. There were also frequent debriefings to the supervisory team and any enquiries were resolved. An audit trail of the analysis process was maintained. Finally, reflections on the research process are discussed in Chapter 9.

3.3.3. Ethics & ethical considerations

3.3.3.1. Ethics approvals

Approval for the administration of the survey and conduct of telephone interviews to on-treatment participants was granted by the Faculty Research Ethics Committee (FREC 2016/43) at OBU on 15/06/2017; the East of Scotland Research Ethics Service (REC Reference 17-ES-0112) on 18/08/2017; the Health Research Authority on the 04/09/2017; and OUH Research and Development (Reference PID13101) on 19/09/2017 (Appendix 2h). Approval was also sought from the Late Phase Oncology Trial Steering Committee at OUH NHS Foundation Trust.

A substantial amendment for the administration of the survey and conduct of telephone interviews to include the post-treatment participants was submitted in January 2018. Approval was granted by the Faculty Research Ethics Committee (FREC 2016/43) at Oxford Brookes University on 22/01/2018; the East of Scotland Research Ethics Service (REC Reference 17-ES-0112/AM01) on 14/02/2018; the Health Research Authority on the 03/04/2017; and OUH Research and Development (Reference PID13101 -A001-SI001) on 10/04/2017 (Appendix 2i). All relevant documents, including amendments and updates versions, were organised in a Trial Master File.

3.3.3.2. Ethical considerations

Ethical considerations were around anonymity of participants, confidentiality and data storage. No personal data were recorded regarding the administration of the survey. On receipt of a questionnaire, a unique identification number was provided by the PI. Data were stored in line with the Data Protection Act 1998 and policies of OBU. Information about the use, retention and destruction of data were given to all participants in the Participant Information Sheet. Completed questionnaires were stored in a locked filing cabinet accessible only to the research team in a lockable office at OBU. Data will be stored for a period of 10 years in accordance with the Policy for Academic Integrity.

At the end of the survey, participants who wanted to be interviewed provided their personal data on the last page of the survey, which was subsequently separated from the rest of the survey by the PI immediately after receipt. Personal data were stored in a locked filing cabinet, different to the one where the questionnaires were kept, accessible only to the research team in a lockable office at OBU. Personal data forms were destroyed after dissemination of findings (September 2019). Consent forms for the telephone interviews were stored in another locked filing cabinet. Audio recordings of interviews were stored on a password-protected computer accessible only by the PI. At the point of transcription, all data were de-identified. Data will be stored for a period of 10 years in accordance with the Policy for Academic Integrity.

There were minimal risks to patients participating in this study; however, in case the survey triggered the participant to look for nutrition information in relation to their condition, at the end of the survey there were information details of sources from which they could obtain support. These sources were the Helpline of Macmillan Cancer Support and Cancer Research UK. In case a participant felt distressed during an interview, the interview would be paused and the participant would be offered a break, the opportunity to reschedule or withdraw.

Chapter 4. Survey findings

4.1. Summary

This chapter presents the results of the survey that was administered to people diagnosed with a pelvic cancer. Results are presented for the whole group, as well as according to treatment stage (on-treatment or post-treatment). The chapter is divided in sub-sections: sample characteristics; treatment side effects and weight changes; dietary habits/changes; supplement use; nutritional awareness; perceptions of the role of diet after diagnosis; support by health professionals or other sources; and interest in learning more about diet and nutrition. Analysis was conducted to identify any differences according to treatment stage (on-treatment and post-treatment group) and across diagnoses (urological, lower gastrointestinal (GI) and gynaecological). Qualitative analysis of open comments further enhanced the findings from the survey (see also Chapter 5).

4.2. Sample characteristics

Of the 671 people who were invited to participate, a total of 254 questionnaires were returned (102 from on-treatment and 152 from post-treatment participants). The response rate was 38.3% (102/266) for the on-treatment group and 37.5% (152/405) for the post-treatment group. Three questionnaires from the post-treatment group were excluded because they contained substantial missing demographic and scale data. Therefore, results are presented for a total of 251 participants: 102 on-treatment and 149 post-treatment. The maximum acceptable error for the achieved sample size was B=0.063 (or 6.3%; see section 3.2.6.1).

4.2.1. Cancer diagnosis and treatment

Table 4.1 shows the reported cancer diagnosis of the study participants. Cancer diagnoses were similar between the on-treatment and the post-treatment groups (bladder cancer: $x^2(1)=1.277$, $P=0.258$; cervical cancer: continuity correction test 0.956, $P=0.328$;

endometrial cancer: continuity correction test 0.137, *P*=0.711; prostate cancer: $x^2(1)=1.404$, *P*=0.236; rectal cancer $x^2(1)=0.294$, *P*=0.588), with the exception of anal cancer where there was a significantly higher proportion in the post-treatment than on-treatment group (15% post-treatment Vs 5% on-treatment, $x^2(1)=6.780$, *P*=0.009). In both groups, prostate cancer survivors accounted for almost half the sample. Numbers were smaller for lower GI (rectal and anal) and gynaecological cancer patients. More survivors in the on-treatment group reported a recurrent cancer diagnosis compared to the post-treatment group (23% Vs 7%, $x^2(1)=12.688$, *P*<0.001).

In addition to pelvic radiotherapy treatment, 41% of respondents (n=104) received chemotherapy, 18% (n=44) hormone therapy, while 28% (n=71) also underwent surgery (Appendix 4a).

Table 4.1: Cancer diagnoses of the studied population (n=251).

Characteristics	**All participants n=251**	**On-treatment n=102**	**Post-treatment n=149**
Cancer diagnosis [(1)]	**n (%)**	**n (%)**	**n (%)**
Prostate	124 (49)	55 (54)	69 (46)
Bladder	12 (5)	3 (3)	9 (6)
Rectal	56 (22)	21 (21)	35 (24)
Anal	28 (11)	5 (5)	23 (15)
Endometrial	10 (4)	3 (3)	7 (5)
Cervical	12 (5)	7 (7)	5 (3)
Other gynaecological (ovarian, vulvar, vaginal)	10 (4)	6 (6)	4 (3)
Testicular	1 (<1)	0 (0)	1 (1)
Other [(2)]	10 (4)	8 (8)	2 (1)

(1) A total of 264 tumour sites were reported (thirteen participants reported two tumour sites). The percentage values exceed 100%.

(2) Other pelvic diagnoses include lymph nodes (n=3), “pelvic” (n=2), Extramammary Perianal Paget's Disease (n=1), bowel (n=1), colon (n=1), renal (n=1) and cancer of unknown primary (n=1).

4.2.2. Age and gender

The age of participants ranged between 30 and 92 years. Median (IQR) age for the whole sample was 70 (62-77) years. Median (IQR) age for the on-treatment group was 70 (62-76) years with a range between 43 and 84 years and median (IQR) age for the post-treatment group was 71 (62-77) years with a range between 30 and 92 years. There was no difference in age according to treatment stage (U=6,357.5, *P*=0.294). Urological cancer survivors were significantly older than lower GI cancer survivors (median (IQR) 74 (70-77) years vs 62 (57-73) years; U=2,316.5, *P*<0.001) and gynaecological cancer survivors (median (IQR) 74 (70-77) years vs 59 (50-66) years; U=421, *P*<0.001). Women with a gynaecological cancer diagnosis were younger than people with a lower GI diagnosis but this was not significant (U=698, *P*=0.026). Figure 4.1 shows the age distribution for the whole sample, the on-treatment group and the-post treatment group.

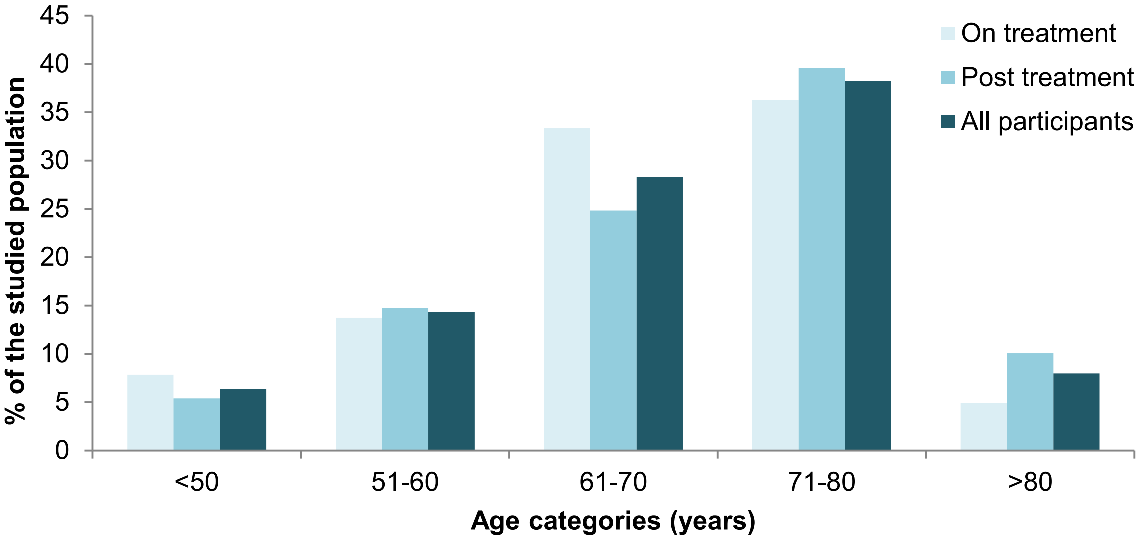


Figure 4.1: Age distribution of the study sample (n=239). Data are missing for 12 participants.

More men than women completed the survey as prostate cancer was the most frequently reported diagnosis. Sixty-one percent (n=153) of the participants were male, 30% (n=76) were female and data on gender was missing for 9% (n=22) of the participants. There was no difference in gender according to treatment stage ($x^2(1)=1.052$, *P*=0.305). Men represented 65% (n=66) of the on-treatment group and 58% (n=87) of the post treatment group, while women represented 27% (n=28) and 32% (n=48) respectively.

4.2.3. Marital, ethnic background, employment and educational status

Most participants were married (74%), retired (66%) and identified themselves as “white” (96%). Participants reported various educational backgrounds, with the “University qualification” reported most often (24%; Appendix 4a). There was no difference in any of the above demographic characteristics according to treatment stage (on treatment vs post-treatment; $P>0.01$ for all comparisons). As a result of older median age, significantly more urological survivors were retired compared to lower GI ($x^2(1)=35.178$, $p<0.001$) and gynaecological ($x^2(1)=21.838$, $p<0.001$) survivors. Marital status, ethnicity and educational status were similar among cancer diagnoses ($P>0.01$ for all comparisons; Appendix 4a).

4.2.4. BMI, smoking and comorbidities

Table 4.2 presents the participants’ BMI status – calculated by the PI from self-reported height and weight – and self-reported comorbidities. Thirty-six percent of the sample (n=90) was classified as overweight (BMI >25 kg/m^2) and 23% (n=57) as obese (BMI >30 kg/m^2). There was no difference in BMI status according to either treatment status (Fisher’s Exact Test=1.356, $P=0.727$) or diagnosis (Fisher’s Exact Test=7.419, $P=0.274$). The most frequently reported comorbidity was high blood pressure (n=84, 33%) followed by arthritis (n=47, 19%) and heart disease (n=38, 15%). Most participants were either ex-smokers (n=132, 53%) or never smoked (n=97, 39%). There was no difference in the report of any comorbidity according to either treatment status or diagnosis, with the exception of heart problems according to diagnosis ($x^2(2)=10.679$, $P=0.005$). More urological cancer survivors reported heart problems compared to gynaecological cancer survivors ($x^2(1)=7.466$, $P=0.006$). Overall, survivors of urological cancer were more likely to report comorbidity than survivors with lower GI ($x^2(1)=11.625$, *P*=0.001) and gynaecological cancers ($x^2(1)=6.821$, *P*=0.009).

Table 4.2: Health characteristics of the studied population (n=251).

Characteristics	All participants n=251	On-treatment n=102	Post-treatment n=149
BMI status (1)	**n (%)**	**n (%)**	**n (%)**
Underweight (BMI <18.5 kg/m^2)	5 (2)	2 (2)	3 (2)
Normal weight (18.5 kg/m^2<BMI<24.9 kg/m^2)	82 (33)	32 (31)	50 (34)
Overweight (25.0 kg/m^2<BMI<29.9 kg/m^2)	90 (36)	35 (34)	55 (37)
Obese (BMI>30 kg/m^2)	57 (23)	27 (26)	30 (20)
Missing	17 (7)	6 (6)	11 (7)
Comorbidities			
Heart disease	38 (15)	17 (17)	21 (14)
Diabetes	24 (10)	11 (11)	13 (9)
High blood pressure	84 (33)	29 (28)	55 (37)
Asthma/chronic lung diseases	24 (10)	10 (10)	14 (9)
Arthritis	47 (19)	15 (15)	32 (21)
Problems with stomach/gallbladder	23 (9)	12 (12)	11 (7)
Osteoporosis	11 (4)	6 (6)	5 (3)
No comorbidity reported	59 (24)	27 (26)	32 (21)
Other (2)	60 (24)	20 (20)	40 (27)
Missing	16 (6)	7 (7)	9 (6)

(1) Body Mass Index (BMI) calculated based on self-reported height and weight. BMI=weight in kg / (height in m)^2.

(2) Other comorbidities include high cholesterol (n=5), kidney disease (n=4), underactive thyroid (n=4), problems with pancreas (n=3), atrial fibrillation (n=3), liver disease (n=2), Alzheimer disease (n=2), epilepsy (n=2), other neurological disease (n=2), Barret's oesophagus (n=2), fibromyalgia (n=2), Crohn's disease (n=2), fitting of a pacemaker (n=2), hiatus hernia (n=2), osteopenia (n=1), acid reflux (n=1), iron deficiency anaemia (n=1), stricture of urethra (n=1), pulmonary embolism (n=1), ulcerative colitis (n=1), depression (n=1), other mental conditions (n=1) , high uric acid (n=1), kyphosis (n=1), ulcerative colitis (n=1), excess fluid retention in bladder (n=1), gout (n=1), polymyalgia rheumatic (n=1), rhinitis (n=1), sarcoidosis (n=1), dropped foot (n=1), knee replacement (n=1), proctitis (n=1), pharyngeal pouch (n=1), peripheral circulation problems (n=1), Bowens disease (n=1), gum problems (n=1).

4.3. Treatment side effects

Overall, on-treatment patients reported more side effects than the post-treatment group. After excluding participants who reported no side effects, on-treatment survivors reported a mean of 3.1 side effects, whereas the post-treatment group a mean of 2.6 side effects. However, statistical significance was shown only for nausea/vomiting ($x^2(1)=8.466$, *P*=0.004) whereas marginal statistical significance was shown for wind/bloating ($x^2(1)=6.369$, *P*=0.012), diarrhoea ($x^2(1)=6.686$, *P*=0.010), taste changes ($x^2(1)=5.993$, *P*=0.014) and appetite loss ($x^2(1)=5.947$, *P*=0.015; Fig. 4.2 and Appendix 4b). For the post-treatment group, there was no difference in the report of side effects and the time since end of radiotherapy treatment (6-12, 13-18 and 19-24 months post-treatment; $x^2(2)=0.132$, *P*=0.936), indicating the persistence of the presence of side effects two years post radiotherapy completion. Age was not associated with presence of side effects (U=3,982.5, *P*=0.444).

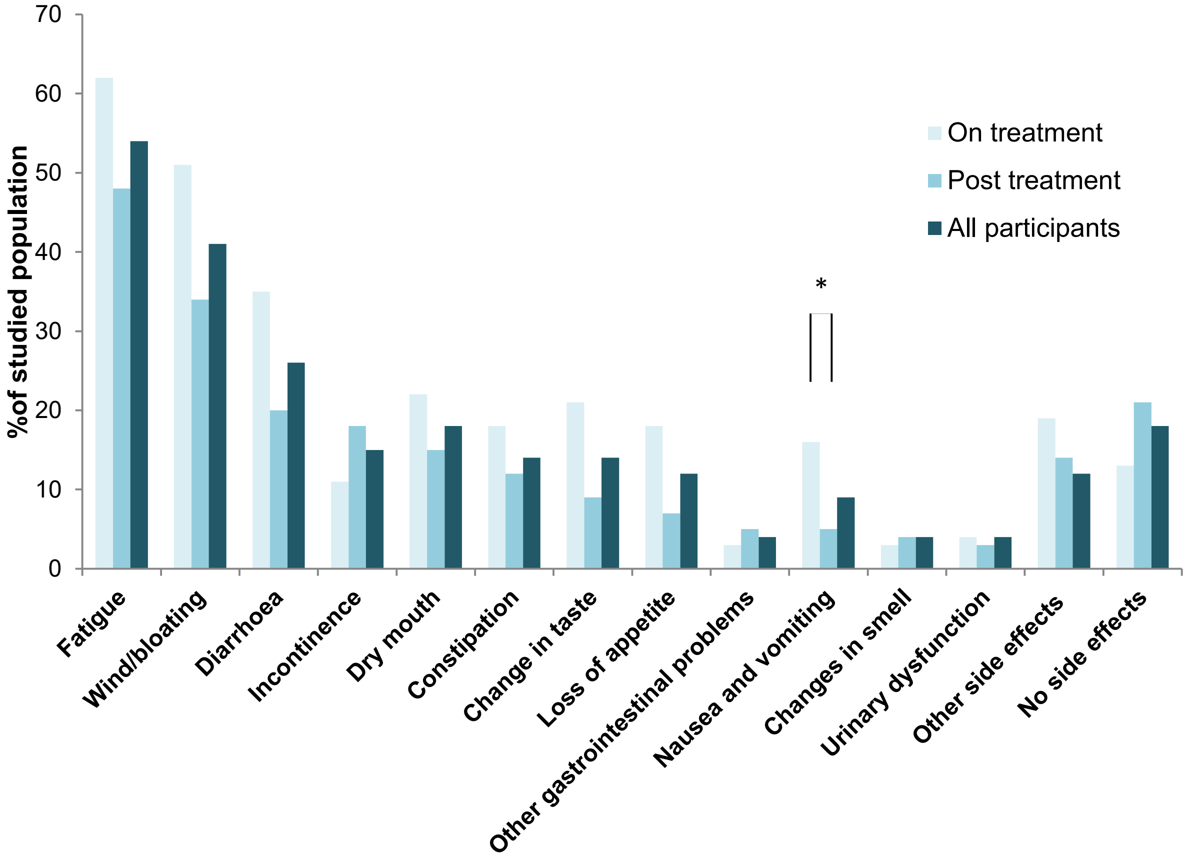


Figure 4.2: Report of treatment side effects (n=251). Other side effects include hot flushes (n=5), mouth sores (n=5), difficulty swallowing (n=5), weight changes (n=3), pain (n=3), itching (n=1), erectile dysfunction (n=1), mucus (n=1), irritable bladder (n=1), radiation induced cystitis (n=1), lymphoedema (n=1), blood in urine (n=1), depression (n=1), lack of concentration (n=1), infection of the buttocks (n=1).
*** denotes significance (P<0.01).**

According to cancer diagnosis, more lower GI survivors reported loss of appetite ($x^2(1)=13.897$, $P<0.001$), taste changes ($x^2(1)=18.325$, $P<0.001$) and nausea ($x^2(1)=9.370$, $P=0.002$) compared to urological cancer survivors. Similarly more gynaecological cancer patients reported loss of appetite ($x^2(1)=20.413$, $P<0.001$), taste changes ($x^2(1)=8.780$, $P=0.003$) and nausea ($x^2(1)=19.172$, $P<0.001$) compared to urological cancer survivors. There were no differences in symptom reporting between lower GI and gynaecological cancer survivors (Appendix 4b).

4.4. Weight changes

Overall, 82 (33%) participants reported weight gain, 65 (26%) weight loss and 98 (39%) did not experience weight change since diagnosis (Fig. 4.3). Weight changes were similar across treatment groups ($P>0.01$ for all comparisons). More women with gynaecological cancers reported weight loss compared to patients with urological cancers ($x^2(1)=8.506$, $P=0.004$). There was no other difference in weight changes among cancer diagnoses ($P>0.01$ for all comparisons; Appendix 4c).

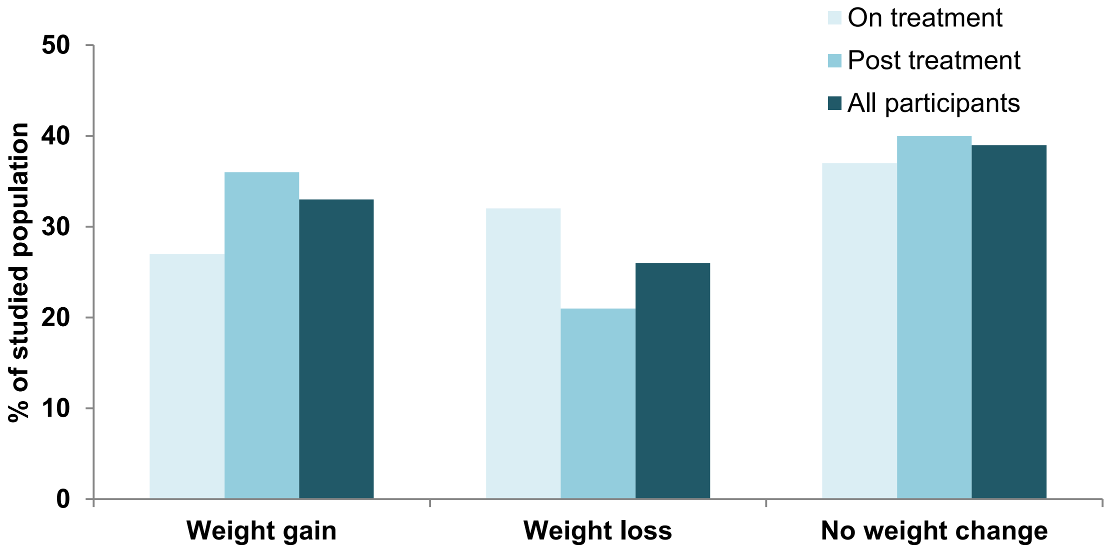


Figure 4.3: Reported weight changes after diagnosis (n=241). Data are missing for 10 participants. Four participants reported weight gain and weight loss. The percentage values exceed 100%.

4.5. Dietary changes

4.5.1. Descriptive analysis

A total of 170 (68%) participants reported changing at least one component in their diet after diagnosis. Responses were similar for the on-treatment (n=70, 69%) and the post-treatment group (n=100, 67%) ($x^2(1)=0.063$, $P=0.801$), as well as across cancer groups ($x^2(2)=5.762$, $P=0.056$). Changes were made to maintain general health (n=99, 58%), assist with treatment side effects (n=77, 45%), support therapy and recovery (n=70, 41%) and reduce the risk of recurrence (n=52, 31%). Other responses included losing weight (n=4, 2%) and diagnosis of diabetes (n=3, 1%). More people on treatment reported changing their diet to assist with treatment side effects ($x^2(1)=16.934$, $P<0.001$) and to support therapy and recovery ($x^2(1)=6.879$, $P=0.009$) compared to the post-treatment group. There was no difference in the responses according to cancer diagnosis (Appendix 4d).

Among the most notable changes, one in three respondents increased their fruit (33%) and vegetable intake (33%), 29% consumed more oily fish and 25% more wholegrain products. Almost one in two (48%) reduced the consumption of sugary foods, 41% alcohol, 40% processed meats and 29% full-fat dairy (Figure 4.4).

According to treatment stage, more on-treatment participants increased their intake of refined grains, compared to the post-treatment group (16% Vs 5%; $x^2(1)=8.863$, $P=0.003$). Also, more on-treatment respondents decreased their alcohol intake, compared to the post-treatment group (52% Vs 33%; $x^2(1)=8.985$, $P=0.003$). No other differences in dietary changes were observed ($P>0.01$ for all other comparisons). According to cancer diagnosis, more lower GI survivors reported reduction of wholegrains (26% Vs 2%; $x^2(1)=28.485$, $P<0.001$) and fruit (19% Vs 4%; $x^2(1)=13.130$, $P<0.001$) compared to urological cancer survivors. Also more gynaecological cancer survivors reduced the intake of wholegrains compared to urological cancer survivors (22% Vs 2%; $x^2(1)=18.770$, *P*<0.001). No other differences in dietary changes were observed based on diagnosis (*P*>0.01 for all other comparisons; Appendix 4d).

Regarding fluid intake, half of the respondents (n=126) reported the consumption of 6-8 glasses (250 ml) of fluids daily and a quarter (27%, n=69) 3-5 glasses, whereas 16% (n=40) had more than 9 glasses and 5% (n=12) 2 glasses or less.

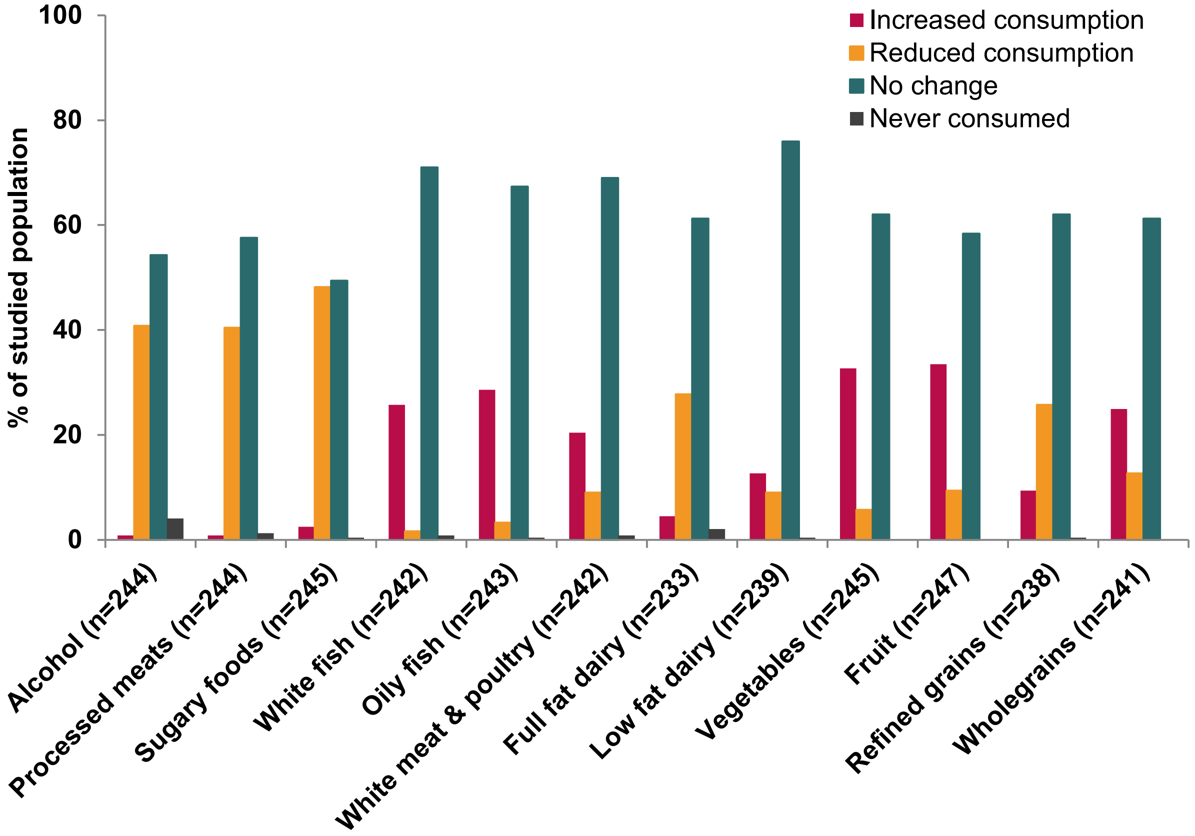


Figure 4.4: Reported dietary changes after cancer diagnosis for the whole sample.

Most respondents (72%; n=181) reported having meals with their spouse or partner. One in four respondents (25%, n=63) also had meals with members of their family, and one in ten (10%, n=26) with friends. Twenty-three percent (n=57) also reported having meals on their own. Meals were prepared either by the respondents themselves (37%, n=94), by their spouses/partners (37%, n=93) or it was a shared task (24%, n=60). Less frequently, respondents' meals were prepared by other family members (9%, n=23) or friends (2%, n=6). There were gender differences with regards to preparation of meals in the household. More men reported having their meal made by spouse/partner than women ($x^2(1)=30.710$, $P<0.001$). On the other hand, more women prepared meals by themselves than men ($x^2(1)=31.032$, $P<0.001$). There was no difference in meal preparation according to treatment stage (Appendix 4d).

Respondents had frequently consumed homemade meals over the past 4 weeks; 64% (n=160) had homemade meals more than five times a week and 24% (n=61) one to four times a week. Ready-made meals were eaten less frequently, as 31% (n=79) had not consumed ready-made meals in the past four weeks and 43% (n=109) consumed ready-made meals one to three times a month. Urological cancer patients reported eating ready meals less often than lower GI ($x^2(1)=13.289$, $P=0.004$) and gynaecological cancer survivors ($x^2(1)=9.225$, $P=0.026$). There was no difference in consumption of ready meals between survivors of a lower GI and gynaecological cancer.

4.5.2. Logistic regression

4.5.2.1. Whole sample

Univariate logistic regression was performed to ascertain the effects of each of the following variables on the likelihood that participants change a component of their diet: treatment stage (on-treatment, post-treatment), diagnosis (urological, lower GI, gynaecological), age, Body Mass Index, qualifications (<=high school/ > high school), employment (retired/not retired), marital status (married/not married), presence of a comorbidity (yes/no), presence of a side effect (yes/no), report of supplement use (yes/no) and nutrition support from health professionals (yes/no). The analysis showed that cancer diagnosis, age, qualifications and nutrition support from a health professional were significantly associated with dietary change (Table 4.3).

Multivariate logistic regression was performed to ascertain the effects of all the above variables together on the likelihood that participants change a component of their diet. Using the stepwise method, the variables “age” and “nutrition support from a health professional” were retained in the model. The logistic regression model was statistically significant, $\chi^2(1) = 18.673$, $P<0.001$. The model explained 14.2% (Nagelkerke pseudo R^2) of the variance in dietary change and correctly classified 67.1% of cases. Participants were 3.6 times more likely to make a change in their diet when they received nutrition support from a health professional compared to participants who did not receive nutrition support from a health professional. The variable “age” was retained in the model, but it was not statistically significant at the 5% level ($P=0.094$; Table 4.4).

4.5.2.2. Urological cancer patients only

Univariate logistic regression analysis for the urological cancer group showed that the variable “qualifications” and “nutrition support from a health professional” were significantly associated with dietary change (Table 4.3). In multivariate logistic regression analysis using the stepwise method, the variables “Body Mass Index”, “qualifications” and “nutrition support from a health professional” were retained in the model. The logistic regression model was statistically significant, $\chi^2(3) = 16.235$, $P=0.001$. The model explained 23.1% (Nagelkerke pseudo R^2) of the variance in dietary change and correctly classified 68.6% of cases. Respondents were 3.4 times more likely to make a change in their diet when they received nutrition support from a health professional compared to patients who did not receive support from a health professional. Participants with a higher BMI were also more likely to report a dietary change (OR=1.15, 95% CI: 1.01-1.31) compared to participants with lower BMI. Although the variable “qualifications” was retained in the model, it was not statistically significant at the 5% level ($P=0.104$; Table 4.4).

Table 4.3: Univariate logistic regression for whole sample, urological cancer group only and lower GI group only (dietary change as dependent variable).

Variables		Whole sample	Urological group	Lower GI group
		OR (95%CI)	**OR (95%CI)**	**OR (95%CI)**
Treatment status	On-treatment	1	1	1
	Post treatment	0.93 (0.54-1.60)	0.83 (0.41-1.70)	0.75 (0.24-2.39)
Cancer diagnosis	Gynaecological	1	N/A	N/A
	Urological	**0.50 (0.29-0.86)**	N/A	N/A
	Lower GI	1.68 (0.93-3.04)	N/A	N/A
Age		**0.97 (0.94-0.99)**	0.96 (0.89-1.02)	0.96 (0.92-1.01)
Body Mass Index		1.00 (0.94-1.06)	1.10 (1.00-1.21)	0.95 (0.85-1.05)
Qualifications	<=high school	1	1	1
	>high school	**0.47 (0.23-0.95)**	**0.49 (0.13-0.99)**	0.95 (0.28-3.20)
Employment	Not retired	1	1	1
	Retired	0.57 (0.32-1.03)	0.58 (0.21-1.60)	0.88 (0.31-2.47)
Marital status	Not married	1	1	1
	Married	0.74 (0.39-1.39)	0.45 (0.18-1.15)	0.84 (0.24-2.94)
Presence of a comorbidity	No	1	1	1
	Yes	0.98 (0.53-1.83)	1.69 (0.65-4.43)	0.70 (0.23-2.14)
Presence of a side effect	No	1	1	1
	Yes	1.55 (0.80-3.03)	1.60 (0.65-3.96)	1.71 (0.50-5.85)
Supplement use	No	1	1	1
	Yes	1.00 (0.57-1.78)	0.87 (0.41-1.86)	1.54 (0.39-6.12)
Nutrition support from health professional	No	1	1	1
	Yes	**3.94 (2.15-7.21)**	**4.44 (1.91-10.31)**	**3.81 (1.21-11.96)**

4.5.2.3. Lower GI patients only

Univariate logistic regression analysis for the lower GI group showed that only support from a health professional was significantly associated with dietary change (Table 4.3). In multivariate logistic regression analysis using the stepwise method, the variables “age”, “Body Mass Index” and “nutrition support from a health professional” were retained in the model. The logistic regression model was statistically significant, $\chi^2(4) = 10.304$, *P*=0.016. The model explained 24.1% (Nagelkerke pseudo R^2) of the variance in dietary change and correctly classified 74.1% of cases. Lower GI survivors were 4.7 times more likely to make a change in their diet when they received nutrition support from a health professional compared to survivors who did not receive nutritional support from a health professional. Increasing age was associated with decreased likelihood of making a dietary change (OR=0.94, 95% CI: 0.89-1.00). The variable “Body Mass Index” was retained in the model but it was not statistically significant on 5% level (*P*=0.076; Table 4.4).

Table 4.4: Multivariate logistic regression (stepwise method) for whole sample, urological cancer group only and lower GI group only (dietary change as dependent variable).

Variables		**Whole sample**	**Urological group**	**Lower GI group**
		OR (95%CI)	**OR (95%CI)**	**OR (95%CI)**
Age		0.97 (0.94-1.01)		**0.94 (0.89-1.00)**
Body Mass Index			**1.15 (1.01-1.31)**	0.87 (0.75-1.01)
Qualifications	<=high school		1	
	>high school		0.38 (0.12-1.22)	
Nutrition support from health professional	No	1	1	1
	Yes	**3.63 (1.82-7.23)**	**3.42 (1.24-9.40)**	**4.74 (1.18-19.01)**

4.5.3. Additional comments (open question C4)

Seventy-three respondents (36 from the on-treatment group and 37 from the post-treatment group) provided additional information about dietary changes after cancer diagnosis. The on-treatment group described dietary changes related to radiotherapy or other treatments and their potential side effects on appetite, bowel function and feelings of nausea, whereas the post-treatment group made dietary changes primarily for future health and prevention of cancer recurrence.

Twenty on-treatment participants made dietary changes to support gastrointestinal health during radiotherapy. These changes included reduced or no consumption of caffeinated (n=10), carbonated (n=6) and citrus drinks (n=3), alcohol (n=5), spices (n=4), dairy products (n=2), chocolate, pulses and cruciferous vegetables and fibre. Six participants reported drinking more water. Three on-treatment participants reduced their food intake as a result of reduced appetite.

Six post-treatment participants described experiences of managing side effects, three of which no longer experienced any. One participant consumed beans to manage constipation and eggs to manage diarrhoea; another participant did not consume breakfast to control output and another one limited food intake to avoid the feeling of nausea. Selected quotes are presented in Table 4.5.

Table 4.5: Selected quotes from Question C4: "Is there anything else you changed in your diet since diagnosis?"

Management of treatment side effects
"Only drinking decaf tea/coffee. No alcohol. No orange/lemon drinks or fizzy soft drinks. No chocolate." (prostate cancer, on-treatment)
"Removal of: fizzy drinks, beans, broccoli, onions." (prostate cancer, on-treatment)
"I have not had any alcohol and have been drinking de-caffeinated drinks. I have been cutting down my '5-a-day' on recommendation of the nurse in order to calm my bowel. And I have avoided spicy foods." (rectal cancer, on-treatment)
"Have no appetite so changes have been made so I eat." (ovarian cancer, on-treatment)
"During radiotherapy/chemo, appetite reduced and lost weight. After treatment, appetite returned and weight increased." (rectal cancer, post-treatment)
Support of health and recovery
"More brown bread, sunflower margarine, more fruit and veg. Less biscuits cakes, crisps, sugar, sweets." (prostate cancer, on-treatment)
"Reduced portion sizes to reduce weight." (prostate cancer, post-treatment)
"Increase nuts, seeds, yogurt, water. Decrease sweets." (rectal cancer, post-treatment)
"Greatly decreased consumption of red meat. Increased consumption of turmeric and garlic and flaxseed. Try to get more variety of vegetables, fruit etc." (rectal cancer, post-treatment)
"Tried to be more careful in identifying and cutting out hidden sugar, particularly that added to supposedly savoury foods." (endometrial cancer, post-treatment)
"I take relevant vitamin supplements which may help recovery & (prevent) recurrence." (rectal cancer, post-treatment)

Participants, more from the post-treatment (n=25) and fewer from the on-treatment group (n=7), made dietary changes to improve future health and in relation to weight management. Most commonly reported changes included reduction or avoidance of red and processed meats (n=9), reduction of portion sizes (n=7; three of which did so to reduce body weight), alcohol (n=4; post-treatment group only), salt (n=2) and convenience foods (n=2). Three post-treatment participants increased water/fluid intake and two on-treatment participants increased consumption of eggs. One post-treatment participant started taking vitamin supplements to prevent cancer recurrence. Selected quotes are presented in Table 4.5.

4.6. Supplement use

4.6.1. Descriptive analysis

Thirty-one percent (n=77) of participants reported current use of nutritional supplements. Responses were similar for the on-treatment (n=26, 25%) and the post-treatment group (n=51, 34%) ($x^2(1)=2.388$, $P=0.122$). The most frequently reported supplement was Vitamin D (n=38, 49%), followed by omega-3 (n=32, 42%), multivitamins (n=27, 35%), Vitamin C (n=22, 29%), B vitamins (n=10, 13%), calcium (n=9, 12%), glucosamine sulphate (n=9, 12%), iron (n=6, 8%) and zinc (n=6, 8%). There was no difference in consumption of Vitamin D, omega-3, multivitamin or Vitamin C supplements across treatment stages or cancer diagnoses ($P>0.01$ for all comparisons).

Participants reported consuming supplements to maintain general health (n=54, 70%), support therapy and recovery (n=21, 27%), assist with treatment side effects (n=18, 23%), and reduce the risk of recurrence (n=8, 10%). There was no difference in the reasons for supplement use according to treatment status or cancer diagnosis, except for the fact that survivors of lower GI cancer were more likely to take supplements to support recovery compared to urological cancer survivors ($x^2(1)=16.319$, $P<0.001$). Sixty-three percent of lower GI survivors who take supplements (10/16) did so to support recovery, compared to 10% of urological cancer survivors (4/39; Appendix 4e).

4.6.2. Logistic regression

4.6.2.1. Whole sample

Univariate logistic regression was performed to ascertain the effects of each of the following variables on the likelihood that participants consume supplements as part of their diet: treatment stage (on-treatment, post-treatment), diagnosis (urological, lower GI, gynaecological), age, Body Mass Index, qualifications (<=high school/ > high school), employment (retired/not retired), marital status (married/not married), presence of a comorbidity (yes/no), presence of a side effect (yes/no), report of dietary change (yes/no) and nutrition support from health professionals (yes/no). Univariate logistic regression analysis showed that none of the above variables was significantly associated with supplement use (Table 4.6).

Multivariate logistic regression was performed to ascertain the effects of all the above variables together on the likelihood that participants consume supplements. Using the stepwise method, the variables “treatment stage”, “report of a side effect” and “nutrition support from health professional” were retained in the model. The logistic regression model was statistically significant, $\chi^2(4) = 12.895$, $P=0.012$. The model explained 10.0% (Nagelkerke pseudo R^2) of the variance in supplement use and correctly classified 65.3% of cases. Participants were 2.5 times more likely to consume supplements if they experienced at least one side effect compared to participants without any side effects. Participants were also more likely to consume supplements in the post-treatment stage and when they had nutrition support from health professionals, but both variables did not reach statistical significance in the model ($P=0.085$ and $P=0.095$, respectively) (Table 4.7).

4.6.2.2. *Urological cancers only*

Univariate logistic regression analysis for the urological cancer group showed that treatment stage was significantly associated with supplement use (Table 4.6). In multivariate logistic regression analysis using the stepwise method, the variable “report of a side effect” was the only variable retained in the model. The logistic regression model was statistically significant, $\chi^2(1) = 4.518$, P=0.034. The model explained 7.0% (Nagelkerke pseudo R^2) of the variance in supplement use and correctly classified 62.8% of cases. Supplement use was 3.7 times more likely if a urological cancer survivor experienced a side effect but it was non-significant (Table 4.7).

Table 4.6: Univariate logistic regression for whole sample, urological cancer group only and lower GI group only (supplement use as dependent variable).

Variables		**Whole sample**	**Urological group**	**Lower GI group**
		OR (95%CI)	**OR (95%CI)**	**OR (95%CI)**
Treatment status	On-treatment	1	1	1
	Post treatment	1.55 (0.89-2.72)	**2.67 (1.19-5.97)**	1.00 (0.30-3.27)
Cancer diagnosis	Gynaecological	1	N/A	N/A
	Urological	0.95 (0.55-1.62)	N/A	N/A
	Lower GI	0.55 (0.30-1.02)	N/A	N/A
Age		1.00 (0.98-1.03)	1.01 (0.94-1.08)	1.01 (0.96-1.06)
Body Mass Index		1.01 (0.95-1.07)	1.04 (0.95-1.14)	**0.84 (0.72-0.98)**
Qualifications	<=high school	1	1	1
	>high school	1.55 (0.79-3.02)	1.41 (0.54-3.70)	6.38 (0.76-53.28)
Employment	Not retired	1	1	1
	Retired	1.38 (0.77-2.48)	1.58 (0.54-4.65)	1.26 (0.42-3.79)
Marital status	Not married	1	1	1
	Married	0.94 (0.50-1.76)	0.64 (0.27-1.54)	2.33 (0.48-11.47)
Presence of a comorbidity	No	1	1	1
	Yes	1.21 (0.64-2.31)	0.83 (0.30-2.26)	1.47 (0.45-4.81)
Presence of a side effect	No	1	1	1
	Yes	1.75 (0.82-3.75)	2.55 (0.81-8.04)	1.94 (0.39-9.63)
Report of dietary change	No	1	1	1
	Yes	1.00 (0.57-1.78)	0.87 (0.41-1.86)	1.54 (0.39-6.12)
Nutrition support from health professional	No	1	1	1
	Yes	1.19 (0.69-2.04)	1.20 (0.56-2.57)	1.03 0.34-3.11)

4.6.2.3. Lower GI cancers only

Univariate logistic regression analysis for the lower GI group showed that “Body Mass Index” was significantly associated with supplement use (Table 4.6). In multivariate logistic regression analysis using the stepwise method, the variable “Body Mass Index” was retained in the model. The logistic regression model was statistically significant, $\chi^2(1)=4.922$, $P=0.027$. The model explained 13.3% (Nagelkerke pseudo R^2) of the variance in supplement use and correctly classified 77.8% of cases. Increasing BMI was associated with decreased likelihood of consuming dietary supplements (Table 4.7).

Table 4.7: Multivariate logistic regression (stepwise method) for the whole sample, urological group only and lower GI only (supplement use as dependent variable).

Variables		**Whole sample**	**Urological group**	**Lower GI group**
		OR (95%CI)	**OR (95%CI)**	**OR (95%CI)**
Treatment status	On-treatment	1		
	Post treatment	1.87 (0.92-3.82)		
Body Mass Index				**0.82 (0.67-1.00)**
Presence of a side effect	No	1	1	
	Yes	**2.46 (1.01-6.02)**	3.72 (0.98-14.05)	
Nutrition support from health professional	No	1		
	Yes	1.76 (0.91-3.43)		

4.7. Nutritional awareness

Overall, respondents were familiar with dietary recommendations as published in 2007 by the WCRF/AICR (Figure 4.5). Between 91% and 95% of participants were mostly or very familiar with the recommendations for weight, high calorie foods, consumption of at least five fruit and vegetables per day and alcohol and supplement use. Respondents were less familiar with the recommendations on red and processed meat consumption (30% mostly and 42% very familiar) and salt intake (26% mostly and 57% very familiar; Appendix 4f).

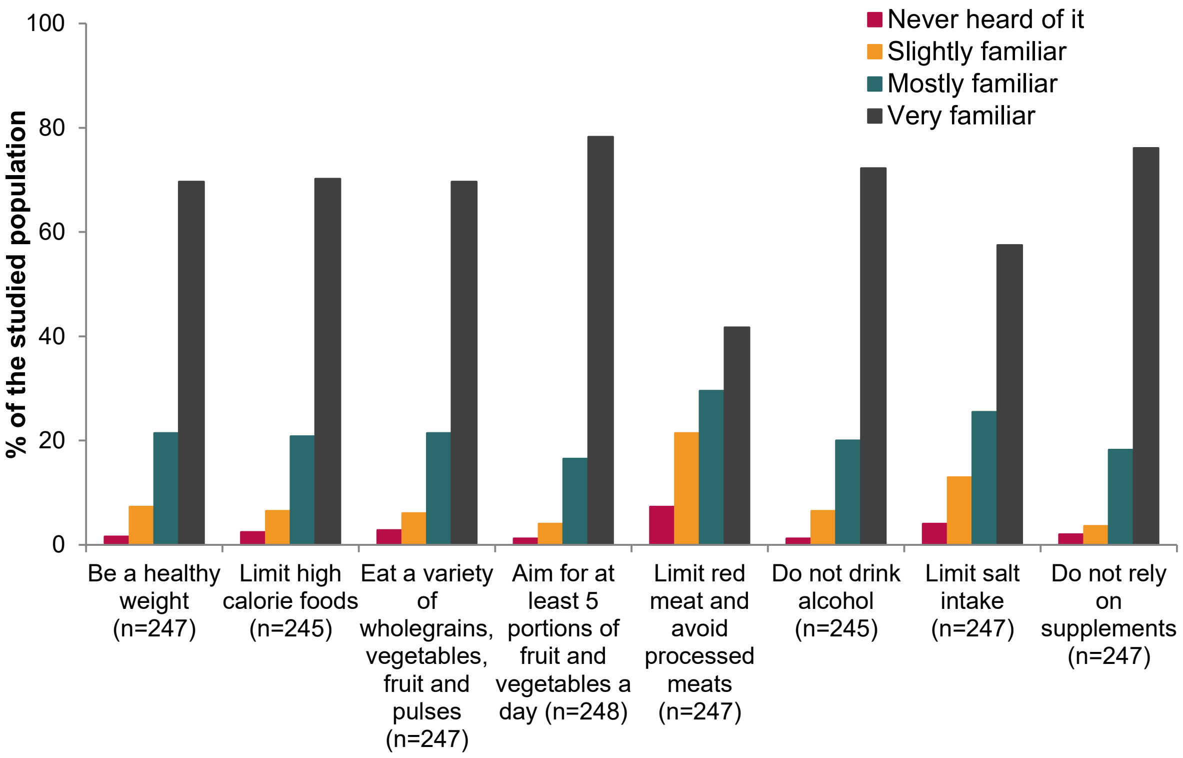


Figure 4.5: Respondents' familiarity with the dietary recommendations published by the WCRF/AICR Second Expert Report (2007).

4.8. Perceptions of diet and nutrition in cancer care

Participants considered the role of diet and nutrition as either important or very important in managing side effects, preventing recurrence, supporting recovery and improving overall health (50-94% of respondents for all statements). Responses were similar across treatment stage and cancer diagnoses (P>0.01 for all comparisons). Participants were more sceptical about the role of diet in reducing appetite side effects and fatigue (36% and 27% respectively assessed diet as not or little important) (Table 4.8 and Appendix 4g)

Table 4.8: Respondents' perceptions of the role of diet after a cancer diagnosis (n=251).

How important is the role of diet in…	Not important	A little important	Important	Very important	Missing
	n (%)	n (%)	n (%)	n (%)	n (%)
Reducing GI side effects?	12 (5)	34 (14)	85 (34)	109 (43)	11 (4)
Reducing appetite side effects?	45 (18)	46 (18)	76 (30)	51 (20)	33 (13)
Reducing the feeling of fatigue?	38 (15)	30 (12)	71 (28)	93 (37)	19 (8)
Preventing cancer recurrence?	19 (8)	39 (16)	82 (33)	102 (41)	9 (4)
Improving overall health?	1 (<1)	10 (4)	73 (29)	163 (65)	4 (2)
Supporting therapy and recovery?	4 (2)	22 (9)	82 (33)	135 (54)	7 (3)

4.9. Support from health professionals

4.9.1. Descriptive analysis

Fifty-seven percent of the participants did not recall receiving nutritional advice and support from their healthcare team (Table 4.9). Responses did not differ between treatment stage ($x^2(1)=1.139$, $P=0.286$) or cancer diagnosis ($x^2(2)=3.592$, $P=0.166$).

For those who received support (43%, n=108), information was provided mainly from a cancer or radiotherapy specialist nurse (59%, n=64), followed by radiographer/oncologist (19%, n=21), dietitian (17%, n=18), general practitioner (9%, n=10) and nutritionist (6%, n=6). Content of information provided was mainly about general healthy eating (75%, n=81) followed by nutritional management of treatment side effects (31%, n=33) and weight management (16%, n=17; Figure 4.6). Dietary information was most often provided as written material (71%, n=77) or in a face-to-face meeting (50%, n=54) and less frequently as links to websites (n=9, 8%), via telephone (n=7, 6%) or in survivorship courses (n=3, 3%). There was no difference in source, content or form of provision of information according to treatment status or cancer diagnosis ($P>0.01$ for all comparisons; Appendix 4h).

Table 4.9: Report of dietary and nutritional support from the healthcare team (n=251).

Have you received any nutrition support in relation to your cancer from your healthcare team?	All participants n=251	On-treatment n=102	Post-treatment n=149
	n (%)	n (%)	n (%)
Yes	108 (43)	48 (47)	60 (40)
No	143 (57)	54 (53)	89 (60)

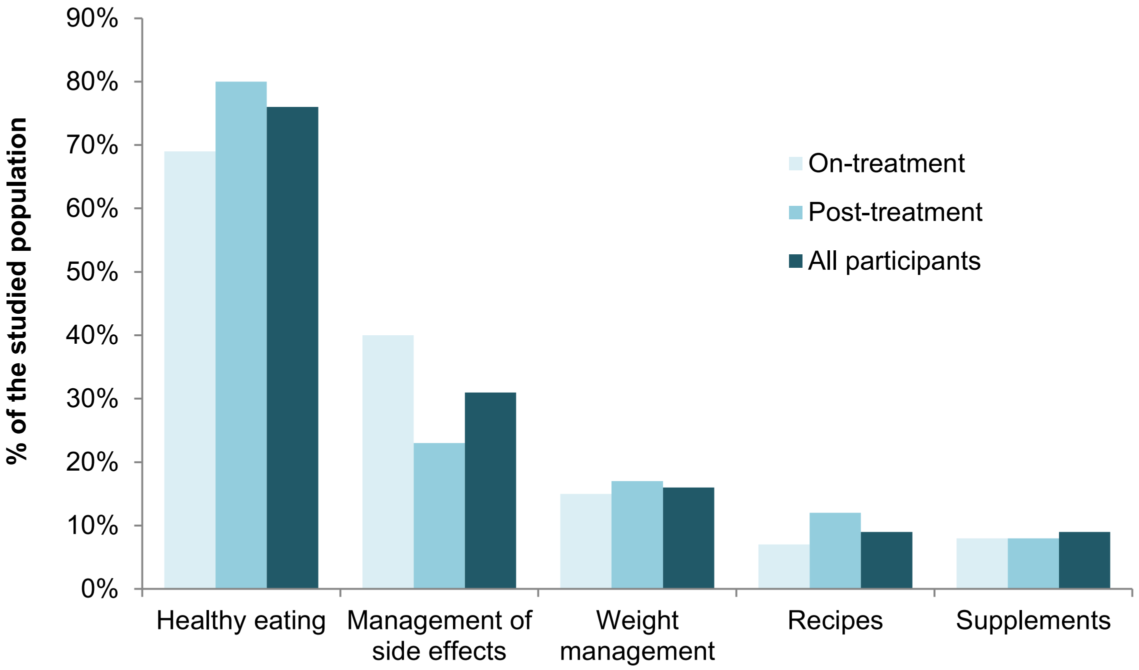


Figure 4.6: Content of information and support in diet and nutrition for survivors who reported receipt of information and support (n=108). Data missing for one participant.

Most participants who received nutritional support perceived their needs to be well or very well met (77%), the advice to be consistent or very consistent (72%) and easy or very easy to follow (76%). Around one-quarter of respondents had neutral responses in relation to satisfaction with information and a few (5-6%) did not have their needs met, perceived the advice to be inconsistent and/or difficult to follow. Provision of support influenced 67% of them (n=73) to change their diet (Table 4.10).

Table 4.10: Influence for dietary change (for participants who reported receipt of support (n=108)).

Did information influence you to change your diet?	All participants n=108	On-treatment n=48	Post-treatment n=60
	n (%)	n (%)	n (%)
Yes	73 (67)	38 (79)	35 (58)
No	33 (31)	10 (21)	23 (38)
Missing	2 (2)	0 (0)	2 (3)

Among participants who did not have discussions with health professionals about diet and nutrition, most were not offered any (n=101, 71%), while some did not know this support existed (n=46, 32%), chose not to receive any (n=13, 9%) and did not think nutrition was important (n=5, 3%). Responses did not differ according to treatment stage or cancer diagnosis (*P*>0.01 for all comparisons). Participants who did not receive any support would have liked to get information about healthy eating (n=53, 37%), nutritional management of treatment side effects (n=39, 27%), weight management (n=37, 26%), nutritional supplements (n=30, 21%) and workshops related to survivorship (n=7, 5%; Fig. 4.7).

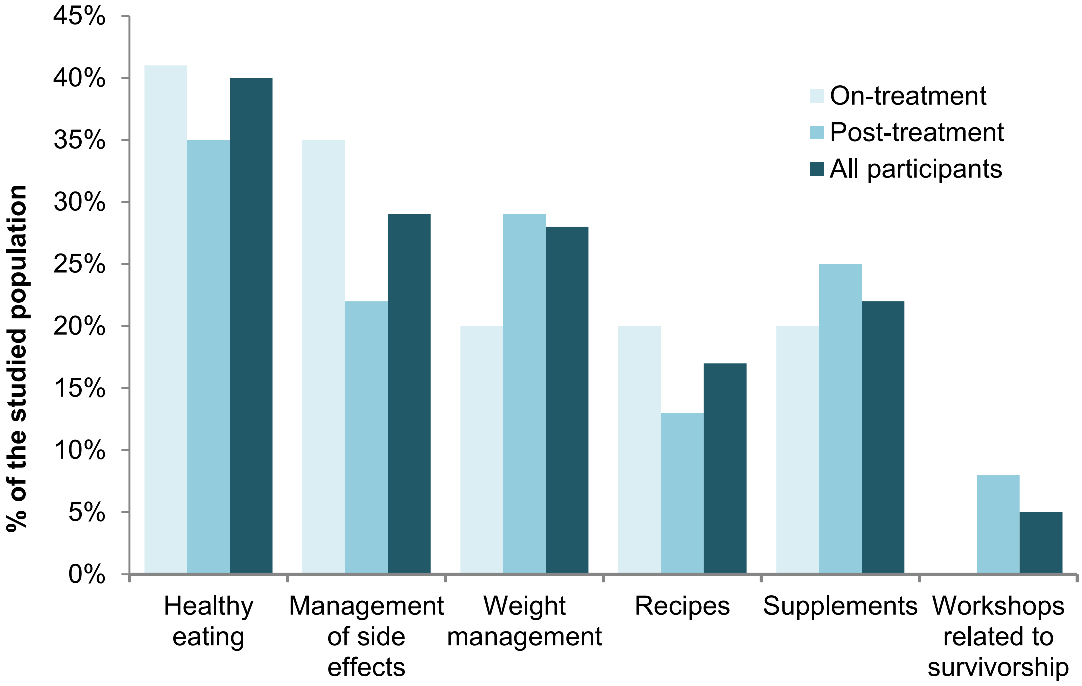


Figure 4.7: Information and support needs in diet and nutrition for survivors who did not receive information and support (n=143). Data missing for 8 participants.

There was a significant difference in the need for information in relation to weight management for the different diagnoses ($x^2(2)=9.564$, *P*=0.008). More urological cancer survivors expressed this compared to GI survivors ($x^2(1)=7.708$, *P*=0.005), which may be related to treatment regimes. No other significant differences on the type of support were observed according to treatment stage or cancer diagnosis (*P*>0.05 for all comparisons).

4.9.2. Logistic regression

4.9.2.1. Whole sample

Univariate logistic regression was performed to ascertain the effects of each of the following variables on the likelihood that participants receive nutrition support from health professionals: treatment stage (on-treatment, post-treatment), diagnosis [urological, lower GI, gynaecological], age, Body Mass Index, qualifications (<=high school/ > high school), employment (retired/not retired), marital status (married/not married), presence of a comorbidity (yes/no), presence of a side effect (yes/no), report of dietary change (yes/no) and supplement use (yes/no). Univariate logistic regression analysis showed that report of dietary change was significantly associated with nutritional support from health professionals (Table 4.11).

Multivariate logistic regression was performed to ascertain the effects of all the above variables on the likelihood that participants receive nutrition support from health professionals. Using the stepwise method, only the variable “dietary change” was retained in the model. The logistic regression model was statistically significant, $\chi^2(1) = 15.747$, $p<0.001$. The model explained 11.9% (Nagelkerke pseudo R^2) of the variance in nutrition support from health professionals and correctly classified 62.9% of cases. Survivors were 3.8 times more likely to have received nutrition support from a health professional if they made a change in their diet compared to those who did not report a dietary change (Table 4.12).

4.9.2.2. Urological cancers only

Univariate logistic regression analysis for the urological cancer group showed that the variables “age” and “report of a dietary change” were significantly associated with receipt of nutrition support from health professionals (Table 4.11). In multivariate logistic regression analysis using the stepwise method, the same variables were retained in the model. The logistic regression model was statistically significant, $\chi^2(2) = 16.164$, $p<0.001$. The model explained 23.3% (Nagelkerke pseudo R^2) of the variance in nutrition support by health professionals and correctly classified 74.4% of cases. Urological cancer survivors were 3.4 times more likely to have received nutrition support from a health professional if they made a change in their diet compared to those who did not change their diet. Younger survivors were also more likely to report nutrition support from health professionals (Table 4.12).

4.9.2.3. Lower GI cancers only

Univariate logistic regression analysis for the lower GI group showed that “report of dietary change” was significantly associated with nutrition support from health professionals (Table 4.11). In multivariate logistic regression analysis using the stepwise method, the variables “marital status” and “report of a dietary change” were retained in the model. The logistic regression model was statistically significant, $\chi^2(2) = 6.523$, $p=0.038$. The model explained 15.2% (Nagelkerke pseudo R^2) of the variance in nutrition support by health professionals and correctly classified 61.1% of cases. Lower GI survivors were 3.9 times more likely to have received nutrition support from a health professional if they made a change in their diet compared to survivors who did not make a change in their diet. The variable “marital status” was retained in the model but it was not statistically significant on 5% level ($P=0.117$; Table 4.12).

Table 4.11: Univariate logistic regression for whole sample, urological group only and lower GI group only (nutrition support from health professionals as dependent variable).

Variables		Whole sample	Urological only	Lower GI only
		OR (95%CI)	**OR (95%CI)**	**OR (95%CI)**
Treatment status	On-treatment	1	1	1
	Post treatment	0.76 (0.46-1.26)	0.60 (0.29-1.22)	0.79 (0.30-2.06)
Cancer diagnosis	Gynaecological	1	N/A	N/A
	Urological	0.68 (0.41-1.12)	N/A	N/A
	Lower GI	1.66 (0.97-2.83)	N/A	N/A
Age		0.98 (0.95-1.00)	**0.91 (0.85-0.98)**	1.02 (0.98-1.06)
Body Mass Index		1.01 (0.96-1.06)	1.02 (0.93-1.11)	0.99 (0.90-1.08)
Qualifications	<=high school	1	1	1
	>high school	0.77 (0.42-1.42)	0.45 (0.18-1.12)	1.20 (0.40-3.59)
Employment	Not retired	1	1	1
	Retired	0.85 (0.50-1.44)	0.46 (0.18-1.18)	2.08 (0.84-5.17)
Marital status	Not married	1	1	1
	Married	0.57 (0.32-1.03)	1.05 (0.44-2.51)	0.21 (0.06-0.72)
Presence of a comorbidity	No	1	1	1
	Yes	1.18 (0.65-2.14)	1.32 (0.47-3.73)	2.33 (0.87-6.20)
Presence of a side effect	No	1	1	1
	Yes	1.63 (0.82-3.20)	1.42 (0.54-3.75)	3.34 (0.96-11.64)
Report of dietary change	No	1	1	1
	Yes	**3.94 (2.15-7.21)**	**4.44 (1.91-10.31)**	**3.81 (1.21-11.96)**
Supplement use	No	1	1	1
	Yes	1.19 (0.69-2.04)	1.20 (0.56-2.57)	1.03 (0.34-3.11)

Table 4.12: Multivariate logistic regression for whole sample, urological group only and lower GI group only (support from health professionals as dependent variable).

Variables		Whole sample	Urological group	Lower GI group
		OR (95%CI)	**OR (95%CI)**	**OR (95%CI)**
Age			**0.88 (0.80-0.97)**	
Marital status	Not married			1
	Married			0.27 (0.05-1.39)
Report of dietary change	No	1	1	1
	Yes	**3.77 (1.90-7.46)**	**3.37 (1.24-9.17)**	**3.93 (1.06-14.51)**

4.9.3. Additional comments (Influence of support in dietary change – D8)

In total, 82/108 participants (37 from the on-treatment group and 45 from the post-treatment group) who received dietary support also provided additional information about the influence of dietary support in dietary change. Most of the comments referred to actual dietary changes, which were presented in the sub-section “Dietary habits/changes”.

Alleviation of side effects was the main reason to influence dietary change, both in the on-treatment (n=8) and the post-treatment group (n=5). Realisation of the importance of diet in future wellbeing was another reason to influence dietary change following support from health professionals (n=5). Participants valued the role of diet in keeping healthy (n=8) and the potential to reduce recurrence (n=1). Reasons for no change were the perception of having had a healthy diet prior to receipt of support (n=11), high perceived awareness of what constitutes a healthy diet (n=4), receipt of confusing information (n=2) and lack of interest in diet and nutrition (n=1). Selected quotes are presented in Table 4.13.

Table 4.13: Selected quotes from Survey Question D8: “Did dietary information/advice influence you to change dietary habits (nutrition support from health professionals)”

People who were influenced to change their diet following diagnosis
“I changed my dietary habits while I was receiving radiotherapy treatment because it helped to offset the effects of the treatment.” (cervical cancer, on-treatment)
“I needed a low fibre diet to combat my diarrhoea, which was very bad.” (bladder cancer, on-treatment)
“Increasing realisation of importance of diet.” (prostate cancer, on-treatment)
“More aware of impact certain foods have on my own body, especially after & during treatment.” (rectal cancer, post-treatment)
People who were not influenced to change their diet following diagnosis
“I already have a good balanced diet and drink sensibly.” (prostate cancer, post-treatment)
“It confirmed that what we were already doing was correct even if we didn’t always get it right.” (prostate cancer, post-treatment)
“Just not interested in food. I have to practically push myself to eat.” (anal cancer, post-treatment)

4.9.4. Additional comments (Requests for additional support – D9)

In open question D9, respondents who received support were asked if they would have liked any additional support from their healthcare team. Twenty-seven respondents (14 in the on-treatment and 13 in the post-treatment group) added comments.

Most comments from on-treatment participants were related to the effect of treatments on diet. Eight participants enquired about additional support on which foods to consume or avoid during treatment. Three participants enquired about the use of nutritional supplements and two wanted to have a face-to-face consultation with a dietitian for tailored advice.

Post-treatment participants wanted guidance in relation to management of side effects (n=3), use of supplements (n=3), weight management (n=2), recipes (n=1) and general healthy eating (n=1). Two participants enquired about tailored nutritional guidance for cancer and other comorbidities. Selected quotes are presented in Table 4.14.

Table 4.14: Selected quotes from Survey Question D8: "What, if any, additional nutrition support would you like to receive/have received?"

"I would like to have had diet/nutritional guidance when first diagnosed to help maintain healthy weight and to avoid bowel problems during radiotherapy. Would also like advice on vitamin and mineral supplements." (prostate cancer, on-treatment)
"Would like to see a dietitian after surgery, as I will have a permanent stoma." (rectal cancer, on-treatment)
"Face to face assistance on dietary issues & weight management." (prostate cancer, post-treatment)
"More in-depth support because I also have IBS, as well as cancer. So it's not one thing, it's two I have now how to manage. Also advice on weight management" (anal cancer, post-treatment)

4.10. Support from other sources

4.10.1. Descriptive analysis

Seventy-nine (32%) respondents looked for information online or from other sources. Responses were similar for the on-treatment (n=28, 27%) and the post-treatment group (n=51, 34%) (x^2 (1)=1.394, *P*=0.238), as well as across cancer groups (x^2 (2)=1.127, *P*=0.569; Table 4.15). Most of these participants searched for information online on cancer charity websites (n=46, 58%) or medical websites (n=28, 35%), followed by receipt of information from a family member/friend (n=19, 24%), a newspaper/magazine/book (n=17, 22%), a recipe book (n=15, 19%), a blog (n=7, 9%) or from other patients (n=5, 6%).

Table 4.15: Report of dietary and nutritional support from other sources (n=251).

Did you seek any information or support in diet and nutrition in relation to cancer online or from another source?	All participants n=251	On-treatment n=102	Post-treatment n=149
	n (%)	n (%)	n (%)
Yes	79 (32)	28 (27)	51 (34)
No	166 (66)	72 (70)	94 (63)
Missing	6 (2)	2(2)	4 (3)

Respondents looked mostly for information about general healthy eating advice (n=61, 77%). Fewer searched for recipes (n=22, 28%), nutritional management of side effects, (n=19, 24%), weight management (n=15, 19%) and nutritional supplements (n=13, 15%).

Most participants perceived information from other sources to meet their needs well or very well (53%), to be consistent or very consistent (60%) and easy or very easy to follow (60%). Twenty-eight to 35% of respondents had neutral responses in relation to satisfaction with information and few (5-12%) did not have their needs met, perceived the advice to be inconsistent and/or difficult to follow. Satisfaction with information from other sources was overall lower than satisfaction with information from health professionals. Information from other sources influenced 57% of participants (n=45) to change their diet (Table 4.16).

Table 4.16: Influence for dietary change (for participants who reported receipt of support from other sources (n=79)).

Did information influence you to change your diet?	All participants n=79	On-treatment n=28	Post-treatment n=51
	n (%)	n (%)	n (%)
Yes	45 (57)	20 (71)	25 (49)
No	27 (34)	7 (25)	20 (39)
Missing	7 (9)	1 (4)	6 (12)

4.10.2. Logistic regression

4.10.2.1. Whole sample

Univariate logistic regression was performed to ascertain the effects of each of the following variables on the likelihood that participants receive nutrition support from other sources: treatment stage (on-treatment, post-treatment), diagnosis (urological, lower GI, gynaecological), age, Body Mass Index, qualifications (<=high school/ > high school), employment (retired/not retired), marital status (married/not married), presence of a comorbidity (yes/no), presence of a side effect (yes/no), report of dietary change (yes/no), supplement use (yes/no) and nutrition support from a health professional (yes/no). Univariate logistic regression analysis showed that “age”, “report of dietary change” and “nutrition support from health professionals” were significantly associated with nutrition support from other sources (Table 4.17).

Multivariate logistic regression was performed to ascertain the effects of all of the above variables on the likelihood that participants receive nutrition support from other sources. Using the stepwise method, the variables “Body Mass Index”, “report of a dietary change” and “nutrition support from a heath professional” were retained in the model. The logistic regression model was statistically significant, $\chi^2(3) = 24.798$, $p<0.001$. The model explained 19.0% (Nagelkerke pseudo R^2) of the variance in nutrition support from other sources and correctly classified 64.9% of cases. Survivors were 3.8 times more likely to look for information in other sources if they have made a change in their diet compared to those who did not make a change in their diet. Also they were 2.2 times more likely to look for information from other sources if they have received nutrition information from health professionals. Respondents with a higher BMI were less likely to look for information from other sources but it was not significant (P=0.054; Table 4.18).

4.10.2.2. Urological cancers only

Univariate logistic regression analysis for the urological cancer group showed that the variables “report of a dietary change” and “support from health professional” were significantly associated with receipt of nutrition support from other sources (Table 4.17). In multivariate logistic regression analysis using the stepwise method, the same variables were retained in the model. The logistic regression model was statistically significant, $\chi^2(2) = 11.366$, P=0.003. The model explained 17.4% (Nagelkerke pseudo R^2) of the variance in support by other sources and correctly classified 67.4% of cases. Urological cancer survivors were 3 times more likely to look for information on other sources if they have made a change in their diet compared to those who did not change their diet and 2.8 times if they have received nutrition support from health professionals (Table 4.18), compared to those who did not receive nutrition support from health professionals.

4.10.2.3. Lower GI only

Univariate logistic regression analysis for the lower GI group showed that “Body Mass Index” and “supplement use” were significantly associated with nutrition support from other sources. (Table 4.17). In multivariate logistic regression analysis using the stepwise method, the variables “age” and “Body Mass Index” were retained in the model. The logistic regression model was statistically significant, $\chi^2(1) = 10.292$, p=0.006. The model explained 24.4% (Nagelkerke pseudo R^2) of the variance in support by other sources and correctly classified 73.6% of cases.

Table 4.17: Univariate logistic regression for whole sample, urological group only and lower GI group only (support from other sources as dependent variable).

Variables		**Whole sample**	**Urological group**	**Lower GI group**
		OR (95%CI)	**OR (95%CI)**	**OR (95%CI)**
Treatment status	On-treatment	1	1	1
	Post treatment	1.40 (0.80-2.43)	1.69 (0.76-3.76)	0.91 (0.32-2.57)
Cancer diagnosis	Gynaecological	1		
	Urological	0.72 (0.42-1.24)		
	Lower GI	1.23 (0.69-2.18)		
Age		**0.97 (0.95-1.00)**	0.96 (0.90-1.04)	0.97 (0.92-1.01)
Body Mass Index		0.97 (0.91-1.04)	1.06 (0.96-1.16)	**0.88 (0.77-0.99)**
Qualifications	<=high school	1	1	1
	>high school	1.00 (0.53-1.92)	0.70 (0.27-1.85)	3.23 (0.81-12.90)
Employment	Not retired	1	1	1
	Retired	0.64 (0.36-1.12)	0.67 (0.24-1.83)	0.67 (0.25-1.77)
Marital status	Not married	1	1	1
	Married	1.09 (0.58-2.06)	0.95 (0.37-2.39)	1.30 (0.40-4.21)
Presence of a comorbidity	No	1	1	1
	Yes	0.84 (0.45-1.56)	0.90 (0.32-2.57)	0.82 (0.30-2.25)
Presence of a side effect	No	1	1	1
	Yes	0.92 (0.46-1.83)	1.12 (0.40-3.11)	0.62 (0.19-2.03)
Report of dietary change	No	1	1	1
	Yes	**5.03 (2.42-10.45)**	**4.59 (1.75-12.06)**	3.45 (0.90-13.24)
Supplement use	No	1	1	1
	Yes	1.53 (0.87-2.71)	1.10 (0.49-2.51)	**6.43 (1.88-21.99)**
Nutrition support from health professional	No	1	1	1
	Yes	**3.04 (1.75-5.30)**	**4.34 (1.93-9.76)**	1.91 (0.72-5.07)

Lower GI survivors with a lower Body Mass Index were more likely to look for nutrition information from other sources compared to lower GI patients with higher BMI. Younger patients with a lower GI cancer were also more likely to look for information online but it was not statistically significant (*P*=0.081; Table 4.18).

Table 4.18: Multivariate logistic regression for whole sample, urological group only and lower GI group only (support from other sources as dependent variable).

Variables		**Whole sample**	**Urological groups**	**Lower GI group**
		OR (95%CI)	**OR (95%CI)**	**OR (95%CI)**
Age				0.95 (0.89-1.01)
Body Mass Index		0.92 (0.85-1.00)		**0.78 (0.65-0.95)**
Report of dietary change	No	1	1	
	Yes	**3.76 (1.67-8.47)**	**3.00 (1.01-8.85)**	
Supplement use	No			
	Yes			
Nutrition support from health professional	No	1	**1**	
	Yes	**2.17 (1.07-4.40)**	**2.77 (1.02-7.49)**	

4.10.3. Additional comments (Open Question D18)

In total, 51/79 participants (32 from the on-treatment group and 19 from the post-treatment group) who received dietary support from other sources also provided additional information about the influence of dietary support in dietary change. Most of the comments referred to actual dietary changes, which were presented in the sub-section “Dietary habits/changes”.

Similarly to what is described in Section 4.9.3. (Additional comments Open Question D8), information from online sources helped a few participants alleviate treatment side effects (n=4 in on-treatment group, n=1 in post-treatment group) and general wellbeing (n=1 in on-treatment group and n=2 in post-treatment group). Reasons for no change were the perception of having had a healthy diet prior to receipt of support (n=12), having already made the necessary dietary changes (n=2), receipt of generic information (n=1) and lack of interest in diet and nutrition (n=1). Selected quotes are presented in Table 4.19.

Table 4.19: Selected quotes from Survey Question D9: "Did dietary information/advice influence you to change dietary habits (support from other sources)"

People who were influenced to change their diet following diagnosis
"To improve/maintain one's general health and fitness" (vaginal cancer, on-treatment)
"Helped me to reduce symptoms/side effects." (other pelvic cancer, on-treatment)
"For my wellbeing." (prostate, post-treatment)
"Yes, it made me feel I could do something positive and be in more control (rectal cancer, post-treatment)
People who were not influenced to change their diet following diagnosis
"Changes had already been made" (prostate cancer, on-treatment)
"Already aware of the advice provided and mostly eat a diet based on the guidelines (anal cancer, post-treatment)

4.11. Interest in getting more information

Most respondents were somewhat to extremely interested in receiving more information about diet and nutrition in relation to their cancer (68%, n=171). Thirty-five participants (14%) were not interested at all (Table 4.20). There was no difference in responses in relation to treatment status [Yes (somewhat, very or extremely interested) Vs No (not or little interested): x^2 (1)=1.535, *P*=0.215] or cancer diagnosis [Yes (somewhat, very or extremely interested) Vs No (not or little interested): x^2 (2)=3.832, *P*=0.147].

Written information was the preferred method of delivery of information (58%, n=145) followed by face-to-face support by a health professional (28%, n=71), via the internet (22%, n=56), via telephone (10%, n=25) or a DVD (5%, n=13). There was no difference in responses according to treatment status or cancer diagnosis (all *P* values >0.001; Appendix 13).

Table 4.20: Interest in receiving (additional) information and support in diet and nutrition (n=251).

Would you be interested in receiving more information about your diet in relation to your cancer?	All participants n=251	On-treatment n=102	Post-treatment n=149
	n (%)	n (%)	n (%)
Not interested at all	35 (14)	10 (10)	25 (17)
A little interested	37 (15)	15 (15)	22 (15)
Somewhat interested	43 (17)	14 (14)	29 (19)
Very interested	75 (30)	37 (36)	38 (26)
Extremely interested	53 (21)	23 (23)	30 (20)
Missing	8 (3)	3 (3)	5 (3)

In terms of the optimal time point to discuss diet and nutrition, respondents gave a variety of answers: 35% (n=88) would welcome diet-related discussions at any time since diagnosis, 24% (n=59) during treatment, 23% (n=57) during diagnosis, 21% (n=53) at the end of treatment and 12% (n=31) on a follow up visit. Most respondents who were not interested in getting dietary support did not answer the questions about optimal mode and time point of delivery of information (hence the high number of missing values in these questions).

Chapter 5. Findings from interviews

5.1. Summary

The first part of this chapter presents the findings of the interviews that took place with a sub-sample of participants who completed the survey. First, basic descriptive information on the sample is presented. Then, the chapter is divided according to the themes and subthemes that were identified from the thematic analysis using the Framework approach, as described by Gale et al. (2013). One overarching theme includes seven themes in which the qualitative findings are organised.

The second part of the chapter presents the free-text findings from the survey, which were also analysed thematically. Themes are similar to themes identified from the analysis of the interview data.

5.2. Sample characteristics

One hundred and fifty-two questionnaire respondents indicated their interest in taking part in a semi-structured telephone interview, and provided contact details. Forty-five were contacted for the telephone interview. Participants who were invited for an interview were selected based on treatment stage, cancer diagnosis, age, Body Mass Index status and qualifications, with a view of obtaining a diverse sample. Attention was also drawn to particular characteristics of participants, such as following a specific dietary pattern (e.g. vegan diet), identifying as from an Ethnic Minority Group and having or having had temporary ostomy. Twenty-eight participants agreed to take part (62%). Each participant was allocated a pseudonym. Interviews were conducted between December 2017 and January 2019. Interviews lasted between 19 and 74 minutes, with an average of 36 minutes of recorded material per interview.

Data saturation was achieved after 26 interviews. Two additional interviews were conducted after data saturation was perceived to have been achieved as the PI felt that the unique characteristics of the study participants were worth exploring. One of them was conducted with a gynaecological cancer on-treatment survivor; this was the only interview with a gynaecological cancer on-treatment survivor. The last interview was with a rectal cancer on-treatment survivor with a temporary stoma bag, as it was important to capture their dietary adjustments and experiences of nutritional support in relation to having a stoma bag. No new information emerged from the last two interviews.

The characteristics of the interviewees are presented in Table 1. Thirteen participants from the on-treatment group and 15 from the post-treatment group were interviewed. Thirteen participants had a prostate cancer diagnosis (46%), eight had rectal cancer (29%), two anal cancer (8%), three endometrial cancer (11%) and two cervical cancer (7%). Age range was 52 – 80 years. The majority of participants had a Body Mass Index over 25 kg/m^2 (29% classified as overweight and 36% as obese) and eight participants (29%) had a University degree. Although attempts were made, it was not possible to conduct interviews with people diagnosed with bladder cancer or some of the more rare gynaecological cancers. Contact details were provided by a few participants from these patient groups (three with bladder, two with vaginal and two with vulvar cancer), however when contacted to take part in a telephone interview they were no longer interested.

5.3. Identifying the themes

Thematic analysis using the Framework approach was used. As described by Braun and Clarke (2006) and Gale et al. (2013), transcription and familiarisation of the data took place first. Initial coding was performed on five interviews and an initial analytical framework was applied to the remaining 23 interviews. Identification of new codes led to further reviewing and applying the analytical framework to the interviews. The Framework matrix was used to organise the data by cases (rows) and codes (columns) and was a useful tool in reviewing, refining and naming the themes.

Table 5.1: Characteristics of the participants who took part in a telephone interview (n=28).

Pseudonym	Cancer diagnosis	Treatment status	Age (years)	BMI status (1)	Qualifications
Thomas	Prostate	On-treatment	72	Obese	Postgraduate degree
Oscar	Prostate	On-treatment	80	Underweight	University degree
Ethan	Prostate	On-treatment	68	Normal weight	University degree
Theodore	Prostate	On-treatment	70	Overweight	Postgraduate degree
Joshua	Prostate	On-treatment	74	Overweight	O level
Benjamin	Prostate	On-treatment	72	Obese	NS
Logan	Prostate	On-treatment	62	Obese	A level
Dylan	Prostate	On-treatment	78	Normal weight	NS
Gabriel	Prostate	On-treatment	55	Obese	A level
Caleb	Prostate	Post-treatment	64	Overweight	Professional qualification
Aaron	Prostate	Post-treatment	69	Obese	NS
Toby	Prostate	Post-treatment	67	Obese	NS
Stanley	Prostate	Post-treatment	70	Overweight	O level
Sophia	Rectal	On-treatment	78	Obese	None
Grace	Rectal	On-treatment	69	Normal weight	NS
Tyler	Rectal	On-treatment	68	Normal weight	O level
Lillian	Rectal	Post-treatment	52	Normal weight	University degree
Dexter	Rectal	Post-treatment	55	Normal weight	A level
Zoey	Rectal	Post-treatment	56	Obese	O level
Isaac	Rectal	Post-treatment	74	Overweight	Professional qualification
Frederic	Rectal	Post-treatment	55	Normal weight	A level
Ellie	Anal	Post-treatment	56	Obese	O level
Blake	Anal	Post-treatment	57	Overweight	Professional qualification
Claire	Cervical	Post-treatment	74	Overweight	O level
Eleanor	Cervical	Post-treatment	65	Normal weight	Postgraduate degree
Penelope	Endometrial	On-treatment	56	Normal weight	University degree
Chloe	Endometrial	Post-treatment	72	Overweight	A level
Scarlett	Endometrial	Post-treatment	62	Obese	University degree

(1) BMI: Body Mass Index. Body Mass Index status calculated from self-reported height and weight from participants' surveys. BMI=weight in kg / (height in m)^2. Classified as underweight (BMI <18.5 kg/m^2); Normal weight (18.5 kg/m^2<BMI<24.9 kg/m^2); Overweight (25.0 kg/m^2<BMI<29.9 kg/m^2); Obese (BMI>30 kg/m^2). NS: Not Stated.

Analysis led to the identification of a number of themes and sub-themes which mapped to the overarching theme “Managing diet and lifestyle post-diagnosis” (see Fig. 5.1). The themes are: “Impact of diagnosis and treatments on dietary choices”, “Personal resources”, “Social resources”, “Comorbidities and disabilities”, “Influence of work”, “Regaining normality” and “Barriers to dietary changes”.

5.4. Theme 1: Impact of diagnosis and treatments on dietary choices

Participants described dietary changes after cancer diagnosis in two ways: as a response to treatment-related effects and seeing the diagnosis as a “trigger” to consider and implement healthy eating habits.

5.4.1. Subtheme 1: Managing altered gastrointestinal function

Participants referred to gastrointestinal side effects, such as diarrhoea, flatulence and bloating, affecting aspects of their daily life. Gastrointestinal problems were particularly reported by people with a lower GI cancer diagnosis (rectum or anus). Participants in the post-treatment phase also described experiences of gastrointestinal side effects, indicating persistence of these problems up to at least 24 months post radiotherapy completion. Alteration of the amount of fibre in diet, reduction of foods that cause bloating (e.g. onions, pulses) and avoiding spicy food were some of the techniques participants used to overcome gastrointestinal problems.

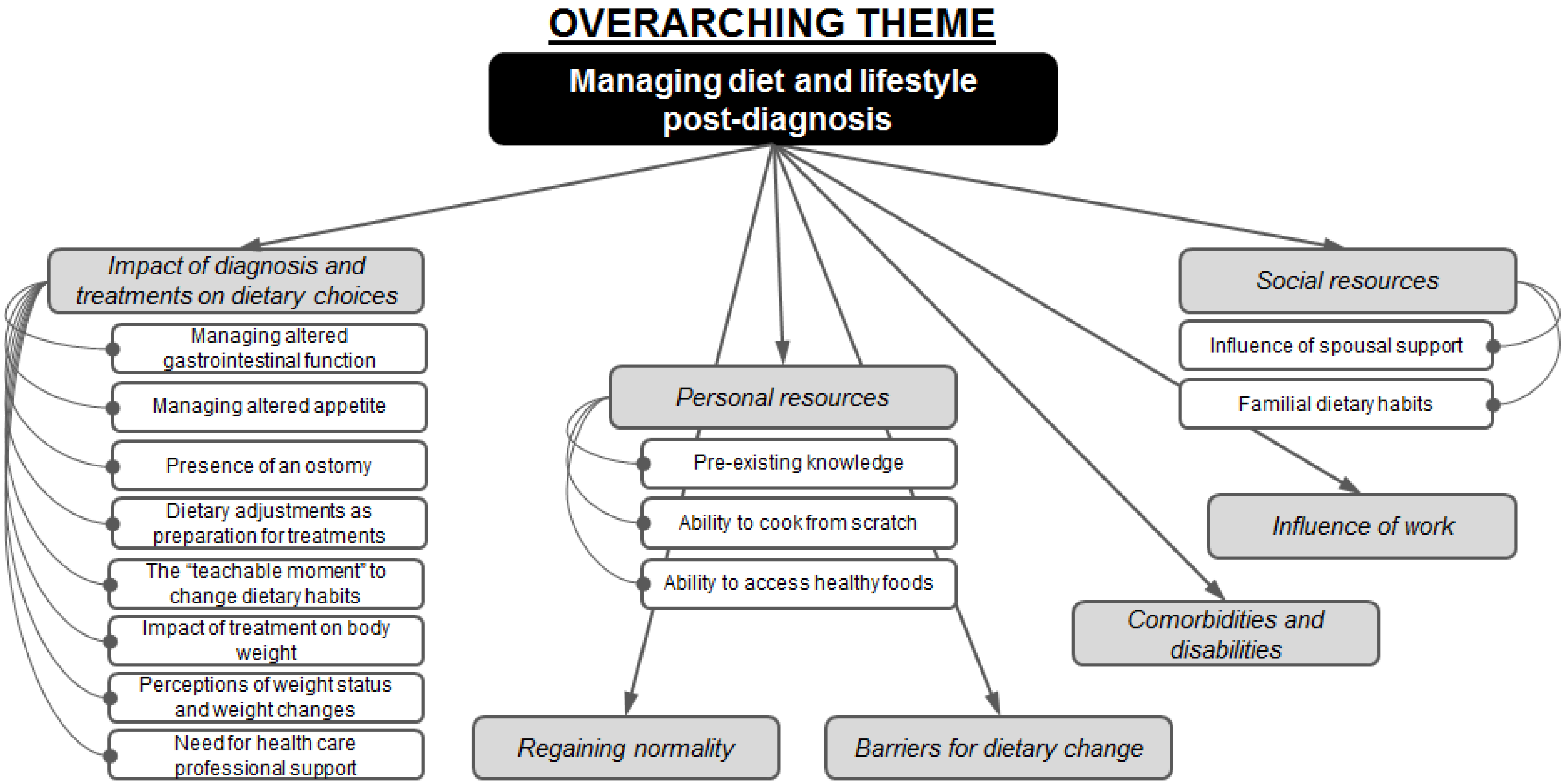


Figure 5.1: Overarching theme (in black box), themes (grey boxes) and subthemes (white boxes).

"I stopped having an Indian meal… during treatment. The spices nearly gave me… the spices gave me diarrhoea for 24 hours. The one time I tried … I used to eat an Indian meal now and again as one of my evening meals. I did it by mistake probably, not by mistake but not thinking while I was being treated and the result of diarrhoea because of the irritation of bowel was awful. So I haven't had one of those since." (Theodore, prostate cancer)

Provision of advice on how to manage gastrointestinal issues was reported by only a few participants, mainly in writing. Information and support influenced people to modify their diet and alleviate side effects.

"I have had less vegetables and less beans and less onions, due to being told that they increase the level of flatulence that was happening post-surgery and through radiotherapy." (Gabriel, prostate cancer)

Other participants did not find written information particularly helpful. People who did not recall receiving any guidance described a *"trial and error"* approach to identify which foods had a negative impact on their gastrointestinal function.

"It contained information like: if you get bladder problems avoid coffee, alcohol, tea and things that would irritate… yeah that was one of the leaflets. The leaflet is called "Managing bladder problems during radiotherapy: Information for patients". […] Nothing specific, not… you know… just this is a list of drinks that you'll find with water and this is a list that can irritate you." (Theodore, prostate cancer)

"*I don't think anybody has spoken to me, you know, through the time about my diet or anything. I've just … they've just asked questions about what I've been eating, but I don't think I really had any help. I've just done it myself and you know, magazines, and I've* *picked up "Eating for cancer" (leaflet) in the hospital. Yeah, so I'm just doing it by trial and error myself".* (Grace, rectal cancer)

5.4.2. Subtheme 2: Managing altered appetite

A few participants currently receiving treatment experienced taste changes and altered appetite. One post-treatment participant also described altered taste currently affecting them. Other post-treatment participants, who mentioned appetite loss and taste changes during treatment, no longer had these symptoms. All participants who described taste changes and loss of appetite received chemotherapy as part of their treatment.

"And also food doesn't taste quite the same as it did. It's quite strong foods I can taste and others I can't really taste the same anymore. An example I can really give you is, you know, curry has quite a strong taste, so I can still taste that but some others are… yeah… not the same." (Frederick, rectal cancer; 11 months post-treatment and still experiences altered taste)

"Well I didn't have any desire to eat, I couldn't taste anything… food was a necessity, which, you know, I was being told I had to have, quite rightly, but I would have been quite happy not bothering" (Isaac, rectal cancer; post-treatment and does not experience appetite problems any more)

None of the participants recalled any dietary advice from health professionals with regards to appetite or taste changes. A few participants with a prostate cancer diagnosis currently receiving treatment mentioned increased appetite, which they attributed to the receipt of hormone treatment (along with radiotherapy). For example, Dylan experienced increased appetite but did not discuss this with a health professional: *"…the (hormone) treatment does seem to have made me put on weight but also it has given me more of an appetite."*

5.4.3. Subtheme 3: Impact of an ostomy

Three participants (one on-treatment, two post-treatment), all with a rectal cancer diagnosis, described the effect of having temporary or permanent ostomy on their diet. Tyler (rectal cancer) described how the foods he ate affected the output and the adjustments he made to make sure the ostomy hole was not blocked. He had to remove high fibrous foods, fruit and specific vegetables from his diet, such as onion, garlic, sweetcorn and peas, as these were not digested and increased the overall output in the ostomy bag. Stoma nurses offered the support he needed to control the stoma output and he was pleased with the guidance on low fibre diet, as he subsequently did not experience gastrointestinal problems.

> *"I basically kept it to whatever the professionals did tell me to do. [...] Basically whatever is in the booklets I got from the professionals is what I follow. That's my bible."*

Lillian (rectal cancer) recently had an ostomy reversal and described how it affected her diet: *"I don't eat breakfast but that is down to having had […] the (stoma) reversal. So I got into the habit of not having breakfast after the reversal so as not to kick the… the digestive process. […] I can't eat things like pulses, lentils, chickpeas; I can't eat any of those. Because my bowel is a bit sensitive really after (reversal) […] I would (avoid), you know, the usual things, broccoli, cauliflower; you know any of those types of vegetables."* All adjustments were made by herself and she did not receive any dietary advice after the reversal, which had a negative impact on her quality of life: "… *and then the stoma reversal I didn't get any support at all. I was really left on my own. […] And even when I rang the GP asking… I had two weeks of hell basically; I couldn't leave the house…"*

5.4.4. Subtheme 4: Dietary adjustments as preparation for treatments

Interviewees currently in receipt of radiotherapy mentioned dietary adjustments necessary for radiotherapy or other treatments. Guidance to avoid alcohol, caffeine and red meat and drink more water was provided by health professionals, to ensure that participants were well hydrated and side effects were minimised. Participants adhered to this guidance but some found it challenging to follow the recommendation to be well hydrated.

"So basically for a period of five weeks I cut out three things from my diet; alcohol, maybe apart from one or two occasions but pretty well cut out, alcohol; caffeine, so now I drink… I still like some tea but I drink decaffeinated tea, so caffeine; and also red meats. For a period of five weeks I didn't eat beef and lamb and pork." (Logan, prostate cancer)

"… because I've been having pelvic radiation, I have to drink a lot of fluids, to be very well hydrated […] I am not a very good drinker. Some people like to drink all the time. I am not one of them […] I used to drink quite a lot of sparkling water and even now I am struggling to drink." (Penelope, endometrial cancer)

5.4.5. Subtheme 5: The "teachable moment" to change dietary habits

Cancer diagnosis was a trigger for some participants to consider making dietary changes for future wellbeing. The level of reported changes varied from small changes in one dietary component to adopting a whole new approach towards diet and nutrition.

"I have changed slightly. We did use to base it on two ounces of meat, which is 56 grams of meat, but […] I cut it down to the safe, 45 to 50 grams. That's about the only change, so the same basics meals as before, but slightly smaller." (Thomas, prostate cancer)

“I'm more likely now to eat maybe more vegetables or more greens. […] …more fruit, less red meat, more white meat, more fish. So all of those things I now do as a matter of course” (Caleb, prostate cancer)

Some interviewees acknowledged the need to pay more attention to their diet as a result of diagnosis. Oscar (prostate cancer) took “*a lot more notice than I used to, to be perfectly honest. Before, frankly, I would eat anything that was there, pretty much, except for the things I don’t like*”. Diagnosis was a trigger for weight loss for another participant: *“"It is a wakeup call I suppose but that’s it basically. I do feel good, eating less and I am going to lose weight.”* (Benjamin, prostate cancer).

Several post-treatment and a few on-treatment participants (mainly those with a prostate cancer diagnosis) talked about healthy eating practices. These participants experienced fewer side effects from treatment, thus were able to implement healthy dietary practices rather than focussing on alleviation of symptoms. Reported dietary changes included reduced consumption of meat and processed meats, alcohol, salt, caffeine, ready meals and increased consumption of fruit, vegetables (especially tomatoes for survivors of a prostate cancer), fibre, fish, nuts and water. Some examples of dietary changes are presented below:

“I am drinking alcohol now but not at the level I drank before… I’ve kept off caffeine, I am still not… wherever I possibly can, not have caffeine. And as far as the red meat is concerned I probably don’t eat as much of that actually. I eat more white meat and vegetables. I also eat… also through this period I started to eat more fruit, as a matter of course drink more water as a matter of course and probably have more fish as well.” (Logan, prostate cancer)

"I don’t eat as much meat as I used to … probably one or two times a week I’ll eat meat. […] (Before diagnosis) I probably ate more meat so out of the seven meals of the week I

> *was probably eating… five or those would be meat where it's probably the opposite now."* (Dexter, rectal cancer)

A few participants described dietary changes to support recovery during and after treatment for cancer, such as using nutritional supplements (e.g. multivitamins), because "*the radiation process is poison of my body and I want to give my body as much support as I can … trying to rectify anything else it's been done over the past six months."* (Gabriel, prostate cancer). Lillian followed a vegetarian diet before cancer diagnosis and decided to add animal protein (but not red meat) in her diet after diagnosis to support recovery from the treatment.

Dietary change was not necessary for some participants, as they considered their previous dietary habits to be healthy and side effects either did not exist anymore or did not have a significant impact on their daily life.

> *I was lucky enough not to feel nausea or sick so I ate exactly the same whilst the treatment was going on, before, after and still now. Exactly the same"* (Claire, cervical cancer)

> *"I don't feel I had to adjust nutrition or eating or lifestyle too much."* (Ethan, prostate cancer)

Diagnosis prompted a few participants to consider further improvements in their diet, despite perceiving their diet to have been healthy prior to diagnosis: *"I would say I didn't eat extremely unhealthfully before […] ...we tend to eat a lot more chicken since I've had this problem and a lot more fish. So we have fish twice a week now."* (Caleb, prostate cancer)

Compared to dietary support for side effects, discussions with health professionals around a healthy diet and future health were more often reported. Guidance was provided mainly in written format, such as booklets available in the waiting room at the hospital or given by nurses and oncologists. Provision of such advice influenced dietary change for some participants but not those who perceived themselves to have had a healthy diet and lifestyle before diagnosis.

"It (the booklet) was telling me to stay away from processed meats which of course I did, it gave me advice on what were good vegetables to eat, which is why I started eating a lot more tomatoes, because that was my other thing, it was strongly recommended. I started eating more fruit as a recommendation." (Oscar, prostate cancer)

"I was given a dietary book by Macmillan, which kind of outlined things to avoid, if possible, and also things that they thought would benefit. Most of that is just healthy foods anyway, you know, keep away from fatty foods and things, which everything kind of fit it the way we live anyway, really." (Frederick, rectal cancer)

5.4.6. Subtheme 6: Impact of treatments on body weight

Most participants mentioned weight changes as a result of diagnosis and treatments. There was a mix of experiences, with some participants losing weight, others gaining weight and a few describing fluctuations over the period of diagnosis, treatment and survivorship. The effect of treatments on weight was expected by most participants. In some cases, changes were perceived as small, while others put on weight as an attempt to keep themselves strong during treatment and avoid weight loss. Health professionals had warned some of the participants about the potential to put on weight as a result of treatment.

"Yes, so… when I had the chemotherapy I put on weight because I think it was probably due to the steroids that they give you each time you have it, so obviously it's to stop the

reaction but it makes you hungry. So I did put on a bit of weight. About…I probably put on 3 kg. And then I lost that 3 kg. So since I've been on radiotherapy, I've lost 3 kg. Pretty much, I've lost what I've gained. So it's not got worse than that." (Penelope, endometrial cancer)

"I put weight on after diagnosis and during treatment, because I was eating what I could to try and keep myself strong, and at which point I added back in chicken… [...] Following the bowel surgery it was pretty normal really, but since having had the reversal, I'm probably down half a stone, which kind of fluctuates. But not much." (Lillian, rectal cancer)

Despite weight changes and the potential impact of treatment on weight, the advice from healthcare professionals was to keep stable body weight during radiotherapy, as it determined the amount of radiation. Some of them managed on their own to keep a stable body weight successfully. One participant had put on weight during treatment but the healthcare team were more concerned about weight loss, rather than weight gain.

"I was told I'd put two stone of weight on. I didn't, because I managed that myself. I was determined not to put weight on" (Oscar, prostate cancer)

"I gained weight during the chemotherapy and radiotherapy treatment for a year. Nearly a stone in weight, which they (the healthcare team) weren't concerned about because, you know, rather than losing weight, it was healthy. (Claire, cervical cancer)

5.4.7. Subtheme 7: Perceptions of weight status and weight changes

There were contrasting views in relation to the perception of weight status. Some participants correctly identified themselves as having excess weight and acknowledged weight problems. Other participants perceived their diet, fitness or weight to be good, but were classified as overweight or obese based on self-reported information on height and weight from the survey. One participant classified as “normal weight” based on Body Mass Index perceived they needed to lose weight: *“I’d like to be a bit lighter, if possible."* (Dylan, prostate cancer), whereas one participant classified as “overweight” perceived his weight to be within the normal range: *"I’ve never had a weight issue or a weight problem"* (Stanley, prostate cancer).

Emotions were expressed with regards to current weight status and body image by some participants, especially from the ones on post-treatment stage. Cancer diagnosis was a trigger to consider weight status and weight loss. One participant managed to lose weight and was feeling good about being able to do activities he was struggling with before and had a positive body image: *"I was getting down on the floor yesterday with my granddaughter and my aches… I didn’t ache the same. […] I wear a lot of T-shirts now and trousers and jeans fit a lot better”* (Benjamin, prostate cancer)

On the other hand, a few participants had put on weight since diagnosis and had a negative body image. *"… because I’ve given up smoking I’m always hungry. […] I don’t like it. […] I feel like I am trying to find a substitute. I know food is not the answer, because my clothes now don’t fit me”* (Ellie, anal cancer)

Scarlett (endometrial cancer) expressed concerns about current weight status, and feared that excess weight was related to the development of her cancer and was a reason for future cancer recurrence; therefore she needed to lose the excess weight but was unsure how. She also did not know what she was doing wrong and could not lose weight. She discussed weight problems with a nurse, who gave her a weight loss target but without guidance on how to achieve that.

> *"I think since I was diagnosed with the cancer that I worried it was because of weight around my tummy so I think… well, now I’ve had my treatment and I need to lose that (weight) otherwise it might come back. […] I think I am frightened if I don’t lose weight I*

sort of almost not deserve… but it may come back. And I think "Did I cause it, did I cause the cancer in the first place? […] It's got to be the quantity of cheese and biscuits or … I don't know. I don't know. That is my problem, I don't know" (Scarlett, endometrial cancer).

Cancer diagnosis had a significant emotional impact on some interviewees, which had a direct effect on their weight – either loss or gain.

"So when I was troubled with the cancer, obviously with all the worry and… I mean you wouldn't eat and whatever, and I went into hospital and had the operation and come out, and he then said you've got to put weight on [...] I went right down to about 100 kilos then" (Toby, prostate cancer)

"...there's been an increase in weight due to certain amount of lack of exercise, emotions and… what do they call it… comfort." (Gabriel, prostate cancer)

5.4.8. Subtheme 8: Need for health care professional support

Several participants mentioned that there had been no provision of advice or discussions with health professionals regarding any dietary issues they may have faced during and after treatment. As described above, issues were related to treatment side effects and weight management and lack of support proved challenging for some of them.

Ethan (prostate cancer) was surprised no discussions were made in relation to consumption of fruit and vegetables and weight management: *"I was surprised they didn't stress more the, sort of, benefits of, you know, the 5-a-day type of diet or diet to make sure you don't put more weight, well, you didn't put on more weight."*

Dexter (rectal cancer) had discussions with the stoma nurses but perceived the advice unsuitable for his individual needs: "*I think, from a NHS point of view I don't think they are really giving detailed dietary or nutritional information, well certainly for me they didn't."*

One participant actively sought support on nutritional practices to support recovery, such as the use of nutritional supplements: *"So I said to him (the consultant): "So, since I'm going to have this treatment, as well as getting ready mentally, from a nutrition point of view what should I be doing to get ready for it? Should I be enhancing my body with Vitamin C or should I be eating seaweed or anything like that?" […] And generally most of the answers I got back were that I didn't need to do anything […] …if they say there is nothing you can do, I have to accept that. It is pointless; there is nothing I can do."* (Gabriel, prostate cancer)

Participants were generally interested in learning more about diet in relation to the management of side effects. Health professionals were considered the most credible sources of information. *"I think it perhaps would be nice, sort of while you're there, perhaps have a quarter of an hour with somebody, it would be quite… […] You know, with the bowel not working as it used to be… how to, sort of, work things out, might be helpful. So something like that would give you some guidance."* (Grace, rectal cancer). Grace continued saying that she acknowledged how challenging it is to provide dietary advice given that each individual may experience different treatment side effects.

> *"I mean, again, it is individuals I think because at the hospital we were all having different types of treatment. Some were having the chemo tablets, some weren't. So I realise it's sort of difficult for people to, you know… If you generalise things, that's not helping, is it?"*

Post-treatment participants would also welcome guidance on weight loss and regular monitoring would act as a trigger for change.

"I would like perhaps to go to a proper diet regime because I would like to lose some weight. So if they do a proper diet… whether they could give me any information on that." (Aaron, prostate cancer)

"I need to motivate myself better to actually do it. […] I do feel that if somebody gave me a target as such that I could […] if someone else said it, I am more likely to go for it and try it, yeah. Yeah, because I feel I am letting them down if I haven't got some weight loss next time. So I think that will help." (Scarlett, endometrial cancer)

Some participants looked for information about diet on the internet or the media. There were mixed reactions with the information they read; some information was useful, some was conflicting. Credible online sources, such as charity websites, were preferred.

"A lot of stuff on the internet you can't believe […] they contradict each other." (Toby, prostate cancer)

Zoey (rectal cancer) had received conflicting information from different sources (media, newspapers, health professionals) and she expressed scepticism on which source was more reliable.

"You speak to one person and then another person says something else. You watch the telly and that will say something completely different. Or you look at a newspaper or a magazine or something and it will say something different again. I just don't know who would be the most reliable source."

5.5. Theme 2: Personal resources

This theme describes participants' level of knowledge regarding diet and nutrition and how they applied this knowledge in living with and beyond cancer. It also highlights how personal interest in diet, awareness of research, health literacy and ability to cook and access healthy foods affected their dietary choices post-diagnosis.

5.5.1. Subtheme 1: Pre-existing knowledge

Most participants showed high awareness of a healthy diet by giving examples of healthy or less healthy foods and dietary practices. Participants' views of a healthy diet were largely in agreement with dietary recommendations available from Public Health England (Eatwell Guide) (Public Health England, 2016) or the WCRF (World Cancer Research Fund/American Institute for Cancer Research, 2018). Some participants emphasised portion control, reading food labels and watching the caloric content of foods as a means of maintaining a healthy diet, indicating personal interest in diet. One participant described how they preferred to consume vegetables over fruit because of the increased natural sugar content of fruit: *"Eating vegetables. And fruit, but mainly vegetables, because fruit obviously have their natural sugars"* (Claire, cervical cancer).

In the case of Dexter (rectal cancer), perceived benefit of a high fibre diet led him to reject the nurse's advice for a low fibre diet as a way for controlling stoma output; he considered the dietary approach *"bland"* and lacking in nutrients. He would rather experience increased output than losing the health benefits of a high fibre diet.

Participants' level of knowledge on diet and nutrition was shaped from past experiences. Some participants, who acknowledged the importance of keeping a healthy weight after diagnosis, had attempted weight loss in the past. Others had worked in health-related environments (e.g. as a nurse or at the Department of Health) and were familiar with what constitutes a healthy diet.

“I’ve got a nursing background so I am fairly au fait with dietary requirements and calories, amounts and, you know, what people need when they’re ill, what people need when they are inactive and that sort of thing” (Penelope, endometrial cancer)

5.5.2. Subtheme 2: Ability to cook

Most participants were able to cook or shared cooking responsibilities with the spouses: *"I always make my food*” (Claire, cervical cancer). Cooking from scratch using fresh ingredients was a habit before diagnosis for several participants and was considered part of having a healthy lifestyle.

Other participants did not have the ability to cook or were not interested in preparing meals. Zoey (rectal cancer) reported mobility problems and found it difficult to stand for long in the kitchen and prepare a meal from scratch. She described how she made quick and (perceived as) healthy meals: *"I’ve just put the cooker on for some… we call it a mince mess, but it is beef mince, a low fat beef mince with vegetables, tomatoes and sauce and … just a mess, I always call it a mess. I tend to use sauces rather than cooking from scratch for things like curries and stews and things like that."* She understood that ready-made sauces were classified as processed food but she felt there was nothing else she could do given the circumstances. *"...the only I have processed really is the ready-made sauces and if I don’t have that in my life then we won’t live, because that’s the easiest thing for me to use."*

5.5.3. Subtheme 3: Ability to access healthy foods

A number of participants had access to and could afford to buy higher quality food. A few bought foods from local markets and some bought organic food as they believed it was better quality. Others bought foods from supermarkets and they often mentioned

“Waitrose” and “Marks and Spencer”, which they would trust because of (what was perceived as) higher quality food.

"… where we live, a lot of my stuff is bought in either M&S or Waitrose, cause I trust them" (Lillian, rectal cancer)

"Quite close to where I’m living there is a place, [...] which is a small-ish farm and they just grow organic food. And we have a market not far away and we go to the market and there are lots … some people that grow their own foods and things and bringing them to sell.” (Dylan, prostate cancer)

Four participants had allotments where they grew their own fruit and vegetables. They commented on the superior quality of the foods they produced and on the fact that gardening contributed to their physical activity levels.

“I am a keen gardener and I have at least one allotment and I was always very conscious on how fresh fruit tasted so much better and I am sure the way I was going… it was a nutritionally higher content, you know.” (Ethan, prostate cancer)

“I have an allotment, so I have plenty of vegetables and I always have two or three vegetables and some meat […]… gardening and allotment keeps you fit” (Claire, cervical cancer)

On the other hand, a few participants acknowledged that finances restricted their choices for healthy food: *“...because we are pensioners and we can’t, we can’t always buy what we want to buy. We have to buy what we can afford. So we are very careful about everything really, we try to be.”* (Sophia, rectal cancer)

5.6. Theme 3: Social resources

This theme describes the influence of family in participants' diet and highlights the role of the spouse in preparing food and caring for the patient.

5.6.1. Subtheme 1: Spousal support

Participants described how their spouse was often in charge of preparing food for the household. Male participants more often mentioned having meals prepared by their spouses than female participants, who were usually in charge of preparing food for the household, but this was often a shared task. On several occasions, participants used the pronoun "we" instead of "I" when referring to dietary habits, cooking and shopping practices.

Spouses had a significant role in actively supporting nutritional needs of participants during and after treatment, through preparation of meals. Factors that influenced quality of meals were appetite problems during treatment and a drive towards a healthy diet and lifestyle post-treatment.

> *"...and I had people here that would make sure I ate. […] "My wife, you know, was trying to make it interesting for me and came up with various ideas. So I was blessed with a lot of help."* (Isaac, rectal cancer)

> *"She has changed the types of food that we eat, so she has deliberately gone out and we eat more fresh fish and we do eat less red meat now so… and, you know, we do have more vegetables… [...] So she has changed the diet actually, she has changed the types of things that we eat now, so … [...] And it is because of, the typical family meals changed somewhat."* (Logan, prostate cancer)

People who were living alone or without a spouse shared experiences of support from their children or other family members. Children had an important role in supporting participants to recover during and after treatment.

> *"...she shops with me and she makes sure, well she makes sure, she advises me on things not to eat and what I should eat because obviously I live by myself."* (Oscar, prostate cancer)

> *"My daughter bought me some Complan (energy supplement) because I couldn't face food. That obviously helped to keep me going"* (Chloe, endometrial cancer)

5.6.2. Subtheme 2: Familial dietary habits

Dietary habits of family members sometimes influenced participants' dietary habits, especially if participants had their meals prepared for them. For some participants, family meals were more important than their individual needs or preferences.

> *"I would like to eat a lot more fish, but the rest of my family generally don't want to eat fish. So on occasion we can have some fish but it is not a regular thing that will be tolerated as a meal. […] There has to be some amount of consensus, because it's pointless to cook a meal that no one's going to eat."* (Gabriel, prostate cancer)

> *"Obviously we try to eat together if we all cook so I wouldn't want us to spoil it for anybody else, you know, so I am quite happy to, sort of… if it is a little bit bland then I just soak it up with it really. I don't necessarily change anything."* (Frederick, rectal cancer)

Spousal dietary habits also influenced participants to adopt a healthier diet.

"But we do try to eat as healthily as we can because she likes to keep count of her weight obviously. So she eats lots of vegetables and consequently I do as well" (Stanley, prostate cancer).

5.7. Theme 4: Comorbidities and disabilities

In some cases, additional comorbidities and/or disabilities affected the diet or lifestyle of participants. Toby (prostate cancer), diagnosed with gout in the past and recently diagnosed with diabetes, described dietary adjustments over time. *"I have cut out all sugars before that (diabetes) because I had gout and I looked into it and red meat and sugar and stuff like that are all uric acid, is what builds it up. So I cut out all sugar, I mean ages before that, but I still got it (diabetes)."*

Stanley perceived that the recent diagnosis of coeliac disease affected his diet more directly than the cancer diagnosis: *"I'm sure they (the general practitioner) will come up with a coeliac plan or coeliac diet sheet of some sort telling me what I can and can't eat because it's directly attributed to diet isn't it… obviously the coeliac disease. Whereas the cancer, the prostate cancer, isn't directly, you know… connected to the diet."*

Zoey also mentioned suffering from depression which had affected her desire to eat well. *"Because I am stuck in the house all the time, I suffer with depression and if I have a bad diet, I just don't bother at all."*

Benjamin's diagnosis of psoriatic arthritis further affected his ability to exercise (apart from fatigue as a treatment side effect for prostate cancer): *I can't do them (exercises) heavy because of my shoulders and the arthritis, which is always there"*

5.8. Theme 5: Influence of work

Several participants were currently working and described how work or travelling to work impacted on their food choices.

"… A light, very light breakfast, for lunch probably a sandwich, some fruit and a cold drink. I work in London so I travel, I get home quite late so my eating meal would be around 8 o'clock " (Logan, prostate cancer)

Most of them, were trying to choose healthier options whilst travelling and managed effectively to combine travelling and work commitments with any effects the cancer diagnosis had on their diet. Ellie (anal cancer), however, started attending a weight loss group but had to stop because of starting her new job. *"So I went to the first one [...] and then unfortunately I started my new job. So I couldn't attend because I had to work in the evenings".* She had not managed to join another weight loss group.

5.9. Theme 6: Regaining normality

In this theme, participants described aspects of their lifestyle that provided them with a sense of "regaining normality", that is getting back to how life was before diagnosis.

The idea of *"going about my daily life unhindered by physical constraints"* was often expressed as an important need to maintain normality in daily life. Although the interview questions focussed on diet, several participants, especially survivors of a prostate cancer, linked normality with mobility, activity, and the ability to do everyday activities and keeping fit. People who experienced fatigue as a treatment side effect highlighted the negative effect of fatigue on the ability to deal with daily activities and carry on with life.

"I was quite lucky until about the fourth week and started getting tired and, uhm, when everything went wrong… I was so tired all the time, I just didn't… I just couldn't care less.

It was a horrible way to be for a while and I am coming down now of that now." (Sophia, rectal cancer)

For some respondents, diet was not seen as the sole lifestyle factor to address after diagnosis, but exercise was also fundamental to regaining normality. These participants often referred to diet as an adjunct to keeping fit, active and healthy and perceived diet as a means to provide the energy in order to keep being active.

"I presume you've got to support that (being active), you know, (diet) to be appropriate for how you're trying to live." (Thomas, prostate cancer)

A few interviewees gave examples of activities that kept them currently fit and healthy. Activities included regular exercise, walking, gardening and having a strenuous job, all of which were activities they were doing before diagnosis.

"But keeping healthy is also to do with activity levels as much as… you are what you eat but also what you do. And I am very active. So it is in some way fuel, you know, if… I tend to my normal day; I walk the dog twice a day, so that's probably up to five miles, four or five miles walking." (Penelope, endometrial cancer)

Others were referring to a combination of exercise and a healthy diet to maintain current health. They also gave examples of specific aspects of diet that would help them keep healthy, such as consumption of fruit and vegetables, portion sizes, having variety in their diet and eating in moderation.

"So that combination for me of exercise and eating well with vegetables and all the good things for you is, is something that I see now is a healthy living style." (Caleb, prostate cancer)

"…eating a good diet with plenty of vegetables and fruit and having as much exercise as you can." (Claire, cervical cancer)

Several participants had a more holistic view of their health and their perceptions of keeping healthy included not only diet and physical activity, but also avoiding alcohol consumption and smoking and maintaining a healthy weight.

"…*exercising regularly, eating a balanced diet and by that, I mean the types of foods I'd described, no smoking and having either zero or low alcohol intake"* (Dexter, rectal cancer)

5.10. Theme 7: Barriers for dietary change

Participants' knowledge of what constitutes a healthy diet was frequently reflected in their dietary habits. However, low motivation and lack of interest in the area of diet and nutrition were barriers to dietary changes. Some participants acknowledged dietary and lifestyle habits that were less healthy but they did not intend to change their habits.

"I am not particularly interested in food. I think if I was… I used to like cooking and now I've just… I am not bothered if I do it or not." (Scarlett, endometrial cancer)

"I do drink alcohol and I would think I probably drink more than… well, not probably, I am sure I drink more than it is good to drink but… […] I've got used to it; it has become some sort of a habit or a ritual" (Dylan, prostate cancer)

In addition, participants with high levels of awareness of the role of diet in health and higher educational background (university or postgraduate degree, as stated in the survey) sometimes expressed scepticism about the importance of diet in survivorship.

They referred to *“research”*, lack of *“evidence”*, *“probability”* and *“likelihood”*, in their accounts.

> *“I am not convinced that… as long as I eat a reasonably healthy diet, a reasonably balanced, let me not use the word healthy, a reasonably balanced diet and take enough exercise to keep me vaguely fit, um… I’ll be fine. And if they won’t move from that situation then you need to provide me evidence.[…] The lifestyle influence on prostate cancer appears to be fairly small, concerning the evidence."* (Theodore, prostate cancer)

> *"I am not aware of any foods that can stop me of recurrence of the cancer or particularly that can help me if I do get it.”* (Chloe, endometrial cancer)

Many of these participants perceived themselves to have led a healthy lifestyle before diagnosis and there was nothing more to do to have a healthier life from now on. Others believed that diet and lifestyle were unrelated to the development of cancer; therefore no further action was required in the survivorship stage. Instead, participants stated that other factors, such as genetics, gut microbiota and hormone imbalance influenced cancer development.

> *"I can’t quite get my head around the fact that it is supposed to be all because of food. I think it is much worse in the world going on, that we could be just as capable of getting cancer from as anything else. And I don’t think this was relevant to my cancer."* (Sophia, rectal cancer)

> *“And I have the sneaking suspicion that, actually, we are very ignorant about what actually causes overweight. […] I noticed there was a report the other week by somebody saying that the gut microflora are incredibly important and the British people, as it happens, are not very best in this respect, compared with the microflora of, for instance, Mediterranean*

> *people. […] Likewise, there are all these hormone balance things which seem to come up…"* (Thomas, prostate cancer)

People with high awareness of a healthy lifestyle and perceived healthy lifestyle prior to diagnosis requested evidence based nutritional information in order to be persuaded for dietary change.

> *"Up to that point, I would consider that my diet was pretty healthy. But I still got the cancer. […] It would take me a bit of convincing, because I, you know, I'm surprised"* (Ellie, anal cancer)

In relation to supplement use, a few participants believed supplements were not needed as they were getting all necessary nutrients from their diet and expressed scepticism on their effectiveness. Supplements were considered necessary only when consumed for health-related reasons, such as anaemia or arthritis.

> *"They are a brilliant marketing tool for taking money off from people.[…] I have seen no consistent long-term evidence that any of the supplements do any good whatsoever as long as you eat a balanced diet".* (Theodore, prostate cancer)

5.11. Analysis of survey free-text comments

At the end of the final section of the questionnaire, participants were invited to add comments on any issues about their diet that they think might be important. Seventeen on-treatment and 63 post-treatment participants added free-text comments. Thematic analysis identified two themes that were similar to themes and subthemes found in the qualitative analysis of the interviews: "Self-management of dietary problems after diagnosis” and “perception of a healthy diet prior to diagnosis”. Findings from the free-text comments, which come from a much larger sample of participants, supplement and enhance the findings from the interviews.

5.11.1. Self-management of dietary problems after diagnosis

Several participants described their experiences and self-management techniques in relation to diet after the cancer diagnosis. Diet had been affected by treatments, as well as the presence of comorbidities that had been developed prior or after the cancer diagnosis. In both situations, participants had adjusted their diet in order to support recovery and manage side effects. Sometimes, dietary adjustments were a result of support from the healthcare team.

“I found it very difficult to eat a very low fibre diet but it was a necessity.” (rectal cancer, post-treatment)

“During treatment my taste was affected but I was determined to stay fit so limited my diet in foods which didn’t give me a nauseous experience i.e. porridge every morning. […] After treatment finished, I began to ring the changes, but found chocolate, muesli, dried fruit and lettuce cause repeated loose stools. White toast moves reluctant stools. While travelling for five weeks, I was especially careful avoiding highly spiced foods and rich sauces” (anal cancer; post-treatment)

“I have been able to maintain necessary weight loss through increased exercise and portion control.” (endometrial cancer, post-treatment)

Some participants described weight changes and how they managed to control their weight during and after treatment. Others lost weight to improve health post-treatment:

"It took a great effort and a strict 5:2 diet to get my weight and waist size back to where I was." (prostate cancer, post-treatment)

After treatment I chose to join Slimming World to lose weight. (rectal cancer, post-treatment)

5.11.2. Perception of a healthy diet prior to diagnosis

Several participants perceived their diet to be healthy before diagnosis and that it continued to be healthy at present. These participants were more likely to report no dietary changes after diagnosis in the questionnaire (Question C1: Have you changed your diet since diagnosis?). They described current dietary habits, such as high consumption of fruit and vegetables and reduced consumption of red meat, which indicated high awareness of what constitutes a healthy diet.

"We eat fruit and vegetables (green, root & potatoes) regularly also meat occasionally. We rarely indulge in pre-prepared meals and currently I only drink alcohol at weekends (Friday and Saturday)" (prostate cancer, on-treatment)

My diet has not changed significantly since diagnosis or therapy. We have always taken care with the known problems – high fat/sugars/alcohol etc. and tried to eat modestly with a balanced diet. (prostate cancer, post-treatment)

I was healthy and eating sensibly before diagnosis and now again. (anal cancer, post-treatment)

Some participants described a more holistic approach to the role of lifestyle after cancer diagnosis:

“Tend to eat healthy foods, home cooked. Don’t drink or smoke. Eat lots of fruit & veg. Try to walk a couple miles per day, weather permitting.” (prostate cancer, on-treatment)

Chapter 6. Integration of findings

6.1. Summary

In this chapter the quantitative findings from the survey and the qualitative findings from the telephone interviews are integrated. Data are integrated through triangulation and presented using a narrative approach (as described in Chapter 3). Data are presented in five sections, according to the study's objectives and to significant findings from the independent analysis of the quantitative and the qualitative arm of the study.

6.2. Structure of integrated findings

For the integration of the results, the study's objectives were taken into account:

- Dietary changes following diagnosis
- Assessment of awareness of and attitudes towards of nutritional recommendations
- Receipt of information support from health professionals or other sources on diet and nutrition.

Significant findings from the survey are listed below and were used for the structure of the integrated findings:

- The association between dietary change and receipt of support
- Increased awareness of dietary recommendations
- Varied attitudes towards the importance of diet and nutrition in the survivorship phase
- Lack of routine support and provision of information from health professionals
- Low use of other sources of support

Independent qualitative analysis of interviews confirmed the above topics and revealed additional important topics:

- Concerns about weight

- Importance of family support through the cancer journey in relation to diet and nutrition.
- Importance of regaining normality

6.3. The association between dietary change and provision of information and support

The survey results showed that 68% of the respondents changed at least one component in their diet after cancer diagnosis. Most of the changes were towards healthy eating recommendations, such as increasing intake of fruit, vegetables and wholegrains and reducing alcohol, sugary foods and processed food. Some respondents changed their diet in the other direction by reducing wholegrains (13%) and fruit (10%) and increasing refined grains (10%). Significant differences were shown between on-treatment and post-treatment respondents in relation to consumption of refined grains and alcohol. On-treatment participants reported increasing consumption of refined grains and decreasing consumption of alcohol compared to post-treatment participants. Also, there were differences among cancer diagnoses in relation to wholegrain intake as more participants of lower GI or a gynaecological cancer reduced wholegrain intake compared to urological cancer participants. Changes were implemented mainly to maintain general health (58%), alleviate treatment side effects (45%) and support recovery (41%). More people on treatment reported changing their diet to assist with treatment side effects and to support therapy and recovery ($P<0.01$) compared to the post-treatment group.

Qualitative findings enhance the survey findings and provide more details of dietary changes as a means of alleviating treatment side effects and improving overall health. The theme “Impact of diagnosis and treatments on dietary choices” describes these dietary changes. Presence and severity of side effects varied, with gastrointestinal problems and appetite loss being reported particularly by lower GI and gynaecological cancer survivors, and fatigue by prostate cancer survivors. In the survey, loss of appetite, taste changes and nausea were reported significantly more often by survivors of a lower GI or gynaecological cancer ($P<0.01$) compared to urological cancer respondents. Interviewees gave rich descriptions of the ways they managed gastrointestinal side effects, which included alteration of the amount of fibre in their diet (some increased and some decreased fibre intake and related foods), reduction of foods that caused bloating, and avoiding spices. Rectal cancer patients with a permanent or temporary ostomy were more careful with their dietary choices and adjustments, to ensure that output was controlled.

Dietary change was not associated with the presence of side effects in logistic regression analysis. Participants who reported at least one side effect were more likely to consume a dietary supplement as part of their diet (OR: 2.46, 95% CI: 1.01-6.02). Results from interviews showed that very few participants consumed supplements, mainly for other health reasons or comorbidities (vitamin B12 and glucosamine sulfate), rather than the alleviation of side effects.

For some participants, cancer diagnosis was also seen as a trigger or a “teachable moment” to take more care of their diet and health. This was particularly mentioned in the interviews by people on the post-treatment phase and among prostate cancer interviewees who experienced fewer side effects. Dietary changes included reduced consumption of meat and processed meats, alcohol, salt, caffeine, ready meals and increased consumption of fruit, vegetables (especially tomatoes for survivors of a prostate cancer), fibre, fish, nuts and water.

On the other hand, 32% of the survey participants did not report any dietary changes following diagnosis. Also, when assessing dietary changes per food group, it was shown that 49% to 76% of participants reported no change in specific food groups. Qualitative findings revealed that some participants felt no changes were necessary, as previous habits were – subjectively – considered good, and presence of side effects did not have a significant impact on their daily life. Even for participants who reported a change in their diet, qualitative findings showed that most of them perceived themselves to have already had a healthy diet and lifestyle overall. Others were not interested in diet and nutrition, despite acknowledging that further improvements could be made in their diet. In the survey, a small percentage (3%) of respondents who did not have discussions with health professionals were not interested in discussing diet and nutrition because they perceived the topic to be unimportant. Also, 14% of participants were not interested at all in receiving additional information about diet and nutrition. Other barriers for dietary change included scepticism of the role of diet post-diagnosis, low motivation and perceived lack of link between diet, nutrition and cancer.

Dietary change was significantly associated with receipt of dietary information and support from the healthcare team (OR: 3.63, 95% CI: 1.82-7.23); however, support was not routinely provided; only 43% of the survey respondents received information. Information was mainly about general healthy eating and less about alleviation of treatment side effects. Findings from interviews further emphasised the lack of routine support and revealed a mix of views and emotions with regards to the quality of the information provided. More interviewees described discussions around general healthy eating and very few reported discussions related to treatment side effects. For some, lack of advice about gastrointestinal problems was a negative and stressful experience.

Most participants who received nutritional support perceived their needs to be well met (77%) and information easy to follow (76%). The rest of the participants either had neutral responses or negative experiences. Provision of support influenced 67% (73/108) to change their diet. Responses from interviews were mixed in this aspect. For example, some participants had a very positive experience of dietary support from the health professionals but other participants considered support inadequate. Support was mainly provided in writing/paper format from cancer specialist nurses and fewer reported face-to-face discussions.

People who did not recall receiving dietary support (57%) would like to have had discussions about topics such as management of side effects, weight management and general healthy eating. This is also depicted in the overall high interest in getting more information about diet and nutrition (68% were moderately to extremely interested). Provision of support in a paper format was preferred by most, and at any time after diagnosis. Interviews also revealed high interest for information and for face-to-face discussions with a health professional. People who were interested in weight management also expressed a request for regular monitoring.

Fewer respondents looked for dietary information in other sources and those who did mainly sought information from cancer charities websites or medical websites. People who looked for information from other sources were more likely to have also received support from health professionals (OR 2.17, 95% CI: 1.07-4.40) and to have changed their diet (OR 3.76, 95% CI: 1.67-8.47). Interviewees also expressed preference for credible online sources, such as the Macmillan website. Experiences of support from other sources were mixed, with several interviewees showing mistrust in online sources. Survey results showed that only about half of the people who sought information from other sources were satisfied with it.

6.4. Weight problems

Based on self-reported height and weight and calculation of Body Mass Index (BMI), 36% of the participants were classified as overweight and an additional 23% as obese. In total, 59% of the sample (n=147) had a BMI over 25kg/m^2. There was no difference in BMI status according to treatment status or among diagnoses.

A third of participants reported weight gain since diagnosis, 26% weight loss and for 39% weight did not change. Qualitative findings showed that some participants experienced fluctuations in their weight, from diagnosis through to survivorship. Concerns about current weight status and body image dissatisfaction were expressed by several interviewees. Some described their effort to lose weight, as they acknowledged weight problems. There were, however, others who perceived their weight to be within the normal range, although their calculated BMI was over 25kg/m^2 based on self-reported survey data.

Provision of advice and support in relation to weight management from health professionals was reported by only 17 participants in the survey, while 15 participants looked for such guidance in other sources (survey data). This corresponds to 16% of those who received support by health professionals and 19% of those who searched for information in other sources. Similarly, only a few interviewees mentioned discussions with health professionals in relation to weight.

6.5. Awareness of and attitudes towards diet and nutrition

Results from the survey showed overall high awareness of nutritional recommendations. Between 91% and 95% of participants were mostly or very familiar with the content of the WCRF (2007) recommendations for weight, high calorie foods, consumption of at least five fruit and vegetables per day and alcohol and supplement use. Lower levels of awareness were shown in relation to the recommendations on red and processed meat consumption (30% mostly and 42% very familiar) and salt intake (26% mostly and 57% very familiar).

Awareness of what constitutes a healthy diet was also evident during the interviews. The theme “Personal resources” described knowledge and attitudes towards the current and future role of diet and nutrition. Overall, participants were aware of different topics around diet and nutrition and how a healthy diet can assist in future health. Several participants also gave examples of dietary habits they considered healthy and they implemented in their daily life. However, not all of them practiced what they perceived was good for their health.

Participants generally believed diet and nutrition is an important aspect post-diagnosis. Diet and nutrition were perceived as important or very important by 74%, 94% and 87% of respondents in relation to reducing the chance of cancer recurrence, improving overall health and supporting recovery, respectively. Respondents were less confident about the role of diet in alleviating side effects. Diet and nutrition were perceived as important or very important by 77%, 50% and 65% of respondents in relation to alleviation of GI side effects, appetite side effects and fatigue, respectively, which are common pelvic radiotherapy side effects. Eighteen percent of respondents believed nutrition was not important at all in improving appetite and 15% did not think nutrition could alleviate fatigue symptoms.

Interviews also revealed some scepticism among participants about the role of diet post-diagnosis. Several participants perceived nutrition to be an important element for future health. They also believed they were following a healthy diet and any changes were temporarily implemented for the alleviation of treatment side effects. People with a higher educational background requested evidence-based dietary advice. Others believed there was no connection between their diet and development of cancer; believing other factors were more important in the development of cancer. Some participants were not convinced about the usefulness of dietary supplements to support health post-diagnosis or post-treatment. These participants were more likely to mention they had no discussions with health professionals because they did not feel they needed any guidance.

6.6. The role of family

This section includes findings predominantly from the qualitative analysis of the interviews. The survey did not include questions about family support since diagnosis in relation to diet and nutrition. A few questions were indirectly related to family support, such as preparation of meals and consumption of homemade and ready meals. Interviews, on the other hand, provided rich content for this section.

Results from the survey showed that most respondents had meals with the spouse/partner (72%) and/or other family members (25%). Also, for some participants, the preparation of meals was the spouse's/partner's responsibility (37%) or a shared task (24%). Participants had frequently consumed home-made meals (64% had home-made food 5 or more times per week) and had avoided ready-made meals (31% had not consumed ready meals and 43% consumed less than 3 meals over a month).

Results from the interviews showed that family members, particularly the spouse, supported participants to deal with treatment side effects and adopt healthier dietary habits since diagnosis. Survivors often referred to dietary habits, as well as cooking and shopping practices with the spouse. Provision of verbal advice and assistance shopping for the household were some of the support practices of family members.

6.7. Ability to self-manage diet after diagnosis

Information in this section also derives exclusively from the qualitative findings, highlighting the advantages of using a mixed-methods research design. The importance of trying to carry on with life as before diagnosis was strongly expressed by several participants. Also, diet was not seen as an isolated lifestyle factor that could change following diagnosis, but also physical activity was frequently mentioned. Several interviewees perceived the combination of a healthy diet and regular physical activity as a means of living healthier from now on.

A number of facilitators and barriers were expressed from participants regarding their ability to self-manage their disease. Perceived high awareness of a healthy diet, family and healthcare support, the ability to shop and cook high quality food and the ability to grow own fruit and vegetables were all enablers of engagement to healthy eating habits. On the other hand, inadequate healthcare support, receipt of conflicting information, weight problems, treatment side effects, comorbidities and disabilities were seen as barriers to dietary change. Figure 6.1 summarises the enablers and barriers to self-management, as these were identified from the quantitative and the qualitative analysis.

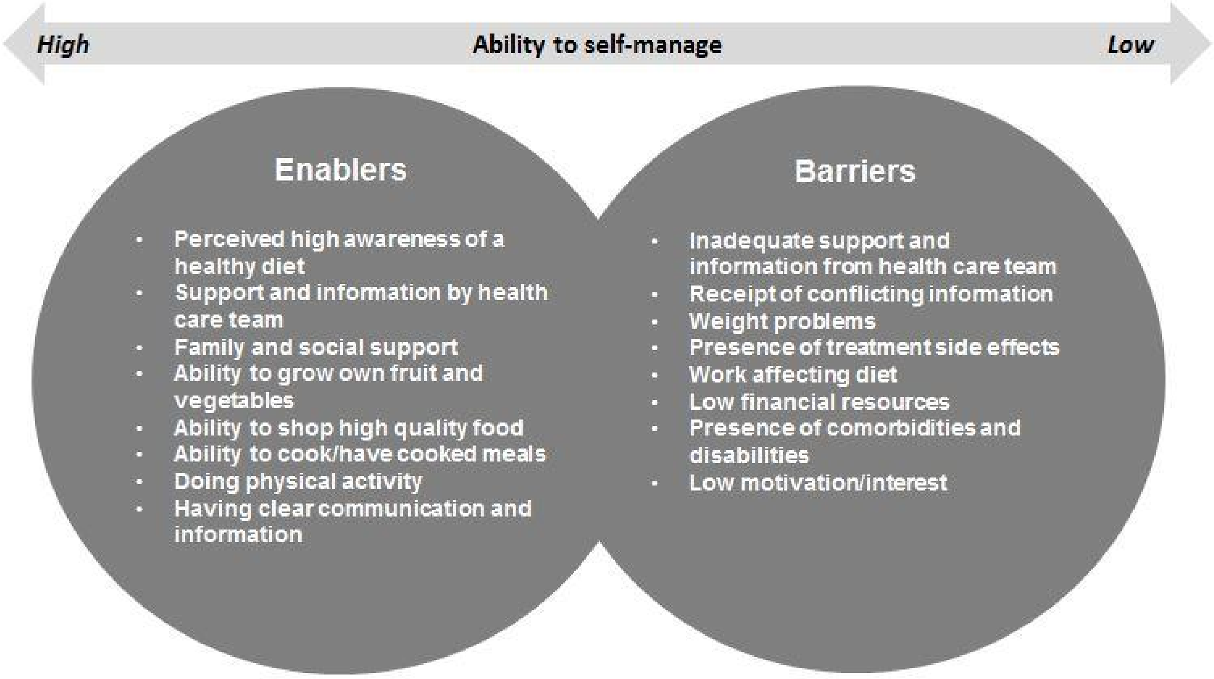


Figure 6.1: The ability to self-manage diet after a cancer diagnosis: Enablers and barriers to managing diet post-diagnosis.

Chapter 7. Discussion

7.1. Introduction

This mixed-methods study aimed to explore dietary changes and experiences of nutritional support from the time of diagnosis through to the post-treatment survivorship phase in people diagnosed with a pelvic cancer and treated with pelvic radiotherapy, with a view to highlighting unmet needs in the area of diet and nutrition. Pelvic cancer survivors were mostly aware of what constitutes a healthy diet and the importance of having a healthy weight and some made dietary changes, but the majority of participants had increased weight, indicating that behaviour change may be a more complex issue. In addition, dietary support was not routinely provided and treatment side effects affected most survivors, further highlighting unmet needs in diet and nutrition post-diagnosis.

There is compelling evidence that cancer patients have unmet support needs in a range of different domains and the NHS has set as a priority addressing these needs to improve quality of life. This PhD provided important information regarding pelvic cancer survivors' nutritional problems in relation to cancer, as well as the current level of support and information on this topic available to patients from a number of sources (i.e. healthcare team, internet, peers, support groups). Exploration of survivors' attitudes towards diet and nutrition and current practices to manage their disease further contributed to the identification of unmet nutritional needs.

It is hoped that the findings from this PhD will feed into the development of appropriate support services, designed to improve patient experiences and outcomes. For example, identification of people who are classified in the overweight or obese category, in the clinical setting, could initiate discussions and support around the need for weight loss after the end of treatments. Self-reported unmet needs are a widely accepted indicator of the difficulties in accessing health care services (Sanmartin et al., 2002). From a health policy perspective, it is important to understand the factors that act as barriers and facilitators to ensure care is equally received by all. Failure to access needed services may result in poorer health and to health inequalities (Allin et al., 2010).

Gaining an understanding of needs, concerns and attitudes of cancer survivors with regards to diet could also lead to the implementation of targeted – and successful – interventions. It is important to first understand a particular behaviour before intervening (Michie et al., 2015). Findings from this PhD related to unmet needs also support the outcomes of Phase I of the Cancer and Nutrition NIHR Collaboration and contribute towards the goals of the collaborative (Cancer and Nutrition NIHR infrastructure collaboration, 2015), which are to highlight the importance of diet and nutrition in cancer treatment and survivorship care.

Dietary support during the course of treatment is important to prevent malnutrition and address any potential treatment side effects that may interfere with dietary intake and quality of diet (Arends et al., 2017a). Research on the role of diet and nutrition in survivorship, particularly after the end of treatments, is currently limited but findings support the benefits of a healthy diet and weight management in improving quality of life in cancer survivors (World Cancer Research Fund/American Institute for Cancer Research, 2018). Prospective, long-term studies will be required to provide stronger evidence regarding the role of diet and weight on cancer recurrence and cancer mortality.

7.2. Treatment side-effects and comorbidities

Seventy-eight percent of respondents reported at least one comorbidity, with hypertension and arthritis being the most prevalent. Comorbidities are common in cancer populations, as shown in Elliot et al’s study (2011) (13% prostate cancer, 11% colorectal cancer), in which one in two cancer survivors reported at least one comorbidity, with arthritis and heart disease being the most prevalent. A recent, retrospective study conducted in cancer survivors in the USA (prostate 31%, colon 11%, uterus 11%, urinary bladder 9%), showed higher rates of comorbidity than the current study, with 64% of survivors diagnosed with hypertension, 56% with dyslipidaemia and 34% with arthritis (Roy et al., 2018). However, the sample was older than the sample of the present study (mean age 72.5 years Vs median age 70 years/mean age 68.8 years) (Roy et al., 2018). Age is a crucial factor for the presence of comorbidities; the older the cancer patient, the higher the number and severity of comorbidities are (Piccirillo et al., 2008). The results highlight that pelvic cancer patients may be a population with multi-morbidity. Results indicate that the needs for nutritional support may also be related to other morbidities, which affect QoL and future health and wellbeing. One of the main themes of the qualitative analysis was the presence of comorbidities and disabilities and their negative impact in managing cancer outcomes nutritionally and everyday life in general. Nutritional support should not be limited to the cancer diagnosis when other morbidities are also present and people should be provided necessary, tailored guidance to deal with all issues.

Similarly, side effects were frequently reported in the present study. Presence of side-effects is common when undergoing pelvic radiotherapy; however, in this sample, treatment side effects still had an impact 6-24 months post-radiotherapy treatment and were reported to a similar extent as the on-treatment group. It has been previously documented that pelvic cancer survivors can experience bowel and urine urgency up to 11 years after the end of radiotherapy treatment, which highlights the long-term impact of the side effects (Adams et al., 2014). Associations of side effects with parameters of QoL were not assessed in the present study; however, previous studies have shown that side effects and comorbidities have been associated with poorer QoL in cancer survivors (Mazzotti et al., 2012, Cummings et al., 2018). Fatigue was the most commonly reported symptom in the present study, followed by wind/bloating and diarrhoea. In the qualitative interviews, fatigue was also perceived as one of the physical constraints patients had to overcome to maintain normality. Several interviewees described how fatigue affected their life and that diet and nutrition can assist in speedy recovery and being active again.

Presence of comorbidities and side effects varied across cancer diagnoses, highlighting potential heterogeneity. Results from the survey showed that urological cancer survivors were older and reported more comorbidities (particularly heart problems) compared to lower GI or gynaecological cancer survivors. Lower GI and gynaecological cancer survivors reported more treatment side effects, such as nausea, taste changes and loss of appetite, compared to urological cancer patients. GI problems were more often mentioned in qualitative interviews by survivors of a lower GI cancer, although participants from all cancer groups faced GI problems. Reduced appetite was most often highlighted by people who received chemotherapy and increased appetite from people who were also treated with hormone therapy. It is, therefore, indicated that treatment regimens and age are likely to be factors for these differences among diagnoses.

7.3. Dietary change, supplement use and nutritional support from health professionals

Presence of side effects and the need to support recovery and future health post diagnosis were the main drivers for dietary change in the surveyed sample. Although 68% reported a dietary change post diagnosis, report of changes per food group were lower. Findings are in line with the study from Kassianos et al. (2017) in prostate cancer survivors, where 72% reported a change to their diet post-diagnosis, but changes per food group were lower, with 43 – 60% of respondents reporting making a healthy change in consumption of fruit, vegetables, red meat, dairy, alcohol, sweets or fish. In another study, 29.2% of men diagnosed with localised prostate cancer reported a dietary change in one or more of five foods/nutrients, generally towards healthy eating patterns (Avery et al., 2013). Less than half colorectal survivors (36%) have reported changing their diet in the PROFILES study which was conducted in the Netherlands (Bours et al., 2015). Most of them reduced consumption of fat, meat, sugar, alcohol and salt, and increased fish, vegetables, fruit and water (Bours et al., 2015).

The most notable changes in the present study were increases in vegetables, fruit and wholegrains and reduction in sugary foods, processed meats and alcohol. The changes in dietary behaviour were in line with the recommendations in the latest report from the WCRF/AICR (World Cancer Research Fund/American Institute for Cancer Research, 2018); respondents reported avoiding products that promoted weight gain, increased intake of plant foods, and decreased intake of processed meat and alcohol. It was not possible to determine whether absence of change was due to the fact that respondents had already been following the recommendations for each food group or because of lack of appropriate guidance. According to the latest National Diet and Nutrition Survey (NDNS) report, mean intakes of saturated fat and free sugars were well above the recommendations and mean intakes of fruit, vegetables and fibre were below the recommendations for people 65-74 years old (Public Health England, 2016).

Some participants reported making dietary changes in the opposite direction, by reducing wholegrain products and fruit and increasing refined grains. In the case of refined grain consumption, significantly more people with a rectal and gynaecological cancer diagnosis increased refined grains following diagnosis, compared to urological cancer survivors. These changes are likely to be related to altered gastrointestinal function. Although prevalence of gastrointestinal side effects was not different between diagnoses in this study, severity of side effects was not assessed. Findings from the interviews also revealed that some participants successfully managed to control symptoms of gastrointestinal toxicity and diarrhoea by reducing the amount of fibre and foods that caused bloating. Anecdotal evidence suggests that many patients are advised to reduce fibre intake during and after pelvic radiotherapy to manage gastrointestinal problems. However, a Cochrane review on nutritional interventions for reducing gastrointestinal toxicity in people undergoing pelvic radiotherapy showed that fibre modification did not have a significant effect in reducing diarrhoea (Henson et al., 2013). Also, a recent randomised-controlled trial in lower GI and gynaecological cancer patients undergoing radiotherapy showed that a high fibre diet was associated with reduced gastrointestinal toxicity (Wedlake et al., 2017). The authors concluded that restriction of dietary fibre during radical pelvic radiotherapy should be avoided, as fibre enhances the production of short-chain fatty acids, which in turn would reduce inflammatory processes (Wedlake et al., 2017).

Dietary supplement use was reported by fewer cancer survivors compared to other studies (Patterson et al., 2002, Demark-Wahnefried et al., 2000, Bours et al., 2015, Song et al., 2017, Inoue-Choi et al., 2014). Higher supplement use was reported mainly in older studies with similar or larger sample size (Demark-Wahnefried et al., 2000, Patterson et al., 2002), which may reflect a health-related practice that is no longer recommended. Indeed, one of the WCRF recommendations is to rely on foods, rather than supplements, for optimal health. Previous studies have shown that supplement users tend to have a higher level of education, have a higher socioeconomic status, and have healthier dietary patterns than non-users (Dickinson and MacKay, 2014). These characteristics were not found to be significantly associated with supplement use in this study; only presence a side effect was associated with supplement use.

The study also showed that provision of advice and support from health professionals in relation to diet and nutrition was associated with survivors making changes to their diet after diagnosis. However, less than half respondents received such advice. Previous research has shown mixed results for pelvic cancer populations; some are in line with the present study (Cha et al., 2012, Clark et al., 2016, Kenzik et al., 2016), few reported higher rates of support (Tseng et al., 2015) and some reported lower rates of support (Zaleta et al., 2017, Sabatino et al., 2007, Holla et al., 2016).

Information and support on diet and nutrition was provided mainly by cancer specialists in the form of written materials. Written materials are generally considered an essential source of additional support for patients (Wills and Holmes-Rovner, 2003). They can be stored and read several times at a patient’s own convenience and, therefore, may contribute to knowledge in the long term (Wills and Holmes-Rovner, 2003, Wallace et al., 2009). It is also worth noting that written materials were the most preferred mode of information provision for survivors who were interested in receiving more information on diet, nutrition and cancer. Although information materials are seen as important, interventions such as participation in behaviour management groups or regular contact with health professionals have been found to be more effective in outcomes such as weight loss compared to provision of written information (Ash et al., 2006) as they may have a more direct influence towards behaviour change.

Health professionals are viewed by patients as the experts for provision of dietary information (Zaleta et al., 2017). Members of the clinical care team are in regular contact with cancer patients throughout the cancer trajectory and, therefore, could potentially play a role in initiating discussions about diet and nutrition, providing accurate information on nutritional issues and weight management or guiding patients in appropriate, evidence-based external information resources (Murphy and Girot, 2013). Face-to-face support by a health professional was the second most preferred method for provision of advice in this study. However, research has shown there are inadequacies regarding health professionals' nutrition education and knowledge, leading to provision of conflicting information or no provision of information (Williams et al., 2015a). Also, several barriers to health professionals providing lifestyle advice have been suggested from small-scale cross-sectional studies, such as lack of guidelines (O'Hanlon and Kennedy, 2014), lack of knowledge (O'Hanlon and Kennedy, 2014), lack of time (Karvinen et al., 2010) and provision of advice not being perceived to be part of their role (Spellman et al., 2014). In the UK, a recent qualitative study among surgeons, physicians, nurses and allied health professionals highlighted lack of time, lack of evidence, coexistence of multiple suboptimal behaviours and fear of blaming the patient as barriers to provision of lifestyle advice (Koutoukidis et al., 2018).

Certain socioeconomic and demographic characteristics were significantly associated with dietary change for survivors of a specific pelvic cancer diagnosis. For urological cancer patients, those with a higher Body Mass Index were more likely to report a dietary change, whereas for lower GI cancer patients, younger patients were more likely to report a dietary change. Younger urological cancer patients also were more likely to report support from health professionals. It is perhaps not surprising that younger patients may be more interested in diet and nutrition after diagnosis and more engaged with improving their future wellbeing (Hoedjes et al., 2017). However, these results should be treated with caution due to small sample size. Socioeconomic and demographic characteristics were not associated with dietary changes in a large population-based cohort study conducted in people with a prostate, breast and GI cancer in France (Fassier et al., 2017). In another large US population-based case-control study, women diagnosed with cancer were shown to have healthier eating behaviours and were more likely to follow dietary recommendations compared to men diagnosed with cancer (LeMasters et al., 2014). In the present study, gender was not entered in the regression analysis, because of high collinearity with the variable “cancer diagnosis”.

Overall, there is an increased need and interest for dietary information (68% being moderately to extremely interesting in receiving such support), which was also reflected in the survey free text comments and the telephone interviews. The findings of this mixed-methods study further support the results of the systematic review (Chapter 2), in which a number of qualitative studies highlighted the current provision of conflicting information or no discussions at all and the need for clear and evidence-based messages (Sutton et al., 2017, Hall et al., 2012, Hardcastle et al., 2018, Koutoukidis et al., 2017, Hardcastle et al., 2017, Anderson et al., 2013). Results also showed that patients may prefer different time points during the cancer trajectory when they would be more receptive to dietary information, suggesting a potential individualised approach to information provision. Interest could be a result of the perceived importance of the role of diet in survivorship, the lack of routine support from the healthcare team or the combination of the two. On the other hand, some respondents were not interested in receiving information, which could be attributed to barriers towards dietary and behaviour change.

7.4. Weight problems

Thirty-six percent and 23% were classified as overweight and obese, respectively, based on self-reported height and weight. Although self-reported height and weight are valid measurements in epidemiological studies in the UK population (Bolton-Smith et al., 2000, Spencer et al., 2002), underestimation of weight is possible (Fillenbaum et al., 2010). The results are slightly lower compared to the results of a national UK survey in cancer survivors (Wang et al., 2015) but similar to other studies with prostate (Thomas et al., 2013), colorectal (Schlesinger et al., 2014), ovarian and endometrial cancer populations (Smits et al., 2015c, Basen-Engquist et al., 2009, van Broekhoven et al., 2017).

Weight loss and weight gain were reported by a substantial proportion of respondents (26% and 33% respectively) and findings were similar between on-treatment and post-treatment patients. During radiotherapy, a stable body weight is a requirement for effectively targeting and treating the tumour. However, patients undergoing pelvic radiotherapy have been shown to experience modest weight loss and up to 15% decreased energy intake (Guren et al., 2006). Weight changes in the present study may also be a result of chemotherapy (42% of the sample underwent chemotherapy) and hormone therapy (18% of the sample received hormone therapy) A study that evaluated weight changes in women who underwent chemotherapy for an ovarian cancer showed that among advanced cancer patients, 37% lost weight, 19% gained weight and 44% had a stable weight during six cycles of chemotherapy. In early ovarian cancer patients, the percentages were 27%, 18% and 55%, respectively (Mardas et al., 2017). Assessment of body weight took place at before the first cycle of chemotherapy and during the third and sixth cycles (Mardas et al., 2017). In a sample of colorectal cancer patients in the USA, 20% lost weight, 27% gained weight and 53% had a stable weight between diagnosis and at 15-21 months post-diagnosis (Meyerhardt et al., 2017). Also, hormone treatment is a commonly used treatment for prostate cancer and known to be related with metabolic changes, including weight gain and fat accumulation (Mitsuzuka and Arai, 2018). Findings from the present study enhance the need for regular body weight monitoring during and after treatment, as different survivors may have different experiences in terms of weight change.

None of the above studies examined weight fluctuations over time and neither did the present study, due to its cross-sectional design. Weight fluctuations from diagnosis to treatment to survivorship were described in the qualitative interviews by some participants. Weight changes (both weight gain and loss) during treatments were anticipated as a treatment side effect. It may be possible that weight changes are not a concern during treatment, as the priority is the cure of the tumour. Instead, concerns and negative emotions about weight status were expressed mainly by post-treatment participants in the interviews. Participants, mainly in the post-treatment stage, acknowledged excess weight and the desire to lose weight and requested guidance and regular monitoring.

Survey findings indicated that only few participants received support in relation to weight management. A study by Tseng et al. (2015) in the USA showed that 50% of endometrial cancer patients discussed weight management with health professionals but they were rarely offered specific guidance and only 6% of them were referred to nutrition specialists for further support. In another study on gynaecological cancer survivors, only 14% of the patients reported weight management counselling (Zaleta et al., 2017). Discussions on weight management may be perceived as a sensitive topic for both patients and health professionals, however it seems many patients would welcome such guidance (Zaleta et al., 2017). Given the detrimental impact of obesity on QoL and cancer outcomes after a cancer diagnosis (Vissers et al., 2017, Smits et al., 2015a), it is important that survivors have the opportunity to engage in weight loss and weight monitoring programs that would incorporate healthy eating and regular physical activity. There is ample evidence of the benefits of maintaining weight within the healthy range (BMI between 18.5 kg/m^2 and 25 kg/m^2), which is the reason why it is one of the recommendations from both ESPEN

(Arends et al., 2017a) and the WCRF (World Cancer Research Fund/American Institute for Cancer Research, 2018) for cancer survivors. A cross-sectional study in the UK showed that advice about weight management was routinely provided only to participants with a BMI > 37 kg/m^2 but to very few participants with a BMI between 25 – 36 kg/m^2 (Jackson et al., 2013). A barrier to provision of such information has been shown to be the perception that weight management advice may not be viewed as part of the health professionals' role (Koutoukidis et al., 2018), despite the National Institute for Health and Care Excellence NICE recommendation for health professionals to engage in conversations about weight management and offer support (Centre for Public Health Excellence at and National Collaborating Centre for Primary, 2006).

7.5. Awareness of and attitudes towards diet

In the present study, most participants were aware of the nutritional recommendations issued by the WCRF in 2007. This was also reflected in interviews with some participants, where survivors perceived they had already been following a healthy diet and lifestyle, in line with the current recommendations, before diagnosis. However, survivors in this study were unsure about the recommendation regarding consumption of red and processed meats, as one in four participants indicated lack of or limited awareness about this recommendation. A study by Hawkins (2015) in colorectal cancer survivors in the USA showed lower levels of awareness compared to this study, especially in relation to consumption of wholegrains, fruit, vegetables and alcohol. However, the statements included in the study were slightly different and reflected recommendations for the US population. Survivors who were most familiar with recommendations were also more likely to follow those (Hawkins et al., 2015). In the current study, this relationship was not assessed due to the very small numbers of survivors who reported "lack of awareness" in each of the recommendations.

Survey results also revealed the survivors' perceived importance of diet and nutrition in overcoming certain problems and supporting future wellbeing. Similar to the survey findings, recent findings from the PROFILES study in colorectal cancer survivors in Holland showed that over half the respondents (52%) held a strong "belief that nutrition influences feelings of wellbeing" (van Veen et al., 2019). Survivors with strong beliefs were more likely to report having received support and information in diet and nutrition from health professionals than survivors with no belief in the link between diet and wellbeing (van Veen et al., 2019). In the same study it was also shown that respondents with a strong belief of role of diet in wellbeing also had a strong belief of diet assisting in recovery after treatment (79% of respondents had a "strong belief"), but there were mixed beliefs about diet preventing recurrence (only 36% had a "strong belief"). In the present study, scepticism was expressed for the role of diet and nutrition in reducing side effects, particularly appetite problems and the feeling of fatigue and, on a smaller scale, reducing cancer recurrence. Indeed, evidence is still limited about the role of diet in reducing fatigue and preventing cancer recurrence and, as a result, there are no specific nutritional recommendations towards this direction. A few interventions have been conducted examining the effect of physical activity in improving cancer-related fatigue, but the role of nutrition has not been explored in depth (Baguley et al., 2017). Also, it is challenging to conduct long-term observational or Randomised Controlled Trials, which are required to evaluate the role of diet in cancer recurrence.

A number of themes from the interviews summarised the perceived role of diet in participants' life and revealed attitudes towards the importance of diet and nutrition, which acted as enablers or barriers towards self-management. Some participants considered the role of nutrition as important in coping with altered bowel function and reduced appetite and believed a healthy diet could help them regain normality in their life after the end of treatments. On the contrary, lack of interest and motivation, scepticism about the importance of making dietary changes and the perception that current dietary habits were already sufficient led some people to believe diet is less important. Attitudes towards diet were mostly in line with a recent qualitative study, which examined factors which motivated prostate, colorectal and breast cancer survivors to change lifestyle behaviours, such as diet and physical activity (Corbett et al., 2018). Maintenance of health, prevention of cancer recurrence and the drive to feel better after treatment were enablers to behaviour change, whereas absence of support to implement changes, rejection of the link between cancer and lifestyle and lack of interest were barriers to behaviour change (Corbett et al., 2018). Interestingly, in the Corbett et al. study (2018), presence of side effects were a barrier to behaviour change (in relation to engaging in physical activity), whereas in the present study side effects were mostly a drive towards dietary change to reduce their impact and improve overall recovery. Findings in both Corbett et al. and the present study are qualitative and it would be interesting to evaluate whether a quantitative assessment of enablers and barriers of engagement in nutrition and physical activity would provide similar results. People may feel more vulnerable and hesitant in engaging in physical activity when they experience side effects, such as gastrointestinal disturbances and fatigue. They may also perceive that physical activity may worsen existing side effects. On the other hand, dietary modification may be viewed as an effective way to alleviate side effects.

The limited evidence base on the role of diet and nutrition in cancer outcomes does make the provision of information challenging, both for patients and providers. For example, management of gastrointestinal problems is primarily based on anecdotal information. Therefore, a reason why support is not provided routinely could be the fact that research is limited and outcomes are not communicated to health professionals, who in turn do not advise their patients or guide them towards appropriate support. However, this should not be the case in support for weight management, as there is good evidence to suggest promotion of weight loss or weight maintenance, where appropriate. Also, a healthy diet has the potential to improve QoL and general health. Given these benefits, appropriate guidance should become part of standard routine care. However, it is generally acknowledged that the evidence on the role of diet in health after a cancer diagnosis is limited and therefore more research is warranted.

7.6. The role of family

The importance of family and social environment in a cancer patient's recovery and wellbeing has been well documented (Glajchen, 2004). Social support – defined as the *"availability of a network of family and friends for information, encouragement, emotional support, and enhancing the environment to support a behaviour"* (Spahn et al., 2010) – has been identified as an important determinant of nutritional behaviour (Spahn et al., 2010). Brug (2008) summarized the evidence from systematic reviews on the association between environmental factors and healthy dietary behaviours and concluded that the social environment (family and friends) appeared to have a consistent influence on individuals' dietary behaviours, although findings were limited by the methodological quality of the studies included. In a more recent study in almost 3,000 healthy individuals, perceived social support acted as a motivator towards healthy eating practices (McSpadden et al., 2016).

Social support has also been found to be an important factor in the implementation of healthy dietary behaviours in cancer survivors. A study of cancer survivors in the USA (n=128) showed that survivors who consumed more than 5 portions of fruit and vegetables per day had higher social support from the spouse/partner, compared to survivors who consumed less than 5 portions daily (Coleman et al., 2014). Another study in South Korea showed that support from the family was particularly helpful for the adoption of a healthy diet, increasing self-leadership and self-management of disease in patients with colorectal cancer (Lee et al., 2018). It should, however, be noted that the impact of family may be different in different cultures.

In the current study, the role of the family – particularly the spouse – was evident in food preparation and food purchasing, which were described either as shared task or sole responsibility of a family member. Also, several survey respondents reported receiving advice and support in diet and nutrition from a family member or a friend. Family support was perceived as an important facilitator in the self-management of diet and nutrition in relation to the disease (also highlighted in section 7.7). Food consumption with family members was another important aspect of participants' social life and a few highlighted how the spouse's/partner's or children's nutritional preferences influenced their own.

Preparation of meals by family members was also the main form of support for survivors with nutritional problems, such as lack of appetite. Regarding nutritional problems related to cancer, literature to date has mostly focussed on advanced cancer. In advanced cancer, the role of the family carer is crucial and challenging, as they may be in charge of food preparation, but also need to encourage the patient to engage in self-help by eating. Involuntary weight loss has been shown to occur to both the patient and the family carer in advanced cancer (Hopkinson, 2018).

Considering the influence of family on different aspects of nutrition for cancer survivors (purchasing, preparation, consumption), it is important to note that nutritional education and support should not only target the survivor, but also the family or people who care for the survivor. In this study, the needs of carers were not examined, but previous literature has shown carers exhibit needs in relation not only to the patient's care but also their own. Caregivers of a patient with cancer have been shown to be more distressed and to exhibit higher anxiety scores compared with the cancer patients they were caring for (Sklenarova et al., 2015). Carers' information needs were highlighted in relation to the patient's physical state and treatment side effects, as well as for their own health, including eating and sleeping adequately (Sklenarova et al., 2015).

Support from family members/carers needs to be reflected in the nutritional support provided to cancer survivors. Guidance and support from healthcare professionals, support groups or other sources should also target carers, so that informed decisions towards care are taken from everyone involved. The family's daily involvement in different aspects of nutritional care can be an additional "tool" that can facilitate patient education, influence dietary change, and improve self-management. For example, if a survivor has their meals cooked by the spouse, it is reasonable for the spouse to be involved in the conversations about adequate nutrition and suitable meals for the survivor's needs. It also important that the spouse is educated on diet and nutrition in relation to the disease and that the spouse's own needs and concerns around diet are also met.

7.7. The ability to self-manage diet after diagnosis

The National Health Service initiative for improving cancer care (Department of Health et al., 2013) emphasises the provision of all necessary support to promote self-management in the survivorship phase. Self-management is a dynamic process in which people manage a chronic disease, such as cancer, in relation to symptoms, medication and interaction with the healthcare system (Richard and Shea, 2011). Schulman-Green et al. (2012) conducted a meta-synthesis of studies which described self-management processes and identified three main categories: processes that focus on illness needs, resources (e.g. family and healthcare professionals) and coping with the illness. All three categories are relevant in diet and nutrition and were evident in the present study. For example, illness needs related to management of treatment side effects and weight issues. Family was identified as a main component of support in nutrition and dietary advice; health professionals were the reliable source of information. Integration of illness into the individual's life related to the notion of "maintaining normality", which was an important qualitative finding. In this study, self-management of diet was a result of contextual influences and receipt of support and information.

A number of enablers and barriers towards dietary change and self-management were identified from the qualitative interviews. Presence and/or severity of treatment side effects, perceptions of weight status and body image, concerns over weight changes, support in diet and nutrition by the family, personal knowledge in the area of nutrition and perceived healthy dietary habits pre-diagnosis which were still currently implemented; were all factors which the patients evaluated before deciding whether dietary change was necessary for them and how dietary change could be achieved.

For many, diet and nutrition was seen as a “vehicle” to get well soon and get back to pre-diagnosis life. Living with a chronic illness, such as cancer, is a process that requires constant integration of the illness into an individual’s daily life. Not only physical, but also emotional aspects of the illness are identified and need to be managed and improved (Schulman-Green et al., 2012). An early, qualitative study by Ekman et al. (2004) showed that maintenance of normal life and being high-spirited were essential characteristics for women with an ovarian cancer diagnosis. A more recent qualitative study in breast and prostate cancer survivors also confirmed that there was a strong desire for their lives to get back to normal. Going back to normality was described as both a physical and a psychological need and was a core social and behavioural process following treatment (Walker et al., 2015). None of these studies linked normality to any lifestyle factors, as the focus was on treatment side effects and emotional stability. In this mixed-methods study, a healthy diet was a supportive means for activity, which in turn was linked to maintenance of normality. Concerns regarding body weight and body image had a negative emotional impact, indicating that issues around weight are important not only in relation to physical health, but also psychological health.

In this study, activity was considered an important lifestyle component in regaining normality. Although this PhD did not assess physical activity, it is worth mentioning that both eating and activity behaviours are targeted in behavioural change interventions and in weight loss strategies (de Vet et al., 2011).

Several interviewees managed their disease well and were able to adjust dietary habits to address potential side effects, including weight issues. For others, challenges related to self-management included the inability to afford healthy foods and to cook meals using raw ingredients. Presence of comorbidities and disabilities also negatively affected the ability to self-manage. Inadequate nutritional support from the healthcare team and conflicting information from other sources (the internet or the media) further reinforced the challenges to manage any dietary problems. Qualitative studies have highlighted that although cancer diagnosis is often perceived as a “teachable moment”, it does not always lead to behaviour change, as barriers can outweigh the motivation to eat healthily (Coa et al., 2015, Corbett et al., 2018).

Content of support and information could be grouped in main categories; alleviation of side effects (particularly gastrointestinal problems, appetite issues and fatigue in the pelvic groups); weight management and future health overall It is also clear that each patient had individual needs that needed to be addressed. A holistic approach to provision of dietary information needs to be implemented, which should take into account how to have a healthy diet while on a low-budget and how to cook healthy meals easily and quickly.

Also, dietary approaches need to take into account other comorbidities and presence of permanent or temporary ostomies. Components of a healthy diet and weight control are essential to overall health and there are clear benefits of dietary or lifestyle interventions on managing hypertension (Semlitsch et al., 2016, Graudal et al., 2017) and improving arthritis problems (Khanna et al., 2017) (those comorbidities were the most commonly reported in the surveyed sample). Finally, the need to regain normalcy in life after diagnosis should also be strongly considered when planning for the survivor’s care, including diet, nutrition but also the feeling of being well and active. The emotional impact of diagnosis and treatment should not be overlooked when addressing behavioural changes in lifestyle, such as diet, weight and activity.

7.8. Strengths and limitations

One of the main strengths of this project is the mixed-methods design, which was adopted to provide a better understanding of unmet needs for information and support in relation to diet and nutrition after a cancer diagnosis. Quantitative and qualitative findings brought together important insights to the research questions and set the foundations for policy implementation and further research, with a view to better support cancer patients in this area.

Albeit the absence of a suitable, validated questionnaire, a non-validated questionnaire was used to explore the research questions in the quantitative arm; however, every effort to obtain face validity was made. The questionnaire was assessed by Patient and Public Involvement contributors in the first phase to ensure no ambiguous, complex or double-barrelled questions, technical jargon or uncommon words were used. Any word that was perceived as technical had an explanation underneath. Also, every effort was made to add neutral and not leading questions.

However, several limitations in relation to the development of the survey occurred. The survey did not include information about gender. As a result, gender was assumed from cancer diagnosis (men had a prostate cancer diagnosis and women had a gynaecological cancer diagnosis) and from personal details provided for the purpose of an interview (for all other diagnoses). This omission resulted in an amount of missing data about gender (n=22). This had an impact in the descriptive analysis but not the logistic regression analysis, in which the variable “gender” was not entered in any of the models (high correlation with the variable “cancer diagnosis”). Also, the survey did not include the food group “red meat” in the section about dietary changes; therefore, no quantitative data were available about change of red meat consumption following diagnosis. Due to this omission, every effort was made to discuss red meat consumption in the interviews.

As expected, missing data occurred for some questions in the survey, although for most of these questions there were only few missing data. More missing data occurred for sensitive questions, such as date of birth (missing data n=12), body weight (n=10) and body weight changes (n=10).

Several limitations in relation to methodological quality of the mixed-methods study should be mentioned. Recruitment of cancer patients took place from one Trust (Oxford University Hospitals NHS Foundation Trust) and, more specifically, one department (Radiotherapy Department, Cancer and Haematology Centre). Patients diagnosed in other counties of the UK may have different socioeconomic, clinical or health characteristics and, therefore, different needs for nutritional support. Also, patients with a pelvic cancer diagnosis who have received chemotherapy, hormone therapy and/or surgery but not radiotherapy may have different needs in diet and nutrition. However, receipt of radiotherapy was one of the inclusion criteria for this PhD.

It should be acknowledged that the recruited sample includes cancer diagnoses that share common characteristics (e.g. obesity rates, pelvic radiotherapy, increasing survival rates) but can also vary considerably. The differences were mainly shown in relation to treatment side effects, which may reflect the different treatment regimens for each cancer diagnosis. For example, prostate cancer may be treated with radiotherapy and/or surgery and/or hormone therapy, whereas hormone therapy is not a treatment option for a lower GI or a gynaecological cancer. These differences may lead to different needs for dietary advice. Analysis according to cancer diagnosis (urological, lower GI, gynaecological) was conducted to identify these differences, although sample size per group was small and the sample may not be representative.

Non-probability sampling was used to recruit participants for the survey (i.e. every pelvic cancer patient who underwent radiotherapy between November 2017 and February 2019 for the on-treatment group and every patient treated with radiotherapy between April 2016 and September 2017, with the exception of prostate cancer subgroup for the post-treatment group) and maximum variation sampling for the interviews. It is not known whether all pelvic cancer patients that underwent radiotherapy during the specified timeframe were invited to take part from the collaborating nurses and radiographers. Increased workload of clinical staff and heavy agendas during clinical review meetings may have led to some patients not being informed about the study. Regardless, this form of recruitment was considered the most effective, given the time restrictions and resources of the PhD studies, but it is acknowledged that the ability to generalise the findings to other pelvic cancer survivors may be limited.

Notably, very small numbers of survivors of a bladder and a gynaecological cancer participated in the survey. Under-representation of these cancer groups should be taken into consideration when interpreting the results to cancer patients receiving pelvic radiotherapy. Studies targeting specific cancer groups (i.e. a study in which the sample size is gynaecological cancers only) may be a more effective strategy to investigate unmet needs in diet and nutrition, rather than recruitment based on treatment regimen. In the current study, larger samples of these cancer populations were expected but, unfortunately, it proved challenging in the given timeframe and was further impacted due to low response. Response rate for the gynaecological cancer group was 26%, as opposed to the prostate cancer patients, where 46% returned the survey.

Other potential forms of bias include non-response and response bias. The overall survey response rate was 38%, and it was not possible to gather data on non-responders and therefore determine whether there were differences in demographic or clinical characteristics between people who responded to the survey and people who did not. It is possible that people who are more interested in the topic of diet and nutrition decided to take part in the survey and the interviews. In order to reduce non-response bias, the questionnaire was assessed by Patient and Public Involvement contributors before administration to ensure it was easy and quick to complete and it included as few sensitive questions (mainly demographics) as possible. Regarding response bias, it is possible that participants were interested in filling in the survey and being interviewed, but they also wanted to be “good subjects” by answering in a way that made them look more favourable. In order to reduce the effect of response bias, leading questions in the survey and interviews were avoided through rigorous survey design/assessment and interviewer training, respectively. Anonymity and confidentiality of data was also assured. However, the fact that the vast majority of respondents were aware of the nutritional recommendations for cancer prevention/survivorship – an unexpected finding – may indicate that response bias might have affected the findings.

It is also important to acknowledge potential self-report bias for the survey and recall bias for both the survey and the interviews. Self-report bias was possible in the completion of survey, as it was a self-administered questionnaire. Recall bias may have occurred in the post-treatment group, as some questions asked were related to their treatment which took place 6-24 months before of the administration of the survey and conduct of interviews.

Regarding regression analysis, methodological limitations, such as response bias, non-response bias and selection bias (non-random sampling), could have influenced the strength of the detected associations. In order to avoid heterogeneity bias in the analysis, sub-group analyses were conducted where possible, but sample size was considerably smaller, possibly increasing the chance of error. All possible explanatory variables were entered in the models and multicollinearity was assessed. However, none of these variables was examined as a confounding factor in the regression models.

Researcher bias in the qualitative analysis may have occurred, as the person who performed the analysis (the PhD researcher) had a nutrition and dietetics qualification. For this reason, analysis was closely monitored by one Co-Director of Studies (Prof Eila Watson) and a qualitative researcher (Dr Lauren Matheson), neither of whom have nutrition or dietetics background. Finally, the survey was completed by patients who were predominantly married, retired and identified themselves as white. Generalisability of results may not be possible for non-married patients, patients living alone, patients of working age and people who identify themselves as Black, Asian and Minority Ethnic (BAME). In the qualitative interviews, though, the use of maximal variation was essential in identifying and interviewing patients that belonged to these groups. Further research in “harder-to-reach” groups could shed light to different information and support needs to the findings of this PhD project.

Finally, as discussed in Chapter 1, available guidelines for diet and nutrition suitable for people after a cancer diagnosis exist from ESPEN (Arends et al., 2016) and the WCRF (World Cancer Research Fund/American Institute for Cancer Research, 2018). The ESPEN guidelines focus on preventing or managing malnutrition, primarily in the clinical setting. This includes adequate nutrition (energy and protein), artificial nutrition and intervention, where appropriate. The WCRF recommendations focus on promoting wellbeing after the end of treatments and possibly reducing recurrence. The use of WCRF recommendations in the current survey may have undermined some more complex needs of patients on-treatment, primarily related to adequate nutrition and prevention/management of malnutrition.

The concept of saturation in qualitative research, evolved from the notion of theoretical saturation in grounded theory, is described as the point at which no new information emerge from data and has been used in the mixed methods study to terminate the conduct of qualitative interviews. Braun and Clarke disagree that saturation could determine sample size in qualitative research, as the philosophy of thematic analysis is based on interpretation of data during continuous and concurrent collection and analysis. Therefore, sample size cannot be determined before data analysis – and perhaps the concept of sample size is not even applicable in thematic analysis (Braun and Clarke, 2019). A clear distinction between types of thematic analysis has been proposed (codebook, coding reliability and reflexive thematic analysis), where the first two types use a mix of deductive and inductive approach and reflexive thematic analysis relies on analytic process and interpretation (Braun and Clarke, 2016, Braun and Clarke, 2019). In codebook and coding reliability, the concept of information redundancy could be an option in estimating sample size, while this would not be the case in reflexive thematic analysis.

In this mixed-methods study, the sample size for the qualitative arm was not determined a priori; however, based on previous research, some of which is included in the systematic review (Chapter 2), and for the purposes of ethical approval, an initial estimation was made (40 participants; 20 from the on-treatment and 20 from the post-treatment group). Due to the heterogeneity of the recruited sample (on/post-treatment, different diagnoses of pelvic cancer), it was assumed that the required sample would be larger than qualitative studies whose sample had a single cancer diagnosis. After each interview, the researcher wrote a reflexive summary of the conversation. Based on the information of the summaries, the conduct of interviews was terminated after 28 interviews. It is acknowledged that the concept of “data saturation” was used to complete data collection prior to analysis but sample size was not determined prior to data collection. For a novice researcher, such as a PhD student with limited background in qualitative research, it was deemed important to recognise qualitative research as a pragmatic activity, shaped and constrained by the time and resources available.

Chapter 8. Online sources

Availability and quality assessment of online nutrition information materials for pelvic cancer patients in the UK

(published at the European Journal of Cancer Care; https://doi.org/10.1111/ecc.13039)

8.1. Summary

In light of the limited nutritional support in the healthcare setting shown in our mixed-methods study, phase 3 of this PhD project aimed to identify and assess the quality of online diet and nutrition information suitable for people with a pelvic cancer. Patient Information Materials (PIMs) available from the NHS, cancer centres and charitable organisations were assessed for quality of content and readability. Consumer feedback was sought through Patient and Public Involvement (PPI) groups. Results showed limited availability of online PIMs for cancer survivors and even fewer tailored to pelvic cancers. Most materials had comprehensive content and acceptable readability. Some PIMs may require improvement.

8.2. Introduction

Results from the mixed-methods study (Chapters 4-6) showed the lack or routine nutritional support after a pelvic cancer diagnosis and highlighted the patients' need for provision of advice and support. High rates of obesity, presence of side effects and comorbidities, in combination with lack of discussions about diet and nutrition in the healthcare setting, show the need for development of services to support cancer survivors to live as healthy a life for as long as possible. Participants were keen in receiving information and guidance on weight management, nutritional management of treatment side effects, which persist up to two years after the end of radiotherapy treatment, as well as future wellbeing. Content and quality of information are essential determinants of promoting healthy behaviours. Results from also showed that provision of written information was the most preferred method of dietary support for this sample of pelvic cancer survivors.

Patient Information Materials (PIMs) complement verbal messages from healthcare professionals and are considered an essential source of additional support for patients

(Wills and Holmes-Rovner, 2003, Wallace et al., 2009). PIMs that provide simple, targeted, evidence-based and culturally appropriate messages on diet and nutrition from credible sources such as clinical settings and charitable organisations, and are available to all cancer patients, could prompt behaviour change. It is, however, acknowledged that information processing and, consequently, elaboration to behaviour change are complex procedures that rely on perceived relevance of the topic, quality of the message and credibility of the source that provides that message (Wilson, 2007).

Guidance on the development of comprehensive PIMs includes evidence-based preparation, readability assessment, content assessment and consumer testing (Lampert et al., 2016, Beaunoyer et al., 2017). Patient involvement has been reported as an essential part of the quality assessment of PIMs, as it reflects patients' perceived information needs (Smith et al., 2014).

Although health professionals are considered the most reliable providers of dietary information, inadequate support may turn patients to look for information on other resources (Playdon et al., 2016, Hartoonian et al., 2014). PIMs in diet and nutrition available online may be a useful aid both for symptom management and for the prevention or management of other diseases, such as cardiovascular diseases, diabetes or a secondary cancer. The aim of this study was therefore to identify the availability and assess the quality of PIMs in relation to diet, nutrition and cancer survivorship suitable for patients with pelvic cancers.

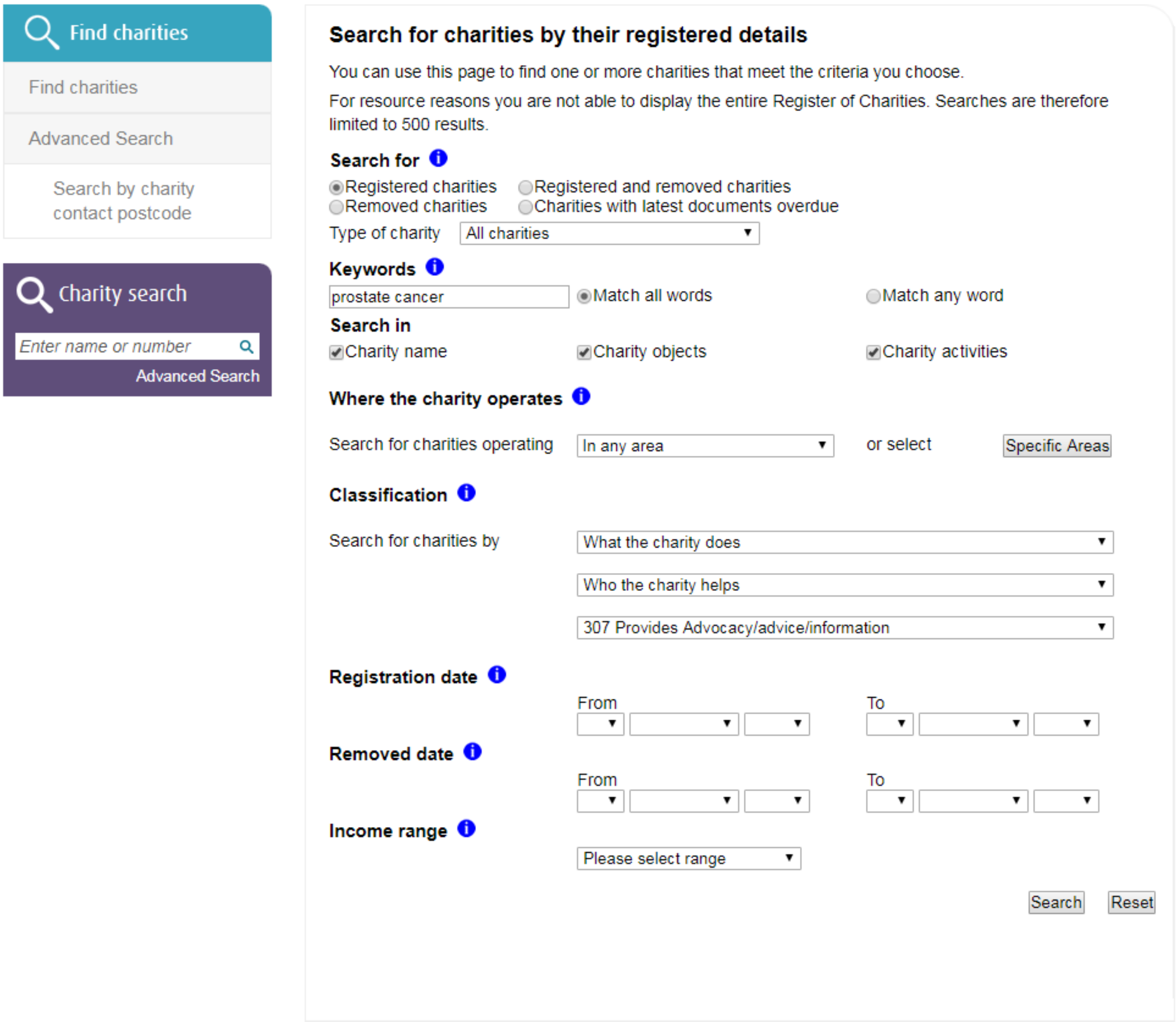
8.3. Methods

8.3.1. Identification of Patient Information Materials (PIMs)

Online PIMs related to diet and nutrition for pelvic cancers (anal, bladder, bowel and reproductive organs) were identified through systematic searches of the National Health Service websites (NHS; official websites and cancer centres) and charitable organisations websites in the UK. PIMs were included if they provided information about diet and nutrition for general health, weight management or management of treatment-related side effects for pelvic cancer. PIMs which provide dietary information for generic cancer were also included, as they were deemed relevant for pelvic cancer patients.

The NHS websites for England, Scotland, Wales and Northern Ireland were searched for any available PIMs in diet and nutrition after a cancer diagnosis. Focus was given to the NHS Choices, section “Cancer” (2017), NHS Inform Scotland, section “Cancer” (2017), NHS Direct Wales, section “Cancer” (2017) and Health and Social Care Online Northern Ireland (2017) websites. All sections relevant to cancer in these websites were searched. The keywords ‘cancer’, ‘diet’ and ‘nutrition’ were also used in each website’s search box to ensure that no sections were missed. For the identification of cancer centres, there is currently no comprehensive list of these in England available. Cancer centres were identified from the NHS Choices website, section “Services” (2017), the Organisation of European Cancer Institutes (2017) and a Google search. The key phrase ‘cancer centre’ was used in the NHS Choices and Google search boxes. Cancer centres in Scotland, Wales and Northern Ireland were identified from the National Cancer Patient Experience Surveys for Scotland (2016), Wales (2014) and Northern Ireland (2015) respectively. Cancer centres in England could not be identified through the National Cancer Patient Experience Survey for England, because it was not possible to distinguish between cancer centres and NHS Trusts that provide cancer treatment and care. In every cancer centre’s website, information under the sections “patient information leaflets” and “dietetics and nutrition” were searched.

Identification of charities was through the Charity Commission for England and Wales (2017), the Charity Commission for Northern Ireland (2017) and the Office for the Scottish Charity Regulator (OSCR) (2017). Charity commissions and OSCR are independent regulators and registars for organisations that have been recognised as charitable by law, including community groups, schools, universities and care providers. Their role as regulators ensures increased public confidence in charities work. Charities that relate to each pelvic cancer type, as well as generic cancer, were searched. Using the advanced search option, each of the following keywords was typed in the keyword box: cancer (when looking for generic cancer charities), prostate cancer, testicular cancer, ovarian cancer, bladder cancer, urological cancer, cervical cancer, bowel cancer, colorectal cancer, rectal cancer, anal cancer, endometrial cancer, uterine cancer, vulvar cancer, womb cancer, male cancer, gynaecological cancer and female cancer. Keywords were searched in charity names, objects or activities. Examples of search are shown in Figures 8.1 and 8.2. To identify PIMs relevant to the aim of this study, only charities with a remit relating to the advancement of health and/ or the provision of advice, advocacy or information were included. The Charity Commission for England and Wales limits the amount of charities shown to 500 for resource reasons. Therefore, due to the large number of generic cancer charities in England and Wales, search was further refined to the ones with an income over £25,000 (financial year 2016-2017). Any materials available up to December 2017 were included.



Search for charities by their registered details

You can use this page to find one or more charities that meet the criteria you choose.

For resource reasons you are not able to display the entire Register of Charities. Searches are therefore limited to 500 results.

Search for

● Registered charities ○ Registered and removed charities
○ Removed charities ○ Charities with latest documents overdue

Type of charity: All charities

Keywords

prostate cancer ● Match all words ○ Match any word

Search in

☑ Charity name ☑ Charity objects ☑ Charity activities

Where the charity operates

Search for charities operating: In any area or select Specific Areas

Classification

Search for charities by: What the charity does
Who the charity helps
307 Provides Advocacy/advice/information

Registration date

From To

Removed date

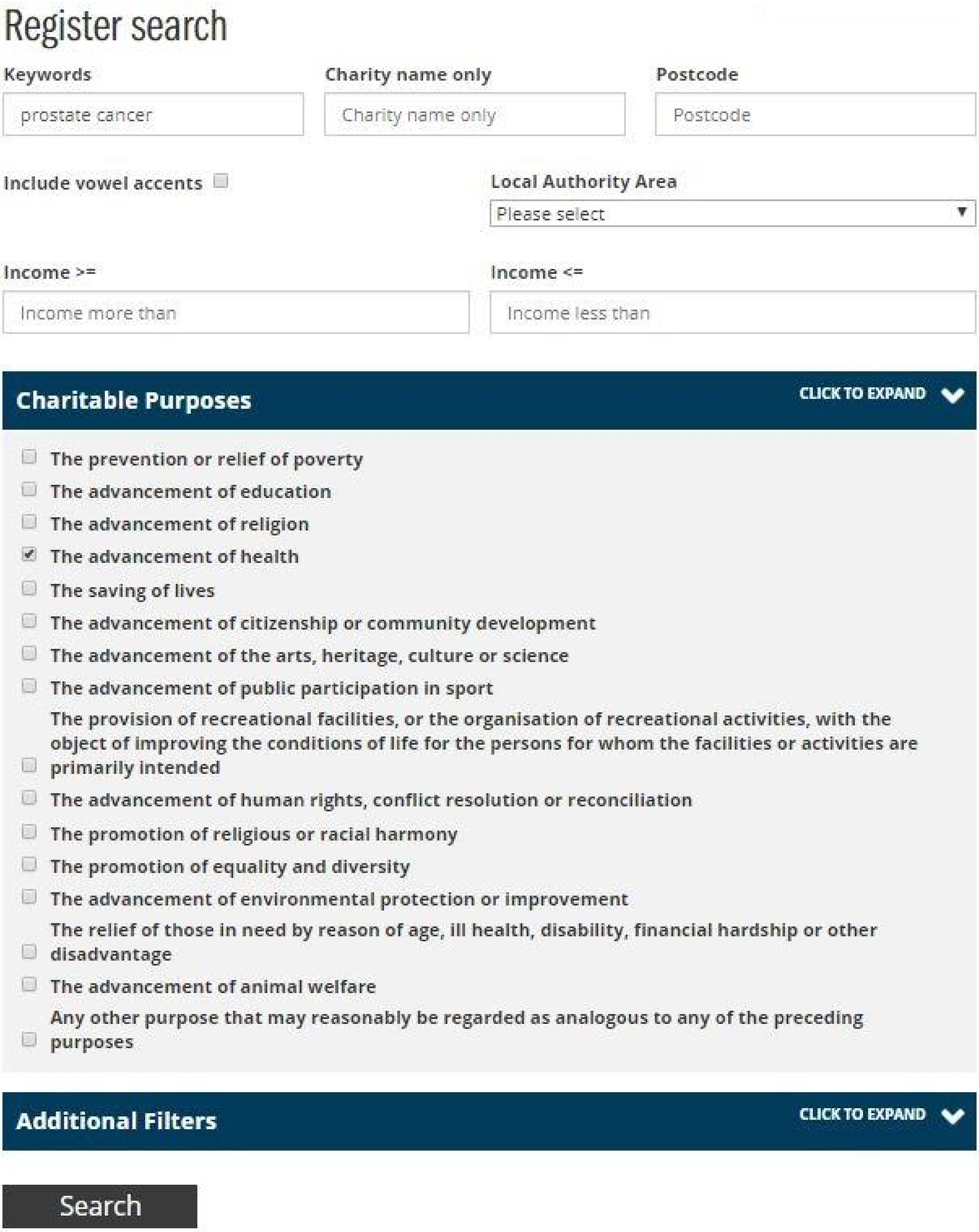
From To

Income range

Please select range

Search Reset

Figure 8.1: An example search of charities in the Charity Commission for England and Wales website (2017). Keyword is “prostate cancer” and keyword is searched in charity name, charity objects and charity activities. To further refine the search, under the section “How the charity operates”, the option “307 Provides advocacy/advice/information” was selected. For generic cancer charities, income range was also modified.



Register search

Keywords: prostate cancer

Charity name only: Charity name only

Postcode: Postcode

Include vowel accents ☐

Local Authority Area: Please select

Income >=: Income more than

Income <=: Income less than

Charitable Purposes CLICK TO EXPAND

- ☐ The prevention or relief of poverty
- ☐ The advancement of education
- ☐ The advancement of religion
- ☑ The advancement of health
- ☐ The saving of lives
- ☐ The advancement of citizenship or community development
- ☐ The advancement of the arts, heritage, culture or science
- ☐ The advancement of public participation in sport
- ☐ The provision of recreational facilities, or the organisation of recreational activities, with the object of improving the conditions of life for the persons for whom the facilities or activities are primarily intended
- ☐ The advancement of human rights, conflict resolution or reconciliation
- ☐ The promotion of religious or racial harmony
- ☐ The promotion of equality and diversity
- ☐ The advancement of environmental protection or improvement
- ☐ The relief of those in need by reason of age, ill health, disability, financial hardship or other disadvantage
- ☐ The advancement of animal welfare
- ☐ Any other purpose that may reasonably be regarded as analogous to any of the preceding purposes

Additional Filters CLICK TO EXPAND

Figure 8.2: An example search of charities in the Office for the Scottish Charity Regulator (OSCR) website (2017). Keyword is “prostate cancer”. To further refine the search, under the section “Charitable purposes”, the option “The advancement of health” was selected.

8.3.2. Assessment of content

An adapted version (Coulter et al., 2006) of “The International Patient Decision Aids Standards instrument” (IPDASi) (Elwyn et al., 2006) was used for the assessment of content. IPDASi is a validated assessment tool, which was originally developed to assess decision aids about treatment or screening options. Coulter et al. (2006) slightly adapted the IPDASi with elements from the DISCERN instrument (Charnock et al., 1999) to reflect differences in the assessment of the content of health-related materials, including healthy eating and obesity. The adapted checklist underwent three rounds of pilot testing before use. It consists of eight categories (Table 8.1). In each category, a minimum of one point and a maximum of five could be given, depending on the clarity of information provided. One point was given when the material did not meet the criteria in any way and five points when the material completely fulfilled the quality criteria. Scores of 2, 3 and 4 were awarded for materials which partially met the criteria with the actual score depending on the assessor’s evaluation. The lowest score that a PIM could receive was 8 and the highest was 40. The higher the score, the better the quality of the content was. An additional point was given if the material provides information on social care issues. A copy of the checklist is available on Appendix 6.

Table 8.1: Checklist for content assessment (Coulter et al., 2006).

Does the information leaflet/website…	***Maximum points***
Start with a clear statement of aims?	/5
Provide unbiased and detailed information about options?	/5
Present probabilities of outcomes in an understandable way?	/5
Contain accurate information?	/5
Help patients to make appropriate decisions	/5
Disclose conflicts of interest?	/5
Have a clear structure and layout?	/5
Help the reader judge its reliability?	/5
Total	***/40***

The content of all PIMs was assessed by the lead researcher and a subsample by an academic collaborator (Dr Jo Brett). Any uncertainties were discussed among all authors, until an agreement was reached.

8.3.3. Assessment of readability

The readability of PIMs was determined using the Flesch-Kincaid Grade Level (FKGL) (Kincaid et al., 1975) and the Simplified Measure of Gobbledygook (SMOG) Grade (McLaughlin, 1969). FKGL is a widely used readability tool, and the SMOG grade is considered the gold standard in health-related information and education materials (Ley and Florio, 1996). All tools have been previously validated and shown good reliability (Ley and Florio, 1996). FKGL uses the number of words per sentence and the number of syllables per word in an equation to calculate the US school grade level necessary to understand the text (Kincaid et al., 1975). The SMOG grade also reflects to the US school grade and is based on the square root of the number of words with three or more syllables on a total of thirty sentences (McLaughlin, 1969).

A random sample of approximately 500 words from each PIM was examined using software that includes both instruments described above (Automatic Readability Checker, 2017). Results of the readability assessment for each PIM sample included reading grade level, corresponding age range and reading ability, as shown in Table 8.2. A readability level of US grade 8 corresponds to the reading ability of 13-14 years old and is generally considered the upper acceptable level for the US population. The Joint Commission suggests PIMs should read on a grade 5 level or lower, which corresponds to the reading ability of 10-11 years old (The Joint Commission, 2010).

Table 8.2: Reading grade level (US) and corresponding age range and reading difficulty.

Reading grade level (US)	Age range (years)	Reading difficulty
5	10-11	Very easy
6	11-12	Easy
7	12-13	Fairly easy
8-9	13-15	Standard
10-12	15-18	Fairly difficult
>13	>18	Difficult or very difficult

8.3.4. Assessment of face validity

Face validity is defined as the extent to which a test is subjectively viewed as covering the concept it purports to measure (Holden, 2010). Public involvement was sought to assess the face validity of a number of PIMs. The national advisory body INVOLVE defines public involvement in research as “research carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”. The term “public” includes patients, carers and everyone who uses social and health care services. Public involvement is encouraged in health research design and implementation, as it improves the quality of research and makes it more relevant to the target population. The importance of public involvement is depicted on the fact that funding bodies and National Research Ethics Committees in the UK seek information on how the researchers have involved or plan to involve the public in the research (INVOLVE, 2012).

In order to conduct a more comprehensive evaluation of the identified PIMs, public involvement was sought. People who had been diagnosed and treated for a cancer were invited to give their feedback on the quality and content of selected PIMs. It was considered essential to have PIMs evaluated by people who would, in theory, benefit from such materials.

Patient and Public Involvement (PPI) contributors were invited through advisory groups, support groups and PPI web forums, such as the National Cancer Research Institute Consumer Forum group, the Oxfordshire Prostate Cancer support group, the “Patients active in Research" website (https://patientsactiveinresearch.org.uk/) and the Public Involvement in Primary Care research group at the Nuffield Department of Primary Care (advertisement in the "Involvement Matters" monthly newsletter). An example of the invitation letter to gatekeepers is in Appendix 6b. Those who expressed an interest were asked to provide feedback anonymously by answering four open-ended questions regarding the quality of the content, the ease of reading and whether the information they contained was helpful for them. The document that was sent to interested members included the following questions (Appendix 6c):

- How would you rate the information provided in this leaflet?
- How easy was it for you to understand the information?
- How helpful was the leaflet for you?
- Would you change anything?

Invitation to give feedback took place after the evaluation of the content and readability of the PIMs and PPI contributors were provided with PIMs with a range of scores in terms of content and readability. Each contributor was given up to three PIMs. Where possible, members reviewed PIMs that were related to their own type of cancer diagnosis. For example, a prostate cancer survivor would review a PIM from a prostate cancer charity.

Sample size is not determined in Patient and Public Involvement, as people act as advisors and contributors to the project, rather than research participants (INVOLVE, 2012). The aim was to collect feedback from a diverse group of people previously diagnosed with a pelvic malignancy. Regarding sample size, a recent paper on the readability of health-related PIMs recruited five people to evaluate face validity (Williams et al., 2015b). Because of the different cancer diagnoses in the pelvic area and the potential diversity of the sample, it was estimated that feedback from up to 20 people would be adequate for the face validity of the identified PIMs.

8.3.5. Analysis

Content and readability scores were analysed descriptively using the SPSS Statistical Package, version 23.0 (SPSS INC., Chicago, IL, USA). Normality of the content and readability data distribution for was assessed with the Shapiro-Wilk test and it was found that data were not normally distributed. Mann-Whitney U test was used to compare content and readability scores of PIMs from different sources. Results are presented as median and Interquartile Range [Median (IQR)]. Statistical significance was set at $P<0.05$. Feedback from PPI is presented as a summary. There was no aim to conduct qualitative analysis to the feedback, as we treated the participants as contributors to help shape future research.

8.3.6. Ethics and ethical considerations

Ethical approval was granted for the contribution of PPI members was granted by the University Research Ethics Committee (UREC), Oxford Brookes University (UREC 171150). Consent was implied by the return of the completed questionnaire.

Contact with PPI contributors was only via email to ensure minimal disruption and inconvenience. Questionnaires were completely anonymous and no personal information was sought by the research team. Only data about gender are presented in the results. No quotes were used in the presentation of results, minimising the possibility of any member to be identified through any quotes.

8.4. Results

8.4.1. Identification of PIMs

No information regarding diet or nutrition for any cancer type was found in NHS Choices, NHS Direct Wales or Health and Social Care Northern Ireland. The NHS Inform Scotland website had information under the sections “Exercise, diet and healthy living” and “Eating and digestion”. In all NHS websites, there were links to various charities’ website pages. Macmillan Cancer Support and Cancer Research UK were the most frequently mentioned sources for information on diet and nutrition after a cancer diagnosis.

Fifteen cancer centres were identified, eight of which provided information about diet (Table 8.3). Across these eight centres, a total of 26 PIMs were identified online, all of which were generic cancer PIMs and in the form of leaflets or booklets (Table 8.4). PIMs covered mainly topics related to diet during treatment, such as management of treatment-related side effects (eating problems, gastrointestinal disturbances and reduced appetite) and use of soft/liquidised food. PIMs from all cancer centres were available to download and print.

Search for charitable sector organisations yielded 319 results. After removing duplicates (*n*=37) and checking all websites, eight charities were found to provide information about diet after cancer diagnosis. Four charities provided cancer-specific PIMs and four charities provided generic PIMs (Table 8.3). Thirteen online PIMs were identified and assessed (Table 8.4). Topics covered in the materials include healthy eating, management of treatment-related side effects (eating problems, gastrointestinal disturbances and reduced appetite) and weight management. All charities provided information about diet in the form of booklets available to download and print, with the exception of Cancer Research UK, which had online information organised in sections.

Table 8.3: Cancer Centres and Charitable Organisations that provided online PIMs for diet and nutrition.

Cancer Centres
Christie Foundation NHS Trust, England
Clatterbridge Cancer Centre NHS Trust, England
The Royal Marsden NHS Foundation Trust, England
Leeds Teaching Hospitals NHS Trust, England
St Luke's Cancer Centre, Royal Surrey County Hospital NHS Foundation Trust, England
South East Scotland Cancer Network (Edinburgh Cancer Centre), Scotland
Velindre Cancer Centre, Wales
Belfast Cancer Centre, Northern Ireland
Charitable Organisations
Prostate Cancer UK
Fight Bladder Cancer
Beating Bowel Cancer
Bowel Cancer UK
World Research Cancer Fund/UK
Cancer Research UK
Macmillan Cancer Support
Penny Brohn UK

8.4.2. Assessment of content

A total of 40 PIMs were assessed. There was a wide range of scores for content (16 – 37/40). Overall, materials from charities scored higher [32 (4); *n*=13] than those from cancer centres [23 (11), P<0.001; *n*=26]. Comparison of PIMs from NHS sources with PIMs from other sources could not be performed, due to the small number of PIMs from the NHS (*n*=1). Most materials scored high in the categories “Clarity of aims” and “Clear structure and layout” (4 – 5/5). PIMs from six charities and four cancer centres (*n*=17) had the Information Standard logo, indicating that the organisations “have been certified as a producer of reliable health and social care information”. The range in scores is primarily a result of the content quality of PIMs provided by cancer centres. Materials from five cancer centres had an overall high content score whereas materials from three centres scored low in most categories of the checklist (Table 8.4).

8.4.3. Assessment of readability

Table 4 shows the grade reading level of all PIMs. The median reading grade level was 7.5 (2.1) for FKGL and 7.4 (1.7) for SMOG (*P*>0.05). No PIM scored as low as the recommended level of 5th grade (reading ability of 10-11 years old). Eight PIMs from charities (61.5%) and 21 PIMs from NHS/cancer centres (77.8%) had a readability score within acceptable reading grades (6th to 8th grade level; reading ability of 11-14 years old). Eleven PIMs (27.5%) scored higher than 8th grade level (reading ability of 13-14 years old). Materials from charities had a similar average readability level [8.1 (2.1)] to materials from cancer centres [7.2 (1.8); *P*=0.076].

8.4.4. Assessment of face validity

Sixteen PPI members (7 females, 9 males) evaluated eleven PIMs; seven were developed by charities (four pelvic-cancer specific and three generic) and four by cancer centres (Table 8.5). PIMs had a variety of scores in content (18-37/40) and readability (6.2-11.0).

PPI contributors generally praised the quality of these PIMs, as information was generally considered up-to-date with the latest evidence. Information was presented in a simple, direct and straightforward way, especially for smaller PIMs. Also, some PIMs had references for external sources of information and support, which was perceived as positive. However, two PPI contributors questioned the accuracy of information related to consumption of sugar, fizzy drinks and alcohol in some PIMs. Also, according to feedback, pictures did not reflect the educational purpose of the PIMs, as it was not clear what they were trying to portray. For example, an older cancer patient would not perceive a picture of a young person exercising as a realistic motive to increase physical activity to 30 minutes per day.

Table 8.4: Content and readability scores of available online PIMs (n 40).

Source	Title of publication (year)	Content score (/40)	Readability score (in U.S. grades)		Mean (SD)	Age range equivalent (years)
			FKGL	SMOG		
NHS (Scotland)	Eating and digestion/Exercise, diet and healthy living (2017)	23	7.5	7.4	7.5 (0.1)	13-14
Cancer Centre	Eating – Help yourself (2015)	30	10.8	8.7	9.8 (1.5)	15-16
	Advice about soft/liquidised food (2016)	29	6.6	7.0	6.8 (0.3)	12-13
	Eating well following treatment and recovery from cancer (2013)	30	6.8	7.2	7.0 (0.3)	12-13
	Eating well and coping with side effects (2016)	35	6.8	7.0	6.9 (0.1)	12-13
	Eating well when you have cancer (2016)	33	9.0	8.0	8.5 (0.7)	14-15
	Eating well during treatment (2017)	33	5.8	6.1	6.0 (0.2)	11-12
	Eating well during cancer treatment (2017)	34	7.2	7.3	7.3 (0.1)	12-13
	Healthy eating (2013)	23	7.7	7.6	7.7 (0.1)	13-14
	Eating well through your treatment (2013)	23	8.6	8.6	8.6 (0.0)	14-15
	Taste changes (2013)	23	5.3	6.0	5.7 (0.5)	11-12
	Soft diet (2013)	23	7.5	7.7	7.6 (0.1)	13-14
	Nausea and vomiting (2013)	23	8.7	8.0	8.4 (0.5)	13-14
	Loss of appetite (2013)	22	13.6	11.5	12.6 (1.5)	>18
	Diarrhoea (2013)	24	10.8	10.1	10.5 (0.5)	16-17
	Constipation (2013)	21	7.0	7.4	7.2 (0.3)	12-13
	Soft diet (2014)	20	7.0	7.5	7.3 (0.4)	12-13
	Dry mouth (2014)	18	5.9	6.4	6.2 (0.4)	11-12
	Nausea and vomiting (2014)	21	6.3	6.1	6.2 (0.1)	11-12
	Poor appetite (2014)	18	5.9	6.4	6.2 (0.4)	11-12

Source	Title of publication (year)	Content score (/40)	Readability score (in U.S. grades)		Mean (SD)	Age range equivalent (years)
			FKGL	SMOG		
Cancer centre	Taste changes (2014)	19	6.7	6.4	6.6 (0.2)	12-13
	Low fibre diet (2013)	19	6.6	6.8	6.7 (0.1)	12-13
	Poor appetite (2013)	23	7.4	7.2	7.3 (0.1)	12-13
	Constipation (2013)	17	6.5	7.0	6.8 (0.4)	12-13
	Diarrhoea (2013)	16	7.7	8.1	7.9 (0.3)	13-14
	Taste changes (2013)	16	6.5	6.7	6.6 (0.1)	12-13
	Soft diet (2013)	18	9.8	8.7	9.3 (0.8)	14-15
Charity	Eating well – Living with bowel cancer (2017)	26	11.9	10.0	11.0 (1.3)	16-17
	Your diet and lifestyle – Living with and beyond cancer (2017)	34	8.7	7.9	8.3 (0.6)	13-14
	Diet and physical activity for men with prostate cancer (2015)	31	6.9	7.0	7.0 (0.1)	12-13
	Diet and Nutrition (N/A)	26	8.4	8.5	8.5 (0.1)	14-15
	Healthy Living After Cancer (2016)	33	10.1	9.0	9.6 (0.8)	15-16
	Eating well during cancer (2017)	32	10.0	8.9	9.5 (0.8)	15-16
	Healthy Eating Guidelines (2017)	31	9.5	9.0	9.3 (0.4)	14-15
	Healthy Eating and Cancer (2017)	37	7.6	6.7	7.2 (0.6)	12-13
	Managing weight gain after cancer treatment (2016)	34	7.6	7.1	7.4 (0.4)	12-13
	Recipes for people affected by cancer (2015)	32	6.3	6.3	6.3 (0.0)	11-12
	The Building-up diet (2017)	35	7.2	7.3	7.3 (0.1)	12-13
	Eating problems (2017)	35	8.2	7.9	8.1 (0.2)	13-14
	Coping with cancer/Coping physically/Diet problems (2014-2017)	31	8.4	7.8	8.1 (0.4)	13-14

FKGL, Flesch-Kincaid Grade Level; SMOG, Simplified Measure of Gobbledygook; SD, Standard Deviation; NHS, National Health Service; N/A Not Available.

Table 8.5: PIMs assessed for face validity by PPI contributors.

Title of material	PPI feedback (*n*)
Diet and physical activity for men with prostate cancer	6
Healthy Living After Cancer	6
Helpful tips for people with dry mouth	1
Eating well through treatment	1
Eating – help yourself; A guide for patients with eating problems, and their families	5
Healthy eating and cancer	5
Your diet & Lifestyle	3
Eating Well, Living With Bowel Cancer	3
Diet & Nutrition	1
Eat well during cancer	1
Eat well when you have cancer	1

Most PIMs were easy to read and structure was appropriate to navigate easily and find relevant information. Language was considered simple in most PIMs and layout was clear. In larger PIMs, consumers noted that a more concise version would be easier to read.

PPI members thought that the content of most PIMs contained useful information and they would make an informed decision about diet based on it. Most of them did not find the information relevant to their current health status (which was expected), but noted that most PIMs would be useful to newly diagnosed cancer patients, patients who have not considered changing their lifestyle before, or patients who experience specific side effects. Some PIMs would benefit from information about special diets (e.g. vegetarian), according to feedback. In some PIMs, purpose and target audience needed to be explicitly mentioned at the beginning of the material. Consumers found that PIMs related to healthy eating after cancer treatment did not include advice for nutrition issues during treatment and vice versa. Finally, feedback for generic leaflets highlighted the need to address individual needs and provide some information for specific cancers, particularly the common ones (e.g. prostate). PPI feedback was generally positive for all given PIMs, irrespective of their content or readability scores.

8.5. Discussion

This study identified 40 online PIMs available from nine NHS sources (NHS Inform Scotland and eight NHS cancer centres) and eight charitable organisations. Considering the importance of providing sound nutritional advice after a cancer diagnosis in relation to weight management, nutritional management of side effects and healthy eating for future wellbeing (Demark-Wahnefried et al., 2015, Richman et al., 2012, Koutoukidis et al., 2015, Van Blarigan and Meyerhardt, 2015), it is important that such information is widely available. Development of materials from cancer centres indicates that information may be provided in some geographical regions of the UK. However, not all cancer centres had information about diet and nutrition online. Similarly, the NHS Scotland website had information about diet and nutrition in cancer survivorship, whereas the NHS England, Wales or Northern Ireland websites did not. Williams et al. (2015b) has highlighted the lack of any information about lifestyle (diet, physical activity, alcohol or smoking) in cancer survivorship in the NHS England website, despite it being the most preferred source of information for many patients in England (Rozmovits et al., 2004).

Patients may choose to look for nutritional information from a charity specific to their cancer, as they may expect to find information tailored to their individual needs. This study showed that only four cancer specific charities provided such information. Few charities websites had external links of information to generic cancer charities (this was not further assessed) but most websites did not include any information on diet and nutrition. Consumer feedback highlighted the need for tailored nutritional information from reliable sources, especially post-treatment. Results from qualitative studies have shown that when cancer patients receive dietary advice, it is often broad and does not meet their current needs and expectations (Hardcastle et al., 2018, Kwok et al., 2015, Sutton et al., 2017).

The variety in content scores from the checklist was not reflected in PPI consumers' feedback. According to the checklist, most PIMs had a clear structure and layout and included information based on the available (limited) scientific evidence; however, some PIMs would benefit from modifications. On the other hand, consumers' comments focussed mostly on the quality and the practicality of the information, which was considered adequate to make an informed decision in most cases. The IPDASi checklist contains some elements which may not be perceived as essential for cancer survivors, such as presentation of a reference list or the authors' credentials. Nevertheless, provision of PIMs from reliable sources, such as cancer centres and charities, may lead survivors to believe that PIMs have been created from experts who use the latest available evidence; hence the reason why no comments on credentials or references were made where this information was missing.

In terms of readability, although most of the PIMs in this study had an overall acceptable readability score, 28% of them may be perceived as hard to read. Given that 43% of the working population in the UK has low health literacy (Protheroe et al., 2017), it may be difficult for all cancer patients to fully understand the content of the current PIMs and this could contribute to health inequalities (Protheroe et al., 2017, Public Health England, 2015). Even though health literacy may not predict adherence to nutritional guidelines, especially among patients with chronic non-communicable diseases (Carrara and Schulz, 2018), PIMs should score within acceptable readability levels to enhance understanding.

The importance of patient and public involvement (PPI) in health and social care research has been highlighted in a recent systematic review (Brett et al., 2014). Feedback from PPI contributors in our study highlighted a number of positive and negative points about the PIMs that could not have been identified from the evaluation of content or readability. Involvement of service users is strongly recommended in the design of new PIMs and upgrade of existing ones and could possibly contribute to greater understanding and adherence (Smith et al., 2014, Dellson et al., 2016).

This study has both strengths and limitations. Assessment of quality was performed using three parameters; content, readability and face validity, as suggested by Beaunoyer et al. (2017) for the evaluation of online health information. It was not possible to assess the evidence base for the preparation of these materials. The content assessment tool was previously used in the assessment of health-related PIMs produced by UK organisations. One section of the checklist (presentation of probabilities of outcomes) was not relevant to PIMs about diet and nutrition but may be useful for the assessment of other health-related information materials. Also, involvement of patients provided in-depth information about the usefulness of the PIMs; patients or consumers active in research are often highly educated and more knowledgeable about healthcare issues and their views may not reflect the views of all pelvic cancer patients. PPI contributors' level of participation was limited to the provision of feedback based on four open ended questions.

This is not an exhaustive study of resources, as only materials available online were evaluated. For cancer centres, PIMs provided at the healthcare settings may be different to the ones currently available on the websites, as the websites may have not been updated with the latest versions. Access to online information may still be a challenge for older populations, who may have low digital literacy. Finally, the authors acknowledge that new PIMs may have been created and current PIMs may have been updated since the end of the evaluation (December 2017).

In conclusion, the current study found a limited number of online PIMs in diet and nutrition suitable for pelvic cancer populations. Most PIMs had a comprehensive content; however, some PIMs may benefit from modifications. PPI contributors were more interested in the practical information within the PIMs and provided overall positive feedback, irrespective of content or readability score. They also highlighted the need for tailored and evidence-based information in diet and nutrition for symptoms management and improving health.

In future, accessible, evidence-based diet and nutrition information should be made more widely available on NHS and charity sites.

Chapter 9. Conclusions, recommendations and future implications

9.1. Summary of unmet needs and practice recommendations

Findings from the mixed-methods study conducted in pelvic cancer survivors and from the study on availability and assessment of online nutrition materials for pelvic cancer populations have revealed a number of unmet needs, which could be taken into consideration for future practice.

- **The offer of information in diet and nutrition after a cancer diagnosis**

Research in diet and nutrition post-diagnosis is ongoing and there is strong interest from the scientific community in this field. The evidence base on diet, nutrition and cancer survivorship is still limited; however pelvic cancer survivors are interested in learning about diet and nutrition in relation to their diagnosis (Section 4.11).

Lack of routine provision of support (Section 4.9.1; Section 5.4/Theme 1), the expression of interest to learn more about diet and nutrition (Section 4.11) as well as the fact that only a minority considered nutrition unimportant in relation to future health (Section 4.8), all provide evidence of existing unmet needs. Even for people who did get support (from their healthcare team or other sources), a small proportion reported dissatisfaction with the level of advice (Sections 4.9.1, 4.10.1, 5.4.1). There is already sufficient evidence to suggest that healthy eating patterns could contribute to improved QoL and that overweight and obesity are associated with increased cancer mortality and overall mortality. Initiation of and engagement in conversations about diet and nutrition during and after the end of treatments and signposting to appropriate sources outside the clinical environment (support groups, online sources, health professionals outside the hospital) could be an important aspect of routine support. It may also be helpful to involve family members and people who care for survivors in conversations around diet, so that family/carers contribute successfully to patient care, improve outcomes related to diet and promote effective self-management.

- **Addressing diet and nutrition in relation to treatment side effects and comorbidities**

Considering the large number of participants who reported treatment side effects, particularly GI problems (Section 4.3), positive attitudes on the role of nutrition in alleviating side effects (Section 4.8), the low numbers who received support on this topic (n=33 from healthcare team and n=19 from other sources; Sections 4.9.1 and 4.10.1) and the number of people who didn't have discussions but would like to (n=39; Section 4.9.1), it is evident that survivors of a pelvic cancer faced nutritional challenges related to treatment side effects. Findings from this study suggest that some treatment side effects may be more frequent in the on-treatment phase compared to the post-treatment phase, but others seem to persist at least up to two years after the end of radiotherapy. Regular, long-term monitoring of nutritional problems could help patients to maintain optimal nutritional status, alleviate side effects and build the foundations for healthy eating habits and improved QoL in the future.

Acknowledging the presence of comorbidities and addressing nutritional issues relevant to comorbidities in an older population, like the sample in the mixed-methods study (Sections 4.2.2 and 4.2.4), could also be an important aspect of support. Strategies on management of diabetes (10% of surveyed sample) and hypertension (33% of surveyed sample) incorporate modifications on a person's diet. Also, weight management (mainly weight loss) is an effective strategy for the management of hypertension, arthritis and diabetes.

- **Addressing weight management issues**

Most participants had a BMI>25 kg/m2 (Section 4.2.4) and several experienced weight changes during and after cancer treatment (Section 4.4), which sometimes had a significant emotional impact (Sections 5.4.6 and 5.4.7), but support was limited (Sections 4.9.1 and 4.10.1). Whether the concerns involved keeping a stable weight for radiotherapy treatment or achieving weight loss for future health and to reduce the likelihood of cancer recurrence post-treatment (Sections 5.4.6 and 5.4.7), it was evident that some participants struggled and would have liked guidance. Engagement in conversations about weight management would be welcome from patients and could influence them to consider changing lifestyle behaviours to achieve optimal weight. The “teachable moment” of a cancer diagnosis may serve as a stronger motivator for successful weight loss, compared to previous attempts.

- **Provision of evidence based information**

In order to influence behaviour change, patients need to be convinced of the importance of diet and nutrition in the survivorship phase. Although the majority of participants considered diet and nutrition an important topic in survivorship outcomes (Section 4.8), a number of barriers were identified for lack of dietary change or lack of interest in considering diet and nutrition post-diagnosis (Section 5.10). Provision of information should be based on the latest scientific evidence from credible sources. It should, however, be acknowledged that there is still a lot to understand on the link between diet and cancer survivorship outcomes.

- **Signposting to reliable alternative sources of information**

As the study on PIMs showed (Chapter 8), there is some reliable information available to cancer patients from credible resources, but these resources are limited and materials are predominantly generic and designed to be useful across a range of cancer types. Addressing needs and concerns on an individual basis and provision of tailored information are core components of supporting effective self-management. Therefore, current materials are inadequate (can only serve as an additional form of support). As the results from the mixed-methods project showed, only a few participants looked at online sources, indicating that online sources may not be a priority source for information (as opposed to healthcare professionals). Also, several participants were not satisfied with the information they obtained (Section 4.10.1), highlighting a potential need for reliable and tailored information. Signposting to reliable alternative sources of information would reduce some of the burden to healthcare professionals. Other sources, such as support groups, could also be considered.

- **Education for health professionals on diet, nutrition and its relation to cancer**

All of the points above may be difficult to implement without the input from health professionals, as they are the main contact after a cancer diagnosis and are seen as the ‘experts’ by patients. Dietitians are the experts in relation to diet and nutrition; however, not every cancer patient is seen by a dietitian. In the absence of a dietitian, other health professionals could be educated (perhaps by dietitians) so they can provide reliable information / signposting to patients. It is important for health professionals to be educated on the role of diet and nutrition post diagnosis, from management of side effects to optimal nutritional status to weight management throughout treatment and post-treatment, and be provided with the appropriate resources. Although this PhD does not include “the health professional’s view” on diet and nutrition, there was some indication of dissatisfaction (needs not well met from survey findings; “trial and error” approach from interviews).

9.2. Future research directions

This PhD project has provided valuable input in identifying and understanding pelvic cancer survivors’ unmet needs for information and support in diet and nutrition after diagnosis. In order to implement successful strategies and interventions for behaviour change, Mitchie, Atkins and West (2014) suggested that the first step is to understand the behaviour. Understanding the behaviour signifies the need to define the problem in behavioural terms, select and specify the target behaviour and identify what needs to change. It is important to first understand the nature and range of the unmet needs – from management of side effects to weight issues – before designing and trialling successful dietary or lifestyle interventions. Interventions could include information resources, weight loss programmes, nutritional counselling and /or physical activity and fatigue management.

Moreover, as the samples of women with gynaecological cancer and people with bladder cancer were very small in the current project, it would be very useful to further explore diet and nutrition issues of these cancer groups, with the potential to identify unique unmet needs that this project may have not highlighted.

In relation to the development of reliable written information materials in diet and nutrition, new materials should take into account needs that arise from each individual cancer diagnosis and provide tailored information. They could also follow guidelines for development which could improve content and readability.

Apart from “the patient’s view”, it is also important to explore the “health professional’s view” with regards to provision of support to pelvic cancer patients and their level of awareness in diet and nutrition issues, with a view to identify potential unmet education and support needs. Interventions with the aim of enhancing health professionals’ knowledge could further impact on initiating discussions around diet and nutrition with cancer patients.

9.3. Personal reflections

Undertaking PhD studies is a learning process. Throughout the past three years of my studies I have come across a number of difficulties and challenges, from design and implementation to analysis and interpretation.

9.3.1. Reflections on study design

Regarding the study design, the formation of a questionnaire from scratch was a challenging procedure, as there was no existing suitable questionnaire. The input from clinical colleagues and members of the NIHR Cancer and Nutrition infrastructure collaboration PPI Group was valuable to ensure the questionnaire was easy and quick to complete but also able to capture the important points of the research questions.

Obtaining ethics approval for the mixed-methods study was also a time-consuming process, from which I got valuable experience regarding the complexities of obtaining ethics from NRES and HRA. Overall, the study needed to be approved by four committees (FREC, NRES, HRA & OUH R&D) before implementation and it took overall six months (April – October 2017) to get the final approval.

Had I had the opportunity to repeat any part of the PhD, I would have made a few changes. I would have preferred to have the survey administered to the same sample twice; once during treatment and once around 12 months post-treatment. This way, I would have had comparable data of dietary changes, nutritional awareness and nutritional support over time. Although this design had been suggested, it would have been impossible to implement within the time restrictions of this PhD. Instead, the design was cross-sectional and the two groups (on-treatment, post-treatment) were different. Moreover, the questionnaire would have included questions regarding gender and red meat consumption.

9.3.2. Relying on others for recruitment of the required sample

The mixed-methods study involved the recruitment of cancer patients from the healthcare setting; however, I am not a NHS staff member and recruitment relied exclusively on members of the clinical team. Acknowledging that cancer nurses and radiographers have a very busy schedule daily, it has been very much appreciated that they invested time to administer the survey to eligible participants. All collaborators at OUH NHS trust were very helpful throughout the recruitment period. However, it is understood that some suitable patients may have not been invited to participate if clinical staff forgot or did not have sufficient time to discuss it with them (on-treatment group). After all, there are certain priorities in a review clinical meeting and discussions about the study were made at the end of this meeting.

9.3.3. First exposure to qualitative research

Possibly the most challenging, and at the same time exciting part of this PhD, was the first exposure to qualitative research. I designed the topic guide, decided which individuals I would interview, transcribed verbatim and undertook the analysis using Framework; all were new to me.

Telephone interviews proved to be a successful method of interviewing, as all participants felt comfortable enough to describe their dietary habits and experiences of nutritional support. There were few exceptions, mainly in relation to describing cancer diagnosis and treatments (this was the opening topic for the first two interviews), in which participants were hesitant in being open about their disease. Since this was not the main focus of the interviews, I changed the opening discussion topic and no problems occurred. Lack of confidence from my side was apparent in the first two telephone interviews but improved rapidly in the next interviews.

A few more challenges during the interviews occurred. One participant got emotional as they described their experiences and it was difficult to offer support and comfort over the phone. The only thing I was able to do is ask if they were alright and if they wanted the interview to stop. Had it been a face-to-face interview, I might have been able to be more supportive. There were also – luckily very few – rude people who decided to drop out but expressed themselves in a rude way before hanging up. All distressing events were discussed in detail with the supervisory team.

Throughout the study I have used a research diary and made summaries of the content for each interview and some personal comments and reflections. The research diary helped me understand the point I reached “data saturation” and aided in reflecting on my role as a nutritionist and researcher in conducting interviews and analysing the data.

9.3.4. Reflection on analysis

Due to the exploratory nature of the PhD, logistic regression analysis proved more difficult than initially anticipated. After thorough reading of relevant literature, I identified several factors that could be included in the logistic regression models and I was very careful on which factors I would include in my final model. There were more data generated than initially planned, which significantly increased my analysis workload but it was also exciting to explore new combinations between variables. Due to the large amount of non-parametric tests of associations, I decided to set the level of confidence at 99% ($p<0.01$) to minimise the probability of Type-I error.

Regarding analysis of qualitative data, Framework proved a valuable tool for a researcher without prior experience in qualitative research. The Excel spreadsheet provided the right structure I needed to organise data and allowed me a clear view of where the codes could be combined. Some data would not “fit” under my initial themes but after discussion with the supervisors and Dr Lauren Matheson, these issues were successfully resolved.

9.3.5. Dissemination activities and involvement with WCRF

During the past three years, I have been invited to disseminate findings from my PhD in six conferences (in three of them I received a bursary), one networking meeting, one Masterclass (scholarship from the WCRF), two postgraduate research events at OBU and a clinical team meeting. My work attracted interest in the scientific community and I was grateful to present my work and engage with other researchers who work in the field of cancer survivorship.

The highlight of my PhD studies is the recognition of my work by the WCRF, which awarded me with an Academy fellowship to attend the Nutrition and Cancer Masterclass in Holland in 2019. I am now one of the few WCRF Academy Fellows and an “ambassador” of their work.

9.4. Conclusion

Overall, this PhD thesis makes a significant and novel contribution to the understanding of the information and support needs that people diagnosed with a pelvic cancer have in relation to diet and nutrition. Research in the role of diet and nutrition in survivorship outcomes is emerging and is relatively new. Despite known benefits of healthy dietary patterns in cancer survivors, research has generally focussed on breast cancer survivors and other populations have been under researched. Identification of unmet needs is the first step towards the design of successful behaviour change interventions and this PhD contributes to knowledge regarding unmet needs through the implementation of a mixed-methods research design.

The findings highlight that diet and nutrition is valued as an important lifestyle component in survivorship and that some improvements in clinical practice are warranted to ensure pelvic cancer patients have the information they require and feel well supported. Identification of the unmet needs can also feed into the development of future dietary interventions in these populations with the aim of improving future wellbeing. Appropriate guidance that leads to effective self-management is a core component of the NHS initiative in cancer care and should be the ultimate goal for the healthcare system before patient discharge.

BIBLIOGRAPHY

ABDI, H. 2007. The Bonferonni and Šidák Corrections for Multiple Comparisons. *Encyclopedia of Measurement and Statistics.* Thousand Oaks (CA): Sage.

ADAMS, E., BOULTON, M. G., HORNE, A., ROSE, P. W., DURRANT, L., COLLINGWOOD, M., OSKROCHI, R., DAVIDSON, S. E. & WATSON, E. K. 2014. The Effects of Pelvic Radiotherapy on Cancer Survivors: Symptom Profile, Psychological Morbidity and Quality of Life. *Clinical Oncology,* 26**,** 10-17.

ADAMS, S. V., CEBALLOS, R. & NEWCOMB, P. A. 2016. Quality of Life and Mortality of Long-Term Colorectal Cancer Survivors in the Seattle Colorectal Cancer Family Registry. *Plos One,* 11**,** 13.

ALLEMANI, C., MATSUDA, T., DI CARLO, V., HAREWOOD, R., MATZ, M., NIKŠIĆ, M., BONAVENTURE, A., VALKOV, M., JOHNSON, C. J., ESTÈVE, J., OGUNBIYI, O. J., AZEVEDO E SILVA, G., CHEN, W.-Q., ESER, S., ENGHOLM, G., STILLER, C. A., MONNEREAU, A., WOODS, R. R., VISSER, O., LIM, G. H., AITKEN, J., WEIR, H. K., COLEMAN, M. P., BOUZBID, S., HAMDI-CHÉRIF, M., ZAIDI, Z., MEGUENNI, K., REGAGBA, D., BAYO, S., CHEICK BOUGADARI, T., MANRAJ, S. S., BENDAHHOU, K., FABOWALE, A., BRADSHAW, D., SOMDYALA, N. I. M., KUMCHER, I., MORENO, F., CALABRANO, G. H., ESPINOLA, S. B., CARBALLO QUINTERO, B., FITA, R., DIUMENJO, M. C., LASPADA, W. D., IBAÑEZ, S. G., LIMA, C. A., DE SOUZA, P. C. F., DEL PINO, K., LAPORTE, C., CURADO, M. P., DE OLIVEIRA, J. C., VENEZIANO, C. L. A., VENEZIANO, D. B., LATORRE, M. R. D. O., TANAKA, L. F., REBELO, M. S., SANTOS, M. O., GALAZ, J. C., APARICIO ARAVENA, M., SANHUEZA MONSALVE, J., HERRMANN, D. A., VARGAS, S., HERRERA, V. M., URIBE, C. J., BRAVO, L. E., GARCIA, L. S., ARIAS-ORTIZ, N. E., MORANTES, D., JURADO, D. M., YÉPEZ CHAMORRO, M. C., DELGADO, S., RAMIREZ, M., GALÁN ALVAREZ, Y. H., TORRES, P., MARTÍNEZ-REYES, F., JARAMILLO, L., QUINTO, R., CASTILLO, J., MENDOZA, M., CUEVA, P., YÉPEZ, J. G., BHAKKAN, B., DELOUMEAUX, J., JOACHIM, C., MACNI, J., CARRILLO, R., SHALKOW KLINCOVSTEIN, J., RIVERA GOMEZ, R., POQUIOMA, E., TORTOLERO-LUNA, G., ZAVALA, D., ALONSO, R., BARRIOS, E., ECKSTRAND, A., NIKIFORUK, C., NOONAN, G., TURNER, D., KUMAR, E., ZHANG, B., MCCRATE, F. R., RYAN, S., et al. 2018. Global surveillance of trends in cancer survival 2000-14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries. *The Lancet,* 391**,** 1023-1075.

ALLIN, S., GRIGNON, M. & LE GRAND, J. 2010. Subjective unmet need and utilization of health care services in Canada: what are the equity implications? *Soc Sci Med,* 70**,** 465-472.

ANDERSON, A. S., STEELE, R. & COYLE, J. 2013. Lifestyle issues for colorectal cancer survivors--perceived needs, beliefs and opportunities. *Supportive Care In Cancer: Official Journal Of The Multinational Association Of Supportive Care In Cancer,* 21**,** 35-42.

ANDREYEV, H. J., WOTHERSPOON, A., DENHAM, J. W. & HAUER-JENSEN, M. 2011. "Pelvic radiation disease": new understanding and new solutions for a new disease in the era of cancer survivorship. *Scand J Gastroenterol,* 46**,** 389-97.

AREM, H., PFEIFFER, R. M., MOORE, S. C., IRWIN, M. L., LAMONTE, M. J., SARTO, G. E., NASSIR, R., LUO, J., CHLEBOWSKI, R. T., BRINTON, L. A. & MATTHEWS, C. E. 2017. Post-diagnosis body mass index and mortality among women diagnosed with endometrial cancer: Results from the Women's Health Initiative. *PLoS One,* 12**,** e0171250.

ARENDS, J., BACHMANN, P., BARACOS, V., BARTHELEMY, N., BERTZ, H., BOZZETTI, F., FEARON, K., HÜTTERER, E., ISENRING, E., KAASA, S., KRZNARIC, Z., LAIRD, B., LARSSON, M., LAVIANO, A., MÜHLEBACH, S., MUSCARITOLI, M., OLDERVOLL, L., RAVASCO, P., SOLHEIM, T., STRASSER, F., DE VAN DER SCHUEREN, M. & PREISER, J. C. 2017a. ESPEN guidelines on nutrition in cancer patients. *Clin Nutr,* 36**,** 11-48.

ARENDS, J., BARACOS, V., BERTZ, H., BOZZETTI, F., CALDER, P. C., DEUTZ, N. E. P., ERICKSON, N., LAVIANO, A., LISANTI, M. P., LOBO, D. N., MCMILLAN, D. C., MUSCARITOLI, M., OCKENGA, J., PIRLICH, M., STRASSER, F., DE VAN DER SCHUEREN, M., VAN GOSSUM, A., VAUPEL, P. & WEIMANN, A. 2017b. ESPEN expert group recommendations for action against cancer-related malnutrition. *Clin Nutr,* 36**,** 1187-1196.

ASH, S., REEVES, M., BAUER, J., DOVER, T., VIVANTI, A., LEONG, C., O'MOORE SULLIVAN, T. & CAPRA, S. 2006. A randomised control trial comparing lifestyle groups, individual counselling and written information in the management of weight and health outcomes over 12 months. *Int J Obes (Lond),* 30**,** 1557-64.

AUTOMATIC READABILITY CHECKER. 2017. Available: http://www.readabilityformulas.com/free-readability-formula-tests.php [Accessed December 2017].

AVERY, K. N., DONOVAN, J. L., HORWOOD, J., NEAL, D. E., HAMDY, F. C., PARKER, C., WADE, J. & LANE, A. 2014. The importance of dietary change for men diagnosed with and at risk of prostate cancer: a multi-centre interview study with men, their partners and health professionals. *BMC family practice,* 15**,** 81.

AVERY, K. N. L., DONOVAN, J. L., GILBERT, R., DAVIS, M., EMMETT, P., DOWN, L., OLIVER, S., NEAL, D. E., HAMDY, F. C. & LANE, J. A. 2013. Men with prostate cancer make positive dietary changes following diagnosis and treatment. *Cancer Causes & Control: CCC,* 24**,** 1119-1128.

BAGULEY, B. J., BOLAM, K. A., WRIGHT, O. R. L. & SKINNER, T. L. 2017. The Effect of Nutrition Therapy and Exercise on Cancer-Related Fatigue and Quality of Life in Men with Prostate Cancer: A Systematic Review. *Nutrients,* 9**,** 30.

BARBOUR, R. S. 1999. The case for combining qualitative and quantitative approaches in health services research. *J Health Serv Res Policy,* 4**,** 39-43.

BASEN-ENGQUIST, K., SCRUGGS, S., JHINGRAN, A., BODURKA, D. C., LU, K., RAMONDETTA, L., HUGHES, D. & TAYLOR, C. C. 2009. Physical activity and obesity in endometrial cancer survivors: associations with pain, fatigue, and physical functioning. *American Journal of Obstetrics and Gynecology,* 200**,** 8.

BEAUNOYER, E., ARSENAULT, M., LOMANOWSKA, A. M. & GUITTON, M. J. 2017. Understanding online health information: Evaluation, tools, and strategies. *Patient Educ Couns,* 100**,** 183-189.

BEAVER, K., LATIF, S., WILLIAMSON, S., PROCTER, D., SHERIDAN, J., HEATH, J., SUSNERWALA, S. & LUKER, K. 2010. An exploratory study of the follow-up care needs of patients treated for colorectal cancer. *J Clin Nurs,* 19**,** 3291-300.

BEAVER, K., WILSON, C., PROCTER, D., SHERIDAN, J., TOWERS, G., HEATH, J., SUSNERWALA, S. & LUKER, K. 2011. Colorectal cancer follow-up: patient satisfaction and amenability to telephone after care. *Eur J Oncol Nurs,* 15**,** 23-30.

BENOOT, C., HANNES, K. & BILSEN, J. 2016. The use of purposeful sampling in a qualitative evidence synthesis: A worked example on sexual adjustment to a cancer trajectory. *BMC Med Res Methodol,* 16**,** 21.

BLANCHARD, C. M., COURNEYA, K. S. & STEIN, K. 2008. Cancer survivors' adherence to lifestyle behavior recommendations and associations with health-related quality of life: results from the American Cancer Society's SCS-II. *J Clin Oncol,* 26**,** 2198-204.

BLUETHMANN, S. M., BASEN-ENGQUIST, K., VERNON, S. W., COX, M., GABRIEL, K. P., STANSBERRY, S. A., CARMACK, C. L., BLALOCK, J. A. & DEMARK-WAHNEFRIED, W. 2015. Grasping the 'teachable moment': time since diagnosis, symptom burden and health behaviors in breast, colorectal and prostate cancer survivors. *Psychooncology,* 24**,** 1250-1257.

BOLTON-SMITH, C., WOODWARD, M., TUNSTALL-PEDOE, H. & MORRISON, C. 2000. Accuracy of the estimated prevalence of obesity from self reported height and weight in an adult Scottish population. *Journal of Epidemiology and Community Health,* 54**,** 143-148.

BOUILLON, K., HADDY, N., DELALOGE, S., GARBAY, J. R., GARSI, J. P., BRINDEL, P., MOUSANNIF, A., LE, M. G., LABBE, M., ARRIAGADA, R., JOUGLA, E., CHAVAUDRA, J., DIALLO, I., RUBINO, C. & DE VATHAIRE, F. 2011. Long-term cardiovascular mortality after radiotherapy for breast cancer. *J Am Coll Cardiol,* 57**,** 445-52.

BOURS, M. J., BEIJER, S., WINKELS, R. M., VAN DUIJNHOVEN, F. J., MOLS, F., BREEDVELD-PETERS, J. J., KAMPMAN, E., WEIJENBERG, M. P. & VAN DE POLL-FRANSE, L. V. 2015. Dietary changes and dietary supplement use, and underlying motives for these habits reported by colorectal cancer survivors of the Patient Reported Outcomes Following Initial Treatment and Long-Term Evaluation of Survivorship (PROFILES) registry. *British Journal of Nutrition,* 114**,** 286-296.

BRAUN, V. & CLARKE, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology,* 3**,** 77-101.

BRAUN, V. & CLARKE, V. 2016. (Mis)conceptualising themes, thematic analysis, and other problems with Fugard and Potts' (2015) sample-size tool for thematic analysis. *International Journal of Social Research Methodology,* 19**,** 739-743.

BRAUN, V. & CLARKE, V. 2019. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health***,** 1-16.

BRAY, F., FERLAY, J., SOERJOMATARAM, I., SIEGEL, R. L., TORRE, L. A. & JEMAL, A. 2018. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin,* 68**,** 394-424.

BRETT, J., STANISZEWSKA, S., MOCKFORD, C., HERRON-MARX, S., HUGHES, J., TYSALL, C. & SULEMAN, R. 2014. Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expect,* 17**,** 637-50.

BROWN, S., GREENFIELD, D. & THOMPSON, J. 2016. Knowledge and awareness of long-term and late treatment consequences amongst colorectal cancer survivors: A qualitative study. *European Journal of Oncology Nursing,* 20**,** 191-198.

BRUG, J. 2008. Determinants of healthy eating: motivation, abilities and environmental opportunities. *Fam Pract,* 25 Suppl 1**,** i50-5.

BRYMAN, A. 2012. Mixed methods research: combining quantitative and qualitative research. *Social research methods.* 4th ed. New York: Oxford University Press.

BURDEN, S., JONES, D. J., SREMANAKOVA, J., SOWERBUTTS, A. M., LAL, S., PILLING, M. & TODD, C. 2019. Dietary interventions for adult cancer survivors. *Cochrane Database of Systematic Reviews*.

CAMPBELL, P. T., NEWTON, C. C., DEHAL, A. N., JACOBS, E. J., PATEL, A. V. & GAPSTUR, S. M. 2012. Impact of body mass index on survival after colorectal cancer diagnosis: the Cancer Prevention Study-II Nutrition Cohort. *J Clin Oncol,* 30**,** 42-52.

CANCER AND NUTRITION NIHR INFRASTRUCTURE COLLABORATION 2015. Report of Phase One.

CANCER RESEARCH UK. 2017. *Side effects of cancer drugs* [Online]. Available: https://www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/cancer-drugs/side-effects [Accessed 24/07 2019].

CAO, Y. & MA, J. 2011. Body mass index, prostate cancer-specific mortality, and biochemical recurrence: a systematic review and meta-analysis. *Cancer Prev Res (Phila),* 4**,** 486-501.

CARR, P. R., JANSEN, L., WALTER, V., KLOOR, M., ROTH, W., BLAKER, H., CHANG-CLAUDE, J., BRENNER, H. & HOFFMEISTER, M. 2016. Associations of red and processed meat with survival after colorectal cancer and differences according to timing of dietary assessment. *Am J Clin Nutr,* 103**,** 192-200.

CARRARA, A. & SCHULZ, P. J. 2018. The role of health literacy in predicting adherence to nutritional recommendations: A systematic review. *Patient Educ Couns,* 101**,** 16-24.

CASTRO, F. G., KELLISON, J. G., BOYD, S. J. & KOPAK, A. 2010. A Methodology for Conducting Integrative Mixed Methods Research and Data Analyses. *Journal of Mixed Methods Research,* 4**,** 342-360.

CENTRE FOR PUBLIC HEALTH EXCELLENCE AT, N. & NATIONAL COLLABORATING CENTRE FOR PRIMARY, C. 2006. National Institute for Health and Clinical Excellence: Guidance. *Obesity: The Prevention, Identification, Assessment and Management of Overweight and Obesity in Adults and Children.* London: National Institute for Health and Clinical Excellence (UK)

National Institute for Health and Clinical Excellence.

CESARIO, S., MORIN, K. & SANTA-DONATO, A. 2002. Evaluating the level of evidence of qualitative research. *Jognn-Journal of Obstetric Gynecologic and Neonatal Nursing,* 31**,** 708-714.

CHA, R., MURRAY, M. J., THOMPSON, J., WALL, C. R., HILL, A., HULME-MOIR, M., MERRIE, A. & FINDLAY, M. P. N. 2012. Dietary patterns and information needs of colorectal cancer patients post-surgery in Auckland. *The New Zealand Medical Journal,* 125**,** 38-46.

CHAN, D. S., VIEIRA, A. R., AUNE, D., BANDERA, E. V., GREENWOOD, D. C., MCTIERNAN, A., NAVARRO ROSENBLATT, D., THUNE, I., VIEIRA, R. & NORAT, T. 2014. Body mass index and survival in women with breast cancer-systematic literature review and meta-analysis of 82 follow-up studies. *Ann Oncol,* 25**,** 1901-14.

CHARITY COMMISSION FOR ENGLAND AND WALES. 2017. Available: http://apps.charitycommission.gov.uk/showcharity/registerofcharities/RegisterHomePage.aspx [Accessed November 2017].

CHARITY COMMISSION FOR NORTHERN IRELAND. 2017. Available: https://www.charitycommissionni.org.uk/ [Accessed November 2017].

CHARMAZ, K. 2014. *Constructing grounded theory*.

CHARNOCK, D., SHEPPERD, S., NEEDHAM, G. & GANN, R. 1999. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. *Journal of epidemiology and community health,* 53**,** 105-111.

CLARK, L. H., KO, E. M., KERNODLE, A., HARRIS, A., MOORE, D. T., GEHRIG, P. A. & BAE-JUMP, V. 2016. Endometrial Cancer Survivors' Perceptions of Provider Obesity Counseling and Attempted Behavior Change: Are We Seizing the Moment? *International Journal Of Gynecological Cancer: Official Journal Of The International Gynecological Cancer Society,* 26**,** 318-324.

CLEELAND, C. S., ALLEN, J. D., ROBERTS, S. A., BRELL, J. M., GIRALT, S. A., KHAKOO, A. Y., KIRCH, R. A., KWITKOWSKI, V. E., LIAO, Z. & SKILLINGS, J.

2012. Reducing the toxicity of cancer therapy: recognizing needs, taking action. *Nat Rev Clin Oncol,* 9**,** 471-8.

COA, K. I., SMITH, K. C., KLASSEN, A. C., CAULFIELD, L. E., HELZLSOUER, K., PEAIRS, K. & SHOCKNEY, L. 2014. Capitalizing on the "teachable moment" to promote healthy dietary changes among cancer survivors: the perspectives of health care providers. *Supportive Care in Cancer,* 23**,** 679-686.

COA, K. I., SMITH, K. C., KLASSEN, A. C., THORPE, R. J., JR. & CAULFIELD, L. E. 2015. Exploring important influences on the healthfulness of prostate cancer survivors' diets. *Qual Health Res,* 25**,** 857-70.

COLEMAN, S., BERG, C. J. & THOMPSON, N. J. 2014. Social support, nutrition intake, and physical activity in cancer survivors. *Am J Health Behav,* 38**,** 414-9.

COLLACO, N., RIVAS, C., MATHESON, L., NAYOAN, J., WAGLAND, R., ALEXIS, O., GAVIN, A., GLASER, A. & WATSON, E. 2018. Prostate cancer and the impact on couples: a qualitative metasynthesis. *Support Care Cancer,* 26**,** 1703-1713.

COLLACO, N., WAGLAND, R., ALEXIS, O., GAVIN, A., GLASER, A. & WATSON, E. K. 2019. The challenges on the family unit faced by younger couples affected by prostate cancer: A qualitative study. *Psychooncology,* 28**,** 329-335.

CORBETT, T., CHEETHAM, T., MÜLLER, A. M., SLODKOWSKA-BARABASZ, J., WILDE, L., KRUSCHE, A., RICHARDSON, A., FOSTER, C., WATSON, E., LITTLE, P., YARDLEY, L. & BRADBURY, K. 2018. Exploring cancer survivors' views of health behaviour change: 'Where do you start, where do you stop with everything?'. *Psycho-Oncology,* 27**,** 1816-1824.

COULTER, A., ELLINS, J., SWAIN, D., CLARKE, A., HERON, P., RASUL, F., MAGEE, H. & SHELDON, H. 2006. Assessing the quality of information to support people in making decisions about their health and healthcare.

CUMMINGS, A., GRIMMETT, C., CALMAN, L., PATEL, M., PERMYAKOVA, N. V., WINTER, J., CORNER, J., DIN, A., FENLON, D., RICHARDSON, A., SMITH, P. W. & FOSTER, C. 2018. Comorbidities are associated with poorer quality of life and functioning and worse symptoms in the 5 years following colorectal cancer surgery: Results from the ColoREctal Well-being (CREW) cohort study. *Psychooncology,* 27**,** 2427-2435.

CURRIE, L. & NUNEZ-SMITH, M. 2015. Data Analysis and Integration in Mixed Methods Studies. *Mixed Methods in Health Sciences Research: A Practical Primer.* Thousand Oaks, California: SAGE Publications, Inc.

CURRIE, L. & NUNEZ-SMITH, M. 2017. Determining the Appropriateness and Feasibility of Using Mixed Methods. *Mixed Methods in Health Sciences Research: A Practical Primer.* Thousand Oaks: SAGE Publications.

DE VET, E., DE RIDDER, D. T. & DE WIT, J. B. 2011. Environmental correlates of physical activity and dietary behaviours among young people: a systematic review of reviews. *Obes Rev,* 12**,** e130-42.

DELLSON, P., NILBERT, M. & CARLSSON, C. 2016. Patient representatives' views on patient information in clinical cancer trials. *BMC Health Serv Res,* 16**,** 36.

DEMARK-WAHNEFRIED, W., CLIPP, E. C., LIPKUS, I. M., LOBACH, D., SNYDER, D. C., SLOANE, R., PETERSON, B., MACRI, J. M., ROCK, C. L., MCBRIDE, C. M. & KRAUS, W. E. 2007. Main outcomes of the FRESH START trial: a sequentially tailored, diet and exercise mailed print intervention among breast and prostate cancer survivors. *Journal Of Clinical Oncology: Official Journal Of The American Society Of Clinical Oncology,* 25**,** 2709-2718.

DEMARK-WAHNEFRIED, W., PETERSON, B., MCBRIDE, C., LIPKUS, I. & CLIPP, E. 2000. Current health behaviors and readiness to pursue life-style changes among men and women diagnosed with early stage prostate and breast carcinomas. *Cancer,* 88**,** 674-684.

DEMARK-WAHNEFRIED, W., ROGERS, L. Q., ALFANO, C. M., THOMSON, C. A., COURNEYA, K. S., MEYERHARDT, J. A., STOUT, N. L., KVALE, E., GANZER, H. & LIGIBEL, J. A. 2015. Practical clinical interventions for diet, physical activity, and weight control in cancer survivors. *CA Cancer J Clin,* 65, 167-89.

DEMPSEY, S. E., FINDLAY, N. & MACDONALD-WICKS, L. 2011. Increasing nutritional support for patients undergoing radiation therapy: the radiation therapist perspective. *Journal of Radiotherapy in Practice,* 10, 181-189.

DENLINGER, C. S., CARLSON, R. W., ARE, M., BAKER, K. S., DAVIS, E., EDGE, S. B., FRIEDMAN, D. L., GOLDMAN, M., JONES, L., KING, A., KVALE, E., LANGBAUM, T. S., LIGIBEL, J. A., MCCABE, M. S., MCVARY, K. T., MELISKO, M., MONTOYA, J. G., MOONEY, K., MORGAN, M. A., O'CONNOR, T., PASKETT, E. D., RAZA, M., SYRJALA, K. L., URBA, S. G., WAKABAYASHI, M. T., ZEE, P., MCMILLIAN, N. & FREEDMAN-CASS, D. 2014. Survivorship: introduction and definition. Clinical practice guidelines in oncology. *Journal of the National Comprehensive Cancer Network : JNCCN,* 12, 34-45.

DEPARTMENT OF HEALTH, MACMILLAN CANCER SUPPORT & NHS IMPROVEMENT 2013. Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision. *In:* CROWN (ed.). London.

DES BORDES, J., ABDEL-WAHAB, N., SUAREZ-ALMAZOR, M., LOPEZ-OLIVO, M., DES BORDES, J. K. A. & LOPEZ-OLIVO, M. A. 2016. Assessing information needs on bone health in cancer survivors. *Journal of Cancer Survivorship,* 10, 480-488.

DICKINSON, A. & MACKAY, D. 2014. Health habits and other characteristics of dietary supplement users: a review. *Nutrition Journal,* 13, 8.

DIEPERINK, K. B., HANSEN, S., WAGNER, L., JOHANSEN, C., ANDERSEN, K. K. & HANSEN, O. 2012. Living alone, obesity and smoking: Important factors for quality of life after radiotherapy and androgen deprivation therapy for prostate cancer. *Acta Oncologica,* 51, 722-729.

DOWNES, M. J., BRENNAN, M. L., WILLIAMS, H. C. & DEAN, R. S. 2016. Development of a critical appraisal tool to assess the quality of cross-sectional studies (AXIS). *Bmj Open,* 6, 7.

DRABBLE, L., TROCKI, K. F., SALCEDO, B., WALKER, P. C. & KORCHA, R. A. 2016. Conducting qualitative interviews by telephone: Lessons learned from a study of alcohol use among sexual minority and heterosexual women. *Qualitative social work : QSW : research and practice,* 15, 118-133.

DUNN, J., LYNCH, B., RINALDIS, M., PAKENHAM, K., MCPHERSON, L., OWEN, N., LEGGETT, B., NEWMAN, B. & AITKEN, J. 2006. Dimensions of quality of life and psychosocial variables most salient to colorectal cancer patients. *Psychooncology,* 15, 20-30.

DUSKA, L. R. & DIZON, D. S. 2014. Improving quality of life in female cancer survivors: current status and future questions. *Future Oncology,* 10, 1015-1026.

EBERT, J. F., HUIBERS, L., CHRISTENSEN, B. & CHRISTENSEN, M. B. 2018. Paper- or Web-Based Questionnaire Invitations as a Method for Data Collection: Cross-Sectional Comparative Study of Differences in Response Rate, Completeness of Data, and Financial Cost. *Journal of medical Internet research,* 20, e24-e24.

EDGINGTON, A. & MORGAN, M. A. 2011. Looking Beyond Recurrence: Comorbidities in Cancer Survivors. *Clinical Journal of Oncology Nursing,* 15, 31-31.

EHEMAN, C. R., BERKOWITZ, Z., LEE, J., MOHILE, S., PURNELL, J., RODRIGUEZ, E. M., ROSCOE, J., JOHNSON, D., KIRSHNER, J. & MORROW, G. 2009. Information-seeking styles among cancer patients before and after treatment by demographics and use of information sources. *J Health Commun,* 14, 487-502.

EKMAN, I., BERGBOM, I., EKMAN, T., BERTHOLD, H. & MAHSNEH, S. M. 2004. Maintaining normality and support are central issues when receiving chemotherapy for ovarian cancer. *Cancer Nurs,* 27, 177-82.

ELLIOTT, J., FALLOWS, A., STAETSKY, L., SMITH, P. W. F., FOSTER, C. L., MAHER, E. J. & CORNER, J. 2011. The health and well-being of cancer survivors in the UK: findings from a population-based survey. *British Journal of Cancer,* 105**,** S11-S20.

ELWYN, G., O'CONNOR, A., STACEY, D., VOLK, R., EDWARDS, A., COULTER, A., THOMSON, R., BARRATT, A., BARRY, M., BERNSTEIN, S., BUTOW, P., CLARKE, A., ENTWISTLE, V., FELDMAN-STEWART, D., HOLMES-ROVNER, M., LLEWELLYN-THOMAS, H., MOUMJID, N., MULLEY, A., RULAND, C., SEPUCHA, K., SYKES, A. & WHELAN, T. 2006. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ,* 333**,** 417.

ER, V., LANE, J. A., MARTIN, R. M., PERSAD, R., CHINEGWUNDOH, F., NJOKU, V. & SUTTON, E. 2017. Barriers and facilitators to healthy lifestyle and acceptability of a dietary and physical activity intervention among African Caribbean prostate cancer survivors in the UK: a qualitative study. *BMJ Open,* 7**,** e017217-e017217.

EVANS, M. A., SHAW, A. R. G., SHARP, D. J., THOMPSON, E. A., FALK, S., TURTON, P. & THOMPSON, T. 2007. Men with cancer: is their use of complementary and alternative medicine a response to needs unmet by conventional care? *European Journal of Cancer Care,* 16**,** 517-525.

FADE, S. A. & SWIFT, J. A. 2011. Qualitative research in nutrition and dietetics: data analysis issues. *J Hum Nutr Diet,* 24**,** 106-14.

FALLER, H., KOCH, U., BRAHLER, E., HARTER, M., KELLER, M., SCHULZ, H., WEGSCHEIDER, K., WEIS, J., BOEHNCKE, A., HUND, B., REUTER, K., RICHARD, M., SEHNER, S., SZALAI, C., WITTCHEN, H. U. & MEHNERT, A. 2016. Satisfaction with information and unmet information needs in men and women with cancer. *J Cancer Surviv,* 10**,** 62-70.

FASSIER, P., ZELEK, L., LECUYER, L., BACHMANN, P., TOUILLAUD, M., DRUESNE-PECOLLO, N., GALAN, P., COHEN, P., HOARAU, H., LATINO-MARTEL, P., KESSE-GUYOT, E., BAUDRY, J., HERCBERG, S., DESCHASAUX, M. & TOUVIER, M. 2017. Modifications in dietary and alcohol intakes between before and after cancer diagnosis: Results from the prospective population-based NutriNet-Sante cohort. *Int J Cancer,* 141**,** 457-470.

FILLENBAUM, G. G., KUCHIBHATLA, M. N., WHITSON, H. E., BATCH, B. C., SVETKEY, L. P., PIEPER, C. F., KRAUS, W. E., COHEN, H. J. & BLAZER, D. G. 2010. Accuracy of Self-reported Height and Weight in a Community-Based Sample of Older African Americans and Whites. *Journals of Gerontology Series a-Biological Sciences and Medical Sciences,* 65**,** 1123-1129.

FITCH, M., GRAY, R. E. & FRANSSEN, E. 2000. Perspectives on living with ovarian cancer: young women's views. *Canadian oncology nursing journal = Revue canadienne de nursing oncologique,* 10**,** 101-108.

FITCH, M. I., GRAY, R. E. & FRANSSEN, E. 2001. Perspectives on living with ovarian cancer: older women's views. *Oncology Nursing Forum,* 28**,** 1433-1442.

FLETCHER, C., FLIGHT, I., CHAPMAN, J., FENNELL, K. & WILSON, C. 2017. The information needs of adult cancer survivors across the cancer continuum: A scoping review. *Patient Educ Couns,* 100**,** 383-410.

FUNG, T. T., KASHAMBWA, R., SATO, K., CHIUVE, S. E., FUCHS, C. S., WU, K., GIOVANNUCCI, E., OGINO, S., HU, F. B. & MEYERHARDT, J. A. 2014. Post diagnosis diet quality and colorectal cancer survival in women. *PLoS One,* 9**,** e115377.

GALE, N. K., HEATH, G., CAMERON, E., RASHID, S. & REDWOOD, S. 2013. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology,* 13**,** 117.

GANGADHARAN, A., CHOI, S. E., HASSAN, A., AYOUB, N. M., DURANTE, G., BALWANI, S., KIM, Y. H., PECORA, A., GOY, A. & SUH, K. S. 2017. Protein calorie malnutrition, nutritional intervention and personalized cancer care. *Oncotarget,* 8**,** 24009-24030.

GELLRICH, N.-C., HANDSCHEL, J., HOLTMANN, H. & KRÜSKEMPER, G. 2015. Oral Cancer Malnutrition Impacts Weight and Quality of Life. *Nutrients,* 7**,** 2145-2160.

GLAJCHEN, M. 2004. The emerging role and needs of family caregivers in cancer care. *J Support Oncol,* 2**,** 145-55.

GRAUDAL, N. A., HUBECK-GRAUDAL, T. & JURGENS, G. 2017. Effects of low sodium diet versus high sodium diet on blood pressure, renin, aldosterone, catecholamines, cholesterol, and triglyceride. *Cochrane Database of Systematic Reviews*.

GREENLEE, H., SHI, Z., SARDO MOLMENTI, C. L., RUNDLE, A. & TSAI, W. Y. 2016. Trends in Obesity Prevalence in Adults With a History of Cancer: Results From the US National Health Interview Survey, 1997 to 2014. *J Clin Oncol,* 34**,** 3133-40.

GUREN, M. G., TOBIASSEN, L. B., TRYGG, K. U., DREVON, C. A. & DUELAND, S. 2006. Dietary intake and nutritional indicators are transiently compromised during radiotherapy for rectal cancer. *Eur J Clin Nutr,* 60**,** 113-9.

HALBACH, S. M., ERNSTMANN, N., KOWALSKI, C., PFAFF, H., PFORTNER, T. K., WESSELMANN, S. & ENDERS, A. 2016. Unmet information needs and limited health literacy in newly diagnosed breast cancer patients over the course of cancer treatment. *Patient Educ Couns,* 99**,** 1511-8.

HALL, S., GRAY, N., BROWNE, S., ZIEBLAND, S. & CAMPBELL, N. C. 2012. A qualitative exploration of the role of primary care in supporting colorectal cancer patients. *Supportive Care In Cancer: Official Journal Of The Multinational Association Of Supportive Care In Cancer,* 20**,** 3071-3078.

HANNES, K. 2011. Critical appraisal of qualitative research. *Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions.* Cochrane Collaboration Qualitative Methods Group.

HARDCASTLE, S. J., GLASSEY, R., SALFINGER, S., TAN, J. & COHEN, P. 2017. Factors influencing participation in health behaviors in endometrial cancer survivors. *Psycho-Oncology,* 26**,** 1099-1104.

HARDCASTLE, S. J., MAXWELL-SMITH, C., HAGGER, M. S., O'CONNOR, M. & PLATELL, C. 2018. Exploration of information and support needs in relation to health concerns, diet and physical activity in colorectal cancer survivors. *European Journal of Cancer Care,* 27.

HARRISON, J. D., YOUNG, J. M., PRICE, M. A., BUTOW, P. N. & SOLOMON, M. J. 2009. What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer,* 17**,** 1117-28.

HARTOONIAN, N., ORMSETH, S. R., HANSON, E. R., BANTUM, E. O. & OWEN, J. E. 2014. Information-seeking in cancer survivors: application of the Comprehensive Model of Information Seeking to HINTS 2007 data. *J Health Commun,* 19**,** 1308-25.

HAWKINS, M. L., BUYS, S. S., GREN, L. H., SIMONSEN, S. E., KIRCHHOFF, A. C. & HASHIBE, M. 2017. Do cancer survivors develop healthier lifestyle behaviors than the cancer-free population in the PLCO study? *Journal of Cancer Survivorship,* 11**,** 233-245.

HAWKINS, N. A., BERKOWITZ, Z. & RODRIGUEZ, J. L. 2015. Awareness of Dietary and Alcohol Guidelines Among Colorectal Cancer Survivors. *American Journal Of Preventive Medicine,* 49**,** S509-S517.

HEALTH AND SOCIAL CARE NORTHERN IRELAND. 2017. Available: http://online.hscni.net/ [Accessed December 2017].

HENRIKSEN, H. B., RAEDER, H., BOHN, S. K., PAUR, I., KVAERNER, A. S., BILLINGTON, S. A., ERIKSEN, M. T., WIEDSVANG, G., ERLUND, I., FAERDEN, A., VEIEROD, M. B., ZUCKNICK, M., SMELAND, S. & BLOMHOFF, R. 2017. The Norwegian dietary guidelines and colorectal cancer survival (CRC-NORDIET) study: a food-based multicentre randomized controlled trial. *BMC Cancer,* 17**,** 83.

HENSON, C. C., BURDEN, S., DAVIDSON, S. E. & LAL, S. 2013. Nutritional interventions for reducing gastrointestinal toxicity in adults undergoing radical pelvic radiotherapy. *The Cochrane Database Of Systematic Reviews***,** CD009896.

HEWITT, M. E., GREENFIELD, S., STOVALL, E. & EBRARY, I. 2005. From cancer patient to cancer survivor lost in transition. Washington, DC: National Academies Press.

HOEDJES, M., DE KRUIF, A., MOLS, F., BOURS, M., BEIJER, S., WINKELS, R., WESTERMAN, M. J., SEIDELL, J. C. & KAMPMAN, E. 2017. An exploration of needs and preferences for dietary support in colorectal cancer survivors: A mixed-methods study. *Plos One,* 12**,** e0189178-e0189178.

HOHWÜ, L., LYSHOL, H., GISSLER, M., JONSSON, S. H., PETZOLD, M. & OBEL, C. 2013. Web-based versus traditional paper questionnaires: a mixed-mode survey with a Nordic perspective. *Journal of medical Internet research,* 15**,** e173-e173.

HOLDEN, R. R. 2010. Face Validity. *In:* WEINER, I. B. & CRAIGHEAD, W. E. (eds.) *The Corsini Encyclopedia of Psychology.*

HOLLA, J., POLL-FRANSE, L., HUIJGENS, P., MOLS, F., DEKKER, J., HOLLA, J. F. M., VAN DE POLL-FRANSE, L. V. & HUIJGENS, P. C. 2016. Utilization of supportive care by survivors of colorectal cancer: results from the PROFILES registry. *Supportive Care in Cancer,* 24**,** 2883-2892.

HONG, Q. N., PLUYE, P., BUJOLD, M. & WASSEF, M. 2017. Convergent and sequential synthesis designs: implications for conducting and reporting systematic reviews of qualitative and quantitative evidence. *Syst Rev,* 6**,** 61.

HOPKINSON, J. B. 2018. The Nourishing Role: Exploratory Qualitative Research Revealing Unmet Support Needs in Family Carers of Patients With Advanced Cancer and Eating Problems. *Cancer Nurs,* 41**,** 131-138.

HOREVOORTS, N. J., VISSERS, P. A., MOLS, F., THONG, M. S. & VAN DE POLL-FRANSE, L. V. 2015. Response rates for patient-reported outcomes using web-based versus paper questionnaires: comparison of two invitational methods in older colorectal cancer patients. *Journal of medical Internet research,* 17**,** e111-e111.

INDEPENDENT CANCER TASKFORCE 2015. Achieving world-class outcomes. A strategy for England 2015-2020.

INOUE-CHOI, M., GREENLEE, H., OPPENEER, S. J. & ROBIEN, K. 2014. The Association between Postdiagnosis Dietary Supplement Use and Total Mortality Differs by Diet Quality among Older Female Cancer Survivors. *Cancer Epidemiology Biomarkers & Prevention,* 23**,** 865-875.

INOUE-CHOI, M., ROBIEN, K. & LAZOVICH, D. 2013. Adherence to the WCRF/AICR guidelines for cancer prevention is associated with lower mortality among older female cancer survivors. *Cancer Epidemiol Biomarkers Prev,* 22**,** 792-802.

INVOLVE 2012. Briefing notes for researchers: public involvement in NHS, public health and social care research.

JACKSON, S. E., WARDLE, J., JOHNSON, F., FINER, N. & BEEKEN, R. J. 2013. The impact of a health professional recommendation on weight loss attempts in overweight and obese British adults: a cross-sectional analysis. *BMJ Open,* 3**,** e003693.

JAMES, E. L., STACEY, F. G., CHAPMAN, K., BOYES, A. W., BURROWS, T., GIRGIS, A., ASPREY, G., BISQUERA, A. & LUBANS, D. R. 2015. Impact of a nutrition and physical activity intervention (ENRICH: Exercise and Nutrition Routine Improving Cancer Health) on health behaviors of cancer survivors and carers: a pragmatic randomized controlled trial. *BMC Cancer,* 15**,** 710.

JANG, I., KIM, J.-S., KIM, M. & LEE, E. 2018. Assessing Information Needs Regarding Metabolic Syndrome Among Gynecological Cancer Survivors: A Concurrent Mixed Method. *Cancer Nursing*.

JOCHEMS, S. H. J., VAN OSCH, F. H. M., BRYAN, R. T., WESSELIUS, A., VAN SCHOOTEN, F. J., CHENG, K. K. & ZEEGERS, M. P. 2018. Impact of dietary patterns and the main food groups on mortality and recurrence in cancer survivors: a systematic review of current epidemiological literature. *Bmj Open,* 8**,** 12.

KARVINEN, K. H., DUBOSE, K. D., CARNEY, B. & ALLISON, R. R. 2010. Promotion of physical activity among oncologists in the United States. *J Support Oncol,* 8**,** 35-41.

KASSIANOS, A. P., COYLE, A. & RAATS, M. M. 2015. Perceived influences on post-diagnostic dietary change among a group of men with prostate cancer. *European Journal of Cancer Care,* 24**,** 818-826.

KASSIANOS, A. P., RAATS, M. M. & GAGE, H. 2017. Post-diagnostic dietary changes in prostate cancer: associations with patients' wellbeing and the perceptions of GPs. *European Journal of Cancer Care,* 26.

KENZIK, K., PISU, M., FOUAD, M. N. & MARTIN, M. Y. 2016. Are long-term cancer survivors and physicians discussing health promotion and healthy behaviors? *Journal of Cancer Survivorship,* 10**,** 271-279.

KHANNA, S., JAISWAL, K. S. & GUPTA, B. 2017. Managing Rheumatoid Arthritis with Dietary Interventions. *Frontiers in nutrition,* 4**,** 52-52.

KINCAID, J. P., FISHBURNE, R. P., ROGERS, R. L. & CHISSOM, B. S. 1975. Derivation of new readability formulas (Automated Readability Index, Fog Count and Flesch Reading Ease Formula) for Navy enlisted personnel ; Research Branch Report 8-75.

KOCH, L., JANSEN, L., BRENNER, H. & ARNDT, V. 2013. Fear of recurrence and disease progression in long-term (>= 5 years) cancer survivors-a systematic review of quantitative studies. *Psycho-Oncology,* 22**,** 1-11.

KOTRONOULAS, G., PAPADOPOULOU, C., BURNS-CUNNINGHAM, K., SIMPSON, M. & MAGUIRE, R. 2017. A systematic review of the supportive care needs of people living with and beyond cancer of the colon and/or rectum. *European Journal Of Oncology Nursing: The Official Journal Of European Oncology Nursing Society,* 29**,** 60-70.

KOUTOUKIDIS, D. A., BEEKEN, R. J., LOPES, S., KNOBF, M. T. & LANCELEY, A. 2017. Attitudes, challenges and needs about diet and physical activity in endometrial cancer survivors: a qualitative study. *European Journal of Cancer Care,* 26.

KOUTOUKIDIS, D. A., KNOBF, M. T. & LANCELEY, A. 2015. Obesity, Diet, Physical Activity, and Health-Related Quality of Life in Endometrial Cancer Survivors. *Nutrition Reviews,* 73**,** 399-408.

KOUTOUKIDIS, D. A., LOPES, S., FISHER, A., WILLIAMS, K., CROKER, H. & BEEKEN, R. J. 2018. Lifestyle advice to cancer survivors: a qualitative study on the perspectives of health professionals. *BMJ Open,* 8**,** e020313.

KROENKE, C. H., NEUGEBAUER, R., MEYERHARDT, J., PRADO, C. M., WELTZIEN, E., KWAN, M. L., XIAO, J. & CAAN, B. J. 2016. Analysis of Body Mass Index and Mortality in Patients With Colorectal Cancer Using Causal DiagramsBody Mass Index and Colorectal Cancer PrognosisBody Mass Index and Colorectal Cancer Prognosis. *JAMA Oncology,* 2**,** 1137-1145.

KWOK, A., PALERMO, C. & BOLTONG, A. 2015. Dietary experiences and support needs of women who gain weight following chemotherapy for breast cancer. *Support Care Cancer,* 23**,** 1561-8.

LAMPERT, A., WIEN, K., HAEFELI, W. E. & SEIDLING, H. M. 2016. Guidance on how to achieve comprehensible patient information leaflets in four steps. *Int J Qual Health Care,* 28**,** 634-638.

LAUDICELLA, M., WALSH, B., BURNS, E. & SMITH, P. C. 2016. Cost of care for cancer patients in England: evidence from population-based patient-level data. *Br J Cancer,* 114**,** 1286-92.

LE BOUTILLIER, C., ARCHER, S., BARRY, C., KING, A., MANSFIELD, L. & URCH, C. 2019. Conceptual framework for living with and beyond cancer: A systematic review and narrative synthesis. *Psychooncology,* 28**,** 948-959.

LEE, M. K., PARK, S. Y. & CHOI, G. S. 2018. Association of support from family and friends with self-leadership for making long-term lifestyle changes in patients with colorectal cancer. *Eur J Cancer Care (Engl),* 27**,** e12846.

LEE, P. Y., NG, C. J., ONG, T. A., LEE, Y. K., KHATIJAH LIM, A., CHEONG, A. T. & AZAD HASSAN, A. R. 2017. Post-treatment impact and needs of prostate cancer survivors in Malaysia; a qualitative study. *Malaysian Family Physician: The Official Journal Of The Academy Of Family Physicians Of Malaysia,* 12**,** 18-24.

LEE, Y., SHIN, H., BAE, E. & LIM, H. 2016. Aspects of Health-Related Factors and Nutritional Care Needs by Survival Stage among Female Cancer Patients in South Korea. *Plos One,* 11**,** e0163281-e0163281.

LEMASTERS, T. J., MADHAVAN, S. S., SAMBAMOORTHI, U. & KURIAN, S. 2014. Health behaviors among breast, prostate, and colorectal cancer survivors: a US population-based case-control study, with comparisons by cancer type and gender. *J Cancer Surviv,* 8**,** 336-48.

LEMSTRA, M., BIRD, Y., NWANKWO, C., ROGERS, M. & MORAROS, J. 2016. Weight loss intervention adherence and factors promoting adherence: a meta-analysis. *Patient preference and adherence,* 10**,** 1547-1559.

LEY, P. & FLORIO, T. 1996. The use of readability formulas in health care. *Psychology, Health & Medicine,* 1**,** 7-28.

LIU, J., DAVIDSON, E., BHOPAL, R., WHITE, M., JOHNSON, M., NETTO, G., DEVERILL, M. & SHEIKH, A. 2012. Adapting health promotion interventions to meet the needs of ethnic minority groups: mixed-methods evidence synthesis. *Health Technol Assess,* 16**,** 1-469.

LUCAS, P. J., BAIRD, J., ARAI, L., LAW, C. & ROBERTS, H. M. 2007. Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. *BMC Med Res Methodol,* 7**,** 4.

MACIAS, Y. F. & GLASAUER, P. 2014. Guidelines for assessing nutrition-related Knowledge, Attitudes and Practices (KAP).

MACMILLAN CANCER SUPPORT 2017. *Eating problems and cancer : a practical guide to living with and after cancer*.

MACMILLAN CANCER SUPPORT 2018a. *Managing the late effects of bowel cancer treatment : a practical guide to living with and after cancer*.

MACMILLAN CANCER SUPPORT 2018b. *Pelvic radiotherapy in men : managing the side effects during treatment*.

MACMILLAN CANCER SUPPORT 2018c. *Pelvic radiotherapy in women : managing side effects during treatment*.

MADDAMS, J., UTLEY, M. & MOLLER, H. 2012. Projections of cancer prevalence in the United Kingdom, 2010-2040. *British Journal of Cancer,* 107**,** 1195-1202.

MARDAS, M., STELMACH-MARDAS, M. & MADRY, R. 2017. Body weight changes in patients undergoing chemotherapy for ovarian cancer influence progression-free and overall survival. *Support Care Cancer,* 25**,** 795-800.

MAZZOTTI, E., ANTONINI CAPPELLINI, G. C., BUCONOVO, S., MORESE, R., SCOPPOLA, A., SEBASTIANI, C. & MARCHETTI, P. 2012. Treatment-related side effects and quality of life in cancer patients. *Support Care Cancer,* 20**,** 2553-7.

MCBRIDE, C. M., EMMONS, K. M. & LIPKUS, I. M. 2003. Understanding the potential of teachable moments: the case of smoking cessation. *Health Education Research,* 18, 156-170.

MCLAUGHLIN, H. G. 1969. SMOG grading - a new readability formula. *Journal of Reading,* 12, 639-646.

MCSPADDEN, K. E., PATRICK, H., OH, A. Y., YAROCH, A. L., DWYER, L. A. & NEBELING, L. C. 2016. The association between motivation and fruit and vegetable intake: The moderating role of social support. *Appetite,* 96, 87-94.

MEYERHARDT, J. A., KROENKE, C. H., PRADO, C. M., KWAN, M. L., CASTILLO, A., WELTZIEN, E., CESPEDES FELICIANO, E. M., XIAO, J. & CAAN, B. J. 2017. Association of Weight Change after Colorectal Cancer Diagnosis and Outcomes in the Kaiser Permanente Northern California Population. *Cancer Epidemiol Biomarkers Prev,* 26, 30-37.

MICHIE, S., ATKINS, L. & WEST, R. 2014. *The behaviour change wheel : a guide to designing Interventions*.

MITSUZUKA, K. & ARAI, Y. 2018. Metabolic changes in patients with prostate cancer during androgen deprivation therapy. *Int J Urol,* 25, 45-53.

MOHER, D., LIBERATI, A., TETZLAFF, J. & ALTMAN, D. G. 2009. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med,* 6, e1000097.

MOZAFFARIAN, D., AFSHIN, A., BENOWITZ, N. L., BITTNER, V., DANIELS, S. R., FRANCH, H. A., JACOBS, D. R., JR., KRAUS, W. E., KRIS-ETHERTON, P. M., KRUMMEL, D. A., POPKIN, B. M., WHITSEL, L. P. & ZAKAI, N. A. 2012. Population approaches to improve diet, physical activity, and smoking habits: a scientific statement from the American Heart Association. *Circulation,* 126, 1514-63.

MURPHY, J. L. & GIROT, E. A. 2013. The importance of nutrition, diet and lifestyle advice for cancer survivors the role of nursing staff and interprofessional workers. *Journal of Clinical Nursing,* 22, 1539-1549.

NATIONAL CANCER INSTITUTE. 2019. *NCI Dictionary of Cancer Terms, Definition of Cancer* [Online]. Available: https://www.cancer.gov/publications/dictionaries/cancer-terms/def/cancer [Accessed July 2019].

NATIONAL CANCER REGISTRATION AND ANALYSIS SERVICE. 2017. *Chemotherapy, Radiotherapy and Surgical Tumour Resections in England* [Online]. Available: http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/main_cancer_treatments [Accessed October 2017 2017].

NAYAN, S., GUPTA, M. K., STRYCHOWSKY, J. E. & SOMMER, D. D. 2013. Smoking cessation interventions and cessation rates in the oncology population: an updated systematic review and meta-analysis. *Otolaryngol Head Neck Surg,* 149, 200-11.

NHS CHOICES (SECTION CANCER). 2017. Available: https://www.nhs.uk/conditions/Cancer/ [Accessed December 2017].

NHS CHOICES (SECTION SERVICES; CANCER CENTRES). 2017. Available: https://www.nhs.uk/service-search/Disambiguation/Organisation?serviceName=cancer%20centre [Accessed December 2017].

NHS DIRECT WALES (SECTION CANCER). 2017. Available: https://www.nhsdirect.wales.nhs.uk/encyclopaedia/c/article/cancer [Accessed December 2017].

NHS INFORM SCOTLAND (SECTION CANCER). 2017. Available: https://www.nhsinform.scot/illnesses-and-conditions/cancer [Accessed December 2017].

NIHR 2015. Cancer and Nutrition NIHR infrastructure collaboration: Report of Phase One July 2015. University of Southampton & University Hospital Southampton NHS Foundation Trust.

NIKOLETTI, S., YOUNG, J., LEVITT, M., KING, M., CHIDLOW, C. & HOLLINGSWORTH, S. 2008. Bowel problems, self-care practices, and information needs of colorectal cancer survivors at 6 to 24 months after sphincter-saving surgery. *Cancer Nursing,* 31**,** 389-398.

O'HANLON, E. & KENNEDY, N. 2014. Exercise in cancer care in Ireland: a survey of oncology nurses and physiotherapists. *Eur J Cancer Care (Engl),* 23**,** 630-9.

O'CATHAIN, A., MURPHY, E. & NICHOLL, J. 2010. Three techniques for integrating data in mixed methods studies. *BMJ,* 341**,** c4587.

OFFICE FOR NATIONAL STATISTICS 2017. Cancer Registration Statistics, England: 2015.

OFFICE FOR NATIONAL STATISTICS 2018. Cancer Registration Statistics, England: 2016.

OFFICE FOR NATIONAL STATISTICS 2019. Cancer Registration Statistics, England: 2017.

OFFICE FOR THE SCOTTISH CHARITY REGULATOR. 2017. Available: https://www.oscr.org.uk/ [Accessed November 2017].

ONWUEGBUZIE, A. J. & COLLINS, K. M. T. 2007. A Typology of Mixed Methods Sampling Designs in Social Science Research. *The Qualitative Report,* 12**,** 281-316.

ORGANISATION OF EUROPEAN CANCER INSTITUTES. 2017. Available: http://www.oeci.eu/Membership_l.aspx?Id_Country=21 [Accessed December 2017].

PALESH, O., SCHEIBER, C., KESLER, S., MUSTIAN, K., KOOPMAN, C. & SCHAPIRA, L. 2018. Management of side effects during and post-treatment in breast cancer survivors. *Breast J,* 24**,** 167-175.

PALINKAS, L. A., HORWITZ, S. M., GREEN, C. A., WISDOM, J. P., DUAN, N. & HOAGWOOD, K. 2015. Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Adm Policy Ment Health,* 42**,** 533-44.

PARAMASIVAM, S., PROIETTO, A. & PUVANESWARY, M. 2006. Pelvic anatomy and MRI. *Best Practice & Research in Clinical Obstetrics & Gynaecology,* 20**,** 3-22.

PATTERSON, R. E., NEUHOUSER, M. L., HEDDERSON, M. M., SCHWARTZ, S. M., STANDISH, L. J., BOWEN, D. J. & MARSHALL, L. M. 2002. Types of alternative medicine used by patients with breast, colon, or prostate cancer: predictors, motives, and costs. *Journal Of Alternative And Complementary Medicine (New York, N.Y.),* 8**,** 477-485.

PELENGARIS, S. & KHAN, M. 2013. Overview of Cancer Biology. *In:* PELENGARIS, S. & KHAN, M. (eds.) *The Molecular Biology of Cancer: A Bridge from Bench to Bedside.* Second ed.: John Wiley & Sons.

PERL, G., NORDHEIMER, S., LANDO, S., BENEDICT, C., BRENNER, B., PERRY, S., SHMOISMAN, G., PURIM, O., AMIT, L., STEMMER, S. M. & BEN-AHARON, I. 2016. Young patients and gastrointestinal (GI) tract malignancies - are we addressing the unmet needs? *BMC Cancer,* 16**,** 630-630.

PICCIRILLO, J. F., VLAHIOTIS, A., BARRETT, L. B., FLOOD, K. L., SPITMAGEL, E. L. & STEYERBERG, E. W. 2008. The changing prevalence of comorbidity across the age spectrum. *Critical Reviews in Oncology Hematology,* 67**,** 124-132.

PLAYDON, M., FERRUCCI, L. M., MCCORKLE, R., STEIN, K. D., CANNADY, R., SANFT, T. & CARTMEL, B. 2016. Health information needs and preferences in relation to survivorship care plans of long-term cancer survivors in the American Cancer Society's Study of Cancer Survivors-I. *J Cancer Surviv,* 10**,** 674-85.

PRIMEAU, L. A. 2003. Reflections on self in qualitative research: stories of family. *Am J Occup Ther,* 57**,** 9-16.

PROTANI, M. M., NAGLE, C. M. & WEBB, P. M. 2012. Obesity and Ovarian Cancer Survival: A Systematic Review and Meta-analysis. *Cancer Prevention Research,* 5**,** 901-910.

PROTHEROE, J., WHITTLE, R., BARTLAM, B., ESTACIO, E. V., CLARK, L. & KURTH, J. 2017. Health literacy, associated lifestyle and demographic factors in adult population of an English city: a cross-sectional survey. *Health Expect,* 20**,** 112-119.

PUBLIC HEALTH ENGLAND 2015. Local action on health inequalities: Improving health literacy to reduce health inequalities.

PUBLIC HEALTH ENGLAND 2016. Government Dietary Recommendations. Government recommendations for energy and nutrients for males and females aged 1 – 18 years and 19+ years.: Public Health England.

PULLAR, J. M., CHISHOLM, A. & JACKSON, C. 2012. Dietary information for colorectal cancer survivors: an unmet need. *The New Zealand Medical Journal,* 125**,** 27-37.

PUTS, M. T., PAPOUTSIS, A., SPRINGALL, E. & TOURANGEAU, A. E. 2012. A systematic review of unmet needs of newly diagnosed older cancer patients undergoing active cancer treatment. *Support Care Cancer,* 20**,** 1377-94.

QUALITY HEALTH 2014. Wales Cancer Patient Experience Survey National Report.

QUALITY HEALTH 2015. Northern Ireland Cancer Patient Experience Survey.

QUALITY HEALTH 2016. Scottish Cancer Patient Experience Survey 2015/16.

QUARESMA, M., COLEMAN, M. P. & RACHET, B. 2015. 40-year trends in an index of survival for all cancers combined and survival adjusted for age and sex for each cancer in England and Wales, 1971-2011: a population-based study. *Lancet,* 385**,** 1206-18.

RAMIREZ, A. G., PARMA, D. L., MUNOZ, E., MENDOZA, K. D., HARB, C., HOLDEN, A. E. C. & WARGOVICH, M. 2017. An anti-inflammatory dietary intervention to reduce breast cancer recurrence risk: Study design and baseline data. *Contemp Clin Trials,* 57**,** 1-7.

RATJEN, I., SCHAFMAYER, C., DI GIUSEPPE, R., WANIEK, S., PLACHTA-DANIELZIK, S., KOCH, M., NÖTHLINGS, U., HAMPE, J., SCHLESINGER, S. & LIEB, W. 2017. Postdiagnostic Mediterranean and Healthy Nordic Dietary Patterns Are Inversely Associated with All-Cause Mortality in Long-Term Colorectal Cancer Survivors. *The Journal of Nutrition,* 147**,** 636-644.

RICHARD, A. A. & SHEA, K. 2011. Delineation of self-care and associated concepts. *J Nurs Scholarsh,* 43**,** 255-64.

RICHMAN, E. L., CARROLL, P. R. & CHAN, J. M. 2012. Vegetable and fruit intake after diagnosis and risk of prostate cancer progression. *Int J Cancer,* 131**,** 201-10.

RINNINELLA, E., FAGOTTI, A., CINTONI, M., RAOUL, P., SCALETTA, G., QUAGLIOZZI, L., MIGGIANO, G. A. D., SCAMBIA, G., GASBARRINI, A. & MELE, M. C. 2019. Nutritional Interventions to Improve Clinical Outcomes in Ovarian Cancer: A Systematic Review of Randomized Controlled Trials. *Nutrients,* 11.

ROCK, C. L., FLATT, S. W., BYERS, T. E., COLDITZ, G. A., DEMARK-WAHNEFRIED, W., GANZ, P. A., WOLIN, K. Y., ELIAS, A., KRONTIRAS, H., LIU, J., NAUGHTON, M., PAKIZ, B., PARKER, B. A., SEDJO, R. L. & WYATT, H. 2015. Results of the Exercise and Nutrition to Enhance Recovery and Good Health for You (ENERGY) Trial: A Behavioral Weight Loss Intervention in Overweight or Obese Breast Cancer Survivors. *J Clin Oncol,* 33**,** 3169-76.

ROY, S., VALLEPU, S., BARRIOS, C. & HUNTER, K. 2018. Comparison of Comorbid Conditions Between Cancer Survivors and Age-Matched Patients Without Cancer. *Journal of clinical medicine research,* 10**,** 911-919.

ROZMOVITS, L., ROSE, P. & ZIEBLAND, S. 2004. In the absence of evidence, who chooses? A qualitative study of patients' needs after treatment for colorectal cancer. *Journal Of Health Services Research & Policy,* 9**,** 159-164.

RYAN, A. M., POWER, D. G., DALY, L., CUSHEN, S. J., NI BHUACHALLA, E. & PRADO, C. M. 2016. Cancer-associated malnutrition, cachexia and sarcopenia: the skeleton in the hospital closet 40 years later. *Proc Nutr Soc,* 75**,** 199-211.

SABATINO, S. A., COATES, R. J., UHLER, R. J., POLLACK, L. A., ALLEY, L. G. & ZAUDERER, L. J. 2007. Provider Counseling about health behaviors among cancer survivors in the United States. *Journal of Clinical Oncology,* 25**,** 2100-2106.

SAMUELSSON, K. S., EGENVALL, M., KLARIN, I., LÖKK, J., GUNNARSSON, U. & IWARZON, M. 2018. The older patient's experience of the healthcare chain and information when undergoing colorectal cancer surgery according to the enhanced recovery after surgery concept. *Journal of Clinical Nursing,* 27**,** e1580-e1588.

SANMARTIN, C., HOULE, C., TREMBLAY, S. & BERTHELOT, J. M. 2002. Changes in unmet health care needs. *Health Rep,* 13**,** 15-21.

SAUNDERS, C. L., ELLIOTT, M. N., LYRATZOPOULOS, G. & ABEL, G. A. 2016. Do Differential Response Rates to Patient Surveys Between Organizations Lead to Unfair Performance Comparisons?: Evidence From the English Cancer Patient Experience Survey. *Med Care,* 54**,** 45-54.

SCHEAFFER, R. L. & SCHEAFFER, R. L. 2012. *Elementary survey sampling,* Boston, MA, Brooks/Cole, Cengage Learning.

SCHIFFMANN, J., KARAKIEWICZ, P. I., RINK, M., MANKA, L., SALOMON, G., TILKI, D., BUDAUS, L., POMPE, R., LEYH-BANNURAH, S. R., HAESE, A., HAMMERER, P., HULAND, H., GRAEFEN, M. & TENNSTEDT, P. 2018. Obesity paradox in prostate cancer: increased body mass index was associated with decreased risk of metastases after surgery in 13,667 patients. *World J Urol,* 36**,** 1067-1072.

SCHLESINGER, S., SIEGERT, S., KOCH, M., WALTER, J., HEITS, N., HINZ, S., JACOBS, G., HAMPE, J., SCHAFMAYER, C. & NOTHLINGS, U. 2014. Postdiagnosis body mass index and risk of mortality in colorectal cancer survivors: a prospective study and meta-analysis. *Cancer Causes & Control,* 25**,** 1407-1418.

SCHULMAN-GREEN, D., JASER, S., MARTIN, F., ALONZO, A., GREY, M., MCCORKLE, R., REDEKER, N. S., REYNOLDS, N. & WHITTEMORE, R. 2012. Processes of self-management in chronic illness. *Journal of nursing scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing,* 44**,** 136-144.

SECORD, A. A., HASSELBLAD, V., VON GRUENIGEN, V. E., GEHRIG, P. A., MODESITT, S. C., BAE-JUMP, V. & HAVRILESKY, L. J. 2016. Body mass index and mortality in endometrial cancer: A systematic review and meta-analysis. *Gynecol Oncol,* 140**,** 184-90.

SEMLITSCH, T., JEITLER, K., BERGHOLD, A., HORVATH, K., POSCH, N., POGGENBURG, S. & SIEBENHOFER, A. 2016. Long-term effects of weight-reducing diets in people with hypertension. *Cochrane Database of Systematic Reviews*.

SHOEMAKER, M. L., WHITE, M. C., HAWKINS, N. A. & HAYES, N. S. 2016. Prevalence of Smoking and Obesity Among U.S. Cancer Survivors: Estimates From the National Health Interview Survey, 2008-2012. *Oncol Nurs Forum,* 43**,** 436-41.

SKLENAROVA, H., KRUMPELMANN, A., HAUN, M. W., FRIEDERICH, H. C., HUBER, J., THOMAS, M., WINKLER, E. C., HERZOG, W. & HARTMANN, M. 2015. When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer,* 121**,** 1513-9.

SMITH, F., CARLSSON, E., KOKKINAKIS, D., FORSBERG, M., KODEDA, K., SAWATZKY, R., FRIBERG, F. & OHLEN, J. 2014. Readability, suitability and comprehensibility in patient education materials for Swedish patients with colorectal cancer undergoing elective surgery: A mixed method design. *Patient Education and Counseling,* 94**,** 202-209.

SMITS, A., LOPES, A., BEKKERS, R. & GALAAL, K. 2015a. Body mass index and the quality of life of endometrial cancer survivors--a systematic review and meta-analysis. *Gynecol Oncol,* 137**,** 180-7.

SMITS, A., LOPES, A., DAS, N., BEKKERS, R. & GALAAL, K. 2015b. Quality of life in ovarian cancer survivors: the influence of obesity. *Int J Gynecol Cancer,* 25**,** 616-21.

SMITS, A., SMITS, E., LOPES, A., DAS, N., HUGHES, G., TALAAT, A., POLLARD, A., BOUWMAN, F., MASSUGER, L., BEKKERS, R. & GALAAL, K. 2015c. Body mass index, physical activity and quality of life of ovarian cancer survivors: Time to get moving? *Gynecologic Oncology,* 139**,** 148-154.

SONG, S., YOUN, J., LEE, Y. J., KANG, M., HYUN, T., SONG, Y. & LEE, J. E. 2017. Dietary supplement use among cancer survivors and the general population: a nation-wide cross-sectional study. *Bmc Cancer,* 17**,** 12.

SPAHN, J. M., REEVES, R. S., KEIM, K. S., LAQUATRA, I., KELLOGG, M., JORTBERG, B. & CLARK, N. A. 2010. State of the evidence regarding behavior change theories and strategies in nutrition counseling to facilitate health and food behavior change. *J Am Diet Assoc,* 110**,** 879-91.

SPELLMAN, C., CRAIKE, M. & LIVINGSTON, P. 2014. Knowledge, attitudes and practices of clinicians in promoting physical activity to prostate cancer survivors. *Health Education Journal,* 73**,** 566-575.

SPENCER, E. A., APPLEBY, P. N., DAVEY, G. K. & KEY, T. J. 2002. Validity of self-reported height and weight in 4808 EPIC-Oxford participants. *Public Health Nutrition,* 5**,** 561-565.

SPOTTEN, L. E., CORISH, C. A., LORTON, C. M., UI DHUIBHIR, P. M., O'DONOGHUE, N. C., O'CONNOR, B. & WALSH, T. D. 2017. Subjective and objective taste and smell changes in cancer. *Ann Oncol,* 28**,** 969-984.

STACEY, F. G., LUBANS, D. R., CHAPMAN, K., BISQUERA, A. & JAMES, E. L. 2017. Maintenance of Lifestyle Changes at 12-month Follow-up in a Nutrition and Physical Activity Trial for Cancer Survivors. *Am J Health Behav,* 41**,** 784-795.

STURGES, J. E. & HANRAHAN, K. J. 2004. Comparing Telephone and Face-to-Face Qualitative Interviewing: a Research Note. *Qualitative Research,* 4**,** 107-118.

SUN, V., CRANE, T. E., SLACK, S. D., YUNG, A., WRIGHT, S., SENTOVICH, S., MELSTROM, K., FAKIH, M., KROUSE, R. S. & THOMSON, C. A. 2018. Rationale, development, and design of the Altering Intake, Managing Symptoms (AIMS) dietary intervention for bowel dysfunction in rectal cancer survivors. *Contemp Clin Trials,* 68**,** 61-66.

SUTTON, E., HACKSHAW-MCGEAGH, L. E., ANING, J., BAHL, A., KOUPPARIS, A., PERSAD, R., MARTIN, R. M. & LANE, J. A. 2017. The provision of dietary and physical activity advice for men diagnosed with prostate cancer: a qualitative study of the experiences and views of health care professionals, patients and partners. *Cancer Causes & Control: CCC,* 28**,** 319-329.

TEO, M. T. W., SEBAG-MONTEFIORE, D. & DONNELLAN, C. F. 2015. Prevention and Management of Radiation-induced Late Gastrointestinal Toxicity. *Clinical Oncology,* 27**,** 656-667.

TERRANOVA, C. O., LAWLER, S. P., SPATHONIS, K., EAKIN, E. G. & REEVES, M. M. 2017. Breast cancer survivors' experience of making weight, dietary and physical activity changes during participation in a weight loss intervention. *Support Care Cancer,* 25**,** 1455-1463.

TERRANOVA, C. O., PROTANI, M. M. & REEVES, M. M. 2018. Overall Dietary Intake and Prognosis after Breast Cancer: A Systematic Review. *Nutrition and Cancer,* 70**,** 153-163.

THE JOINT COMMISSION 2010. Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals.

THOMAS, R. J., HOLM, M., WILLIAMS, M., BOWMAN, E., BELLAMY, R., ANDREYEV, J. & MAHER, J. 2013. Lifestyle Factors Correlate with the Risk of Late Pelvic Symptoms after Prostatic Radiotherapy. *Clinical Oncology,* 25**,** 246-251.

THOMSON, C. A., CRANE, T. E., MILLER, A., GARCIA, D. O., BASEN-ENGQUIST, K. & ALBERTS, D. S. 2016. A randomized trial of diet and physical activity in women treated for stage II-IV ovarian cancer: Rationale and design of the Lifestyle Intervention for Ovarian Cancer Enhanced Survival (LIVES): An NRG Oncology/Gynecologic Oncology Group (GOG-225) Study. *Contemp Clin Trials,* 49**,** 181-9.

TORRE, L. A., BRAY, F., SIEGEL, R. L., FERLAY, J., LORTET-TIEULENT, J. & JEMAL, A. 2015. Global cancer statistics, 2012. *CA Cancer J Clin,* 65**,** 87-108.

TRAVIS, L. B., WAHNEFRIED, W. D., ALLAN, J. M., WOOD, M. E. & NG, A. K. 2013. Aetiology, genetics and prevention of secondary neoplasms in adult cancer survivors. *Nature Reviews Clinical Oncology,* 10**,** 289-301.

TSENG, J. H., LONG ROCHE, K., JERNIGAN, A. M., SALANI, R., BRISTOW, R. E. & FADER, A. N. 2015. Lifestyle and weight management counseling in uterine cancer survivors: A study of the uterine cancer action network. *International Journal of Gynecological Cancer,* 25**,** 1285-1291.

VAN BLARIGAN, E. L. & MEYERHARDT, J. A. 2015. Role of physical activity and diet after colorectal cancer diagnosis. *Journal Of Clinical Oncology: Official Journal Of The American Society Of Clinical Oncology,* 33**,** 1825-1834.

VAN BROEKHOVEN, M., DE ROOIJ, B. H., PIJNENBORG, J. M. A., VOS, M. C., BOLL, D., KRUITWAGEN, R., VAN DE POLL-FRANSE, L. V. & EZENDAM, N. P. M. 2017. Illness perceptions and changes in lifestyle following a gynecological cancer diagnosis: A longitudinal analysis. *Gynecologic Oncology,* 145**,** 310-318.

VAN MOSSEL, C., LEITZ, L., SCOTT, S., DAUDT, H., DENNIS, D., WATSON, H., ALFORD, M., MITCHELL, A., PAYEUR, N., COSBY, C., LEVI-MILNE, R. & PURKIS, M. E. 2012. Information needs across the colorectal cancer care continuum: Scoping the literature. *European Journal of Cancer Care,* 21**,** 296-320.

VAN VEEN, M. R., MOLS, F., SMEETS, L., KAMPMAN, E. & BEIJER, S. 2019. Colorectal cancer survivors' beliefs on nutrition and cancer; correlates with nutritional information provision. *Support Care Cancer*.

VAN ZUTPHEN, M., KAMPMAN, E., GIOVANNUCCI, E. L. & VAN DUIJNHOVEN, F. J. B. 2017. Lifestyle after Colorectal Cancer Diagnosis in Relation to Survival and Recurrence: A Review of the Literature. *Current Colorectal Cancer Reports,* 13**,** 370-401.

VARIYAM, J. N. & LIN, B.-H. 2007. NHANES: Development of a flexible consumer behavior survey module. *The FASEB Journal,* 21**,** A53-A53.

VIDAL, A. C., HOWARD, L. E., SUN, S. X., COOPERBERG, M. R., KANE, C. J., ARONSON, W. J., TERRIS, M. K., AMLING, C. L. & FREEDLAND, S. J. 2017. Obesity and prostate cancer-specific mortality after radical prostatectomy: results from the Shared Equal Access Regional Cancer Hospital (SEARCH) database. *Prostate cancer and prostatic diseases,* 20**,** 72-78.

VISSERS, P. A. J., MARTUCCI, R. B., MOLS, F., BOURS, M. J. L., WINKELS, R. M., KAMPMAN, E., WEIJENBERG, M. P., VAN DE POLL-FRANSE, L. V. & BEIJER, S. 2017. The Impact of Body Mass Index and Waist Circumference on

Health-related Quality of Life Among Colorectal Cancer Survivors: Results from the PROFILES Registry. *Nutr Cancer,* 69**,** 1177-1184.

WAGLAND, R., NAYOAN, J., MATHESON, L., RIVAS, C., BRETT, J., DOWNING, A., WILDING, S., BUTCHER, H., GAVIN, A., GLASER, A. W. & WATSON, E. 2019. 'Very difficult for an ordinary guy': Factors influencing the quality of treatment decision-making amongst men diagnosed with localised and locally advanced prostate cancer: Findings from a UK-wide mixed methods study. *Patient Educ Couns,* 102**,** 797-803.

WALKER, R., SZANTON, S. L. & WENZEL, J. 2015. Working Toward Normalcy Post-Treatment: A Qualitative Study of Older Adult Breast and Prostate Cancer Survivors. *Oncology nursing forum,* 42**,** E358-E367.

WALLACE, A. S., SELIGMAN, H. K., DAVIS, T. C., SCHILLINGER, D., ARNOLD, C. L., BRYANT-SHILLIDAY, B., FREBURGER, J. K. & DEWALT, D. A. 2009. Literacy-appropriate educational materials and brief counseling improve diabetes self-management. *Patient Educ Couns,* 75**,** 328-33.

WANG, Z., MCLOONE, P. & MORRISON, D. S. 2015. Diet, exercise, obesity, smoking and alcohol consumption in cancer survivors and the general population: a comparative study of 16 282 individuals. *British Journal of Cancer,* 112**,** 572-575.

WEAVER, K. E., FORAKER, R. E., ALFANO, C. M., ROWLAND, J. H., ARORA, N. K., BELLIZZI, K. M., HAMILTON, A. S., OAKLEY-GIRVAN, I., KEEL, G. & AZIZ, N. M. 2013. Cardiovascular risk factors among long-term survivors of breast, prostate, colorectal, and gynecologic cancers: a gap in survivorship care? *Journal of Cancer Survivorship,* 7**,** 253-261.

WEDLAKE, L., SHAW, C., MCNAIR, H., LALJI, A., MOHAMMED, K., KLOPPER, T., ALLAN, L., TAIT, D., HAWKINS, M., SOMAIAH, N., LALONDRELLE, S., TAYLOR, A., VANAS, N., STEWART, A., ESSAPEN, S., GAGE, H., WHELAN, K. & ANDREYEV, H. J. N. 2017. Randomized controlled trial of dietary fiber for the prevention of radiation-induced gastrointestinal toxicity during pelvic radiotherapy. *The American Journal of Clinical Nutrition,* 106**,** 849-857.

WEST, C. M. & DAVIDSON, S. E. 2009. Measurement tools for gastrointestinal symptoms in radiation oncology. *Curr Opin Support Palliat Care,* 3**,** 36-40.

WHO. 2018. *Fact sheet: Cancer* [Online]. Available: https://www.who.int/news-room/fact-sheets/detail/cancer [Accessed December 2018].

WILLIAMS, K., BEEKEN, R. J., FISHER, A. & WARDLE, J. 2015a. Health professionals' provision of lifestyle advice in the oncology context in the United Kingdom. *European Journal of Cancer Care,* 24**,** 522-530.

WILLIAMS, K., FISHER, A., BEEKEN, R. J. & WARDLE, J. 2015b. Availability of Information About Lifestyle for Cancer Survivors in England: A Review of Statutory and Charitable Sector Organizations and Cancer Centers. *JMIR Cancer,* 1**,** e2.

WILLS, C. E. & HOLMES-ROVNER, M. 2003. Patient comprehension of information for shared treatment decision making: State of the art and future directions. *Patient Education and Counseling,* 50**,** 285-290.

WILSON, B. J. 2007. Designing Media Messages About Health and Nutrition: What Strategies Are Most Effective? *Journal of Nutrition Education and Behavior,* 39**,** S13-S19.

WORLD CANCER RESEARCH FUND/AMERICAN INSTITUTE FOR CANCER RESEARCH 2018. *Diet, nutrition, physical activity and cancer : a global perspective : a summary of the Third expert report*.

WORLD HEALTH ORGANISATION. 2018. *Obesity and overweight Fact Sheet* [Online]. Available: https://www.who.int/news-room/fact-sheets/detail/obesity-and-overweight [Accessed July 2019].

YANG, B., MCCULLOUGH, M. L., GAPSTUR, S. M., JACOBS, E. J., BOSTICK, R. M., FEDIRKO, V., FLANDERS, W. D. & CAMPBELL, P. T. 2014. Calcium, vitamin

D, dairy products, and mortality among colorectal cancer survivors: the Cancer Prevention Study-II Nutrition Cohort. *J Clin Oncol,* 32**,** 2335-43.

YEGANEH, L., HARRISON, C., VINCENT, A. J., TEEDE, H. & BOYLE, J. A. 2018. Effects of lifestyle modification on cancer recurrence, overall survival and quality of life in gynaecological cancer survivors: A systematic review and meta-analysis. *Maturitas,* 111**,** 82-89.

ZALETA, A. K., NEFF, R., MCCANN, G. A., O'MALLEY, D. M. & CARPENTER, K. M. 2017. Perceptions of weight management counseling among gynecologic cancer survivors: opportunities for enhancing survivorship care. *Supportive Care in Cancer,* 25**,** 1537-1545.

ZHANG, X., ZHOU, G., SUN, B., ZHAO, G., LIU, D., SUN, J., LIU, C. & GUO, H. 2015. Impact of obesity upon prostate cancer-associated mortality: A meta-analysis of 17 cohort studies. *Oncology letters,* 9**,** 1307-1312.

Appendices

APPENDIX 1: Chapter 2 (Systematic review)

1a. Search strategy – Web of Science

#1 TOPIC: (Cancer* OR oncolog* OR neoplas* OR *carcinoma* OR tumo?r* OR malignan*)

DocType=All document types; Language=All languages;

#2 TOPIC: (Pelvi* OR urolog* OR bladder or gyn?ecolog* OR ovarian OR endometrial OR cervical OR uterine OR vaginal OR vulvar OR rectal OR colorectal OR testicular OR prostate OR anal OR "reproductive organs" OR bowel)

DocType=All document types; Language=All languages;

#3 TOPIC: (Support* OR advice* OR education* OR counsel* OR information OR guidance OR communication)

DocType=All document types; Language=All languages;

#4 TOPIC: (Need* OR view* OR concern* OR perception* OR perceived)

DocType=All document types; Language=All languages;

#5 TOPIC: (Diet* OR nutrition* OR food* OR feed OR feeding OR lifestyle OR nourishment OR supplement* OR *enteral* OR artificial)

DocType=All document types; Language=All languages;

#6 TOPIC: (diagnosis OR treatment* OR patient* OR survivor*)

DocType=All document types; Language=All languages;

#7 #6 AND #5 AND #4 AND #3 AND #2 AND #1

DocType=All document types; Language=All languages

1b. Quality assessment of qualitative studies

	Anderson et al. 2013	**Avery et al. 2014**	**Beaver et al. 2010**	**Brown et al. 2016**	**Des Bordes et al 2016***	**Dunn et al. 2006**	**Er et al. 2017**	**Evans et al. 2007**	**Hardcastle et al. 2016**	**Hardcastle et al. 2018**	**Hoedjes et al. 2017***	**Kassianos et al. 2015**	**Koutoukidis et al. 2016**	**Rozmovits et al. 2004**	**Sutton et al. 2017**	**Jang et al. 2019***	**Samuelsson et al. 2018**	**Lee et al. 2017**
Descriptive vividness for truth value: Credibility	1	2	1	2	1	1	2	2	2	2	1	1	2	1	1	**1**	**2**	**2**
Methodological Congruence: method description	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	2	3	2
Methodological Congruence: Procedural rigor and consistency: Dependability	2	1	1	2	1	2	1	2	1	2	2	2	3	1	1	**2**	**1**	**1**
Methodological Congruence: ethical rigor	2	3	3	3	3	3	3	2	3	3	1	2	3	3	3	3	3	3
Methodological Congruence: Confirmability (auditability, neutrality)	3	2	3	3	0	2	2	2	3	3	2	1	3	2	2	**1**	**2**	**1**
Analytical Preciseness: conceptualisations developed appropriately?	1	0	2	2	1	1	1	2	2	2	0	2	3	1	1	1	1	1
Theoretical Connectedness to enable	2	3	3	3	2	3	3	3	3	2	3	3	3	3	3	**3**	**3**	**3**

application: transferability																		
Heuristic Relevance: Are there policy and research recommendations	2	3	3	3	1	2	3	1	1	2	3	1	2	2	2	3	3	2
TOTAL SCORE:**	**16**	**17**	**19**	**20**	**12**	**17**	**18**	**17**	**18**	**19**	**15**	**15**	**22**	**16**	**16**	**16**	**18**	**15**

* Part of a mixed-methods paper. ** Based on score, a study is assessed as good, fair or poor; Good: Total score of 18-24 indicates that 75% to 100% of the total criteria were met; Fair: Total score of 12–17 indicates that 50% to 74% of the total criteria were met; Poor: Total score of less than 12 indicates that less than 50% of the total criteria were met.

1b. Quality assessment of cross-sectional studies

		Clark et al. 2016	Demark-Wahnefried et al. 2000	Hoedjes et al. 2017	Lee et al. 2016	Nicoletti et al. 2008	Cha et al. 2012	Tseng et al. 2015	Zaleta et al. 2017	De Bordes et al. 2016	Pullar et al. 2012	Fitch et al. 2000	Fitch et al. 2001	Perl et al. 2016	Beaver et al. (2012)
1	Were the aims/objectives clear?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2	Was the study design appropriate for the stated aim(s)?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3	Was the sample size justified?	N	N	N	N	N	N	N	N	N	N	N	N	N	N
4	Was the target/reference population clearly defined?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
5	Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
6	Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?	N	N	Y	N	N	N	N	N	N	N	N	N	N	Y
7	Were measures undertaken to address and categorise non-responders?	N	N	N	N	N	N	N	N	N	N	N	N	N	N
8	Were the risk factor and outcome variables measured appropriate to the aims of the study?	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
9	Were the risk factor and outcome variables measured correctly using instruments that had been trialled, piloted or published previously?	N	Y	Y	N	Y	N	N	Y	N	N	N	N	Y	Y
10	Is it clear what was used to determined statistical significance and/or precision estimates?	Y	Y	Y	Y	N	N	Y	N	Y	N	Y	Y	Y	Y

		Clark et al. 2016	**Demark-Wahnefried et al. 2000**	**Hoedjes et al. 2017**	**Lee et al. 2016**	**Nicoletti et al. 2008**	**Cha et al. 2012**	**Tseng et al. 2015**	**Zaleta et al. 2017**	**De Bordes et al. 2016**	**Pullar et al. 2012**	**Fitch et al. 2000**	**Fitch et al. 2001**	**Perl et al. 2016**	**Beaver et al. (2012)**
11	Were the methods (including statistical methods) sufficiently described to enable them to be repeated?	Y	Y	Y	Y	Y	N	Y	Y	Y	N	Y	N	Y	Y
12	Were the basic data adequately described?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
13	Does the response rate raise concerns about non-response bias?	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
14	If appropriate, was information about non-responders described?	Y	Y	Y	N	N	N	N	N	N	N	N	N	N	N
15	Were the results internally consistent?	N	Y	N	Y	Y	Y	N	Y	N	Y	Y	Y	Y	Y
16	Were the results for the analyses described in the methods, presented?	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
17	Were the authors' discussions and conclusions justified by the results?	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
18	Were the limitations of the study discussed?	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
19	Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?	N	DK	N	N	DK	N	N	N	N	Y	DK	DK	N	N
20	Was ethical approval or consent of participants attained?	Y	DK	Y	Y	Y	Y	Y	Y	Y	Y	DK	DK	Y	Y

Y: Yes, N: No, DK: Don't know/unclear

APPENDIX 2: Chapter 3 (Methodology and Methods)

2a. Study Invitation Letter (on-treatment participants)

Oxford University Hospitals NHS
NHS Foundation Trust

OXFORD BROOKES UNIVERSITY

FREC study number: 2016/43
REC Reference: 17/ES/0112

04 September 2017

Reference: Nutrition and pelvic cancer: A study to explore dietary habits, nutritional awareness and patient experiences.

I am writing to invite you to consider taking part in a research study being conducted by researchers at Oxford Brookes University, in collaboration with the Radiotherapy Department, Cancer and Haematology Centre, Oxford University Hospitals NHS Foundation Trust.

The study aims to explore dietary and nutrition experiences and concerns in people who are being treated with radiotherapy for cancer in the pelvic area. Cancer in the pelvic area includes cancers of the anus, bladder, rectum, gynaecological cancers (cervix, womb, ovaries, vulva and vagina) and male cancers (prostate and testes).

The research team would like to know about your current dietary habits, what you have heard about dietary guidelines, and what information and support you may have received in this area, or would like to have received. Taking part in the study would involve completing the questionnaire enclosed with this letter and returning it in the reply paid envelope provided. The study findings will help us to understand how we can best support patients in this area.

A patient information sheet is included with this letter, which contains more details about this study**. Involvement in the study is entirely voluntary. If you decide not to participate in the study your care will not be affected in any way. If you do decide to participate you can withdraw at any time without giving any reason.**

If you have any further questions that have not been answered in the patient information sheet, please do not hesitate to contact the research team for further information (George Saltaouras – email: 16021065@brookes.ac.uk, tel: 01865 482669 or Professor Eila Watson – email: ewatson@brookes.ac.uk, tel: 01865 482665).

Thank you for taking the time to read this letter.

Yours sincerely,

Dr Amanda Horne, MB BCH BAO MRCP FRCR
Consultant in Clinical Oncology

2b. Participant Information Sheet (all participants)

FREC study number: 2016/43
REC reference: 17/ES/0112

Study title
Nutrition and pelvic cancer: A study to explore dietary habits, nutritional awareness and patient experiences – the patient's view.

Invitation paragraph

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information explaining the study and your involvement within it. Thank you for your time.

What is the purpose of the study?

Cancer incidence continues to increase but so does cancer survival, due to early detection and improved treatment regimes. Cancer in the pelvic area includes cancers of the anus, bladder, rectum, gynaecological cancers (cervix, womb, ovaries, vulva and vagina) and male cancers (prostate and testes). Patients with pelvic cancer can sometimes experience effects of treatment which impact on diet e.g. bowel problems and lack of energy. Many patients are also interested in changing their diet to help keep them healthy following treatment.

The aim of this study is to find out about the experiences, awareness and concerns of people treated with radiotherapy for cancer in the pelvic area in relation to diet and nutrition. We would like to know about your current dietary habits, what you have heard about dietary guidelines, and what information and support you may have received in this area, or would like to have received. Participants will be recruited over a period of approximately 12 months.

Why have I been invited to participate?

You are being invited to participate because you have been diagnosed with cancer in the pelvis (anus, bladder, rectum, endometrium/womb, cervix, ovaries, vulva, vagina, prostate or testes) and you are being treated or have been treated in the past with radiotherapy.

Do I have to take part?

It is up to you to decide whether or not to take part. Your involvement with this study is entirely voluntary and will not affect the care you receive in any way.

What will happen to me if I take part?

If you are willing to take part we ask you to complete the questionnaire that is included in the study pack with this information sheet and return it in the reply paid envelope provided. We hope to get 200 completed questionnaires returned.

We would also like to conduct an interview with a sample of those who complete the questionnaire to explore their experiences and views in greater detail. At the end of the questionnaire there is a space for you to fill in your contact details, ***only if you are interested in taking part in an interview.*** If not interested, please leave the space blank. If you provide your contact details, the sheet will be detached from your questionnaire on receipt and your answers will be kept with your name removed.

The questionnaire should take no longer than 30 minutes to complete. If there is any question you do not wish to answer, please feel free to leave it blank and carry on to the next question.

The follow on interview would last approximately 35-40 minutes. It would be done over the telephone at a time convenient for you. With permission, we would like to record the interviews.

What are the possible benefits of taking part?

There is no direct benefit to you from taking part in this study. However, the information you and others provide will help inform how best to support patients in this area in the future.

What are the possible disadvantages of taking part?

Discussing issues related to your cancer care could be upsetting and this may sometimes be a disadvantage of taking part. We also appreciate that there is time involved in completing the questionnaire and participating in an interview, although we have tried to keep this to a minimum. If any distress has been caused by participation, please contact a member of your clinical team. Also, if any worries are raised, you could contact Macmillan Cancer Support at 0808 808 0000 or Cancer Research UK at 0808 800 4040 (free from UK landlines).

Will what I say in this study be kept confidential?

Your right to privacy will be respected. All information collected about you in this study will be kept strictly confidential subject to legal limitations. If you provide contact details, the sheet will be detached from your questionnaire. Therefore, data from the questionnaire will be completely anonymous. Also, the questionnaire and your personal data will be stored separately.

Data collected from you will be assigned a random number and can only be traced to you by the researcher. Data from the questionnaire and data from the interview (if provided) will be only linked with a unique ID code. Your questionnaire responses will be entered onto a secure, password protected and encrypted computer at Oxford Brookes University. In accordance with the University's policy on Academic Integrity the data will be kept for a period of 10 years, after which point it will be carefully destroyed.

What should I do if I want to take part?

If you wish to take part in the study, please complete the questionnaire found in this pack. Instructions on completing the questionnaire can be found on the first page. Your questionnaire can be returned via the reply paid envelope. We would ideally like you to complete and return the questionnaire within one week after your clinical team has given it to you. By returning the questionnaire, you consent to take part in the study.

At the end of the questionnaire, you can indicate if you are willing to be interviewed and we will be in touch to arrange a time convenient for you to have a telephone interview. Consent will be taken verbally and we will send you a copy of your consent form, if you wish so.

What will happen to the results of the research study?

The results will be analysed and reported as a PhD thesis. Results will also be discussed and presented at University and external research conferences. We also aim to publish the results in appropriate nutrition and oncology journals. If you want to get a summary of the findings, please get in touch with Professor Eila Watson, Department of Nursing on 01865 482565 or Dr Helen Lightowler, Department of Sport and Health Sciences on 01865 483283 who will be able to provide a copy.

Who is organising and funding the research?

The study is being conducted by a PhD student at Oxford Brookes University, who is supervised by Professor Eila Watson, Dr Helen Lightowler and Dr Shelly Coe. The study has been funded by the Faculty of Health and Life Sciences, Oxford Brookes University.

Who has reviewed the study?

This study has been discussed with a clinical team, consisting of research nurses, therapeutic radiographers and clinical oncologists. Feedback for the survey has also been received by a group of cancer survivors.
The study had approval from the Faculty Research Ethics Committee at Oxford Brookes University and a National Research Ethics Service.

Contact for Further Information

If you have any further questions about the study, please get in touch with George Saltaouras (PhD student) or Professor Eila Watson (supervisor). Please find contact details below.

George Saltaouras (student)	Professor Eila Watson (supervisor)
Tel: 01865 482669 or 01865 483283	Tel: 01865 482665
Email: 16021065@brookes.ac.uk	Email: ewatson@brookes.ac.uk

If you have any concerns regarding how this study has been conducted please contact the Chair of the Faculty Research Ethics Committee at Oxford Brookes University, Kellie Tune on kelly.tune@brookes.ac.uk.

Thank you for taking time to read the information sheet.

FREC Reference: 2016/43
REC number 17/ES/0112

2c: Dietary habits, nutritional awareness and patient experiences in pelvic cancer

Thank you for considering taking part in this study. We would like to know about your dietary habits, your knowledge and experiences regarding diet and nutrition after cancer diagnosis. We hope our research will help inform service developments in the future. The survey is made up of five sections and should take approximately 30 minutes to complete.

Enclosed are a patient information sheet and a FREEPOST envelope. Please read the patient information sheet before completing the questionnaire. Participation in this research study is voluntary. If you do decide to participate in the study, please complete and return the questionnaire. By doing this, you consent for us to use your responses (anonymously) in our research.

Please read each question carefully. There are no right or wrong answers to these questions. If you decide there are any questions you would rather not answer please just go to the next question.

After we have received these survey responses, we would also like to interview a sample of the people who have responded to the survey to gain a more detailed understanding of diet and nutrition experiences and needs. If you are interested in being contacted for an interview, please fill in your contact details in section F. This section will be detached upon receipt and stored separately, so that your answers are kept with your name removed. If you are not interested, please leave that section blank when you return your questionnaire.

All the information you give will be treated as strictly confidential.

If you have any questions about any aspect of completing the questionnaire, or if you require the questionnaire to be supplied in large print, please contact George Saltaouras on **tel: 01865 483283 or 01865 482669** or **email: 16021065@brookes.ac.uk.**

Thank you very much for your help

Date of survey completion: ____/____/________ *(DD/MM/YYYY)*

SECTION A: YOUR DIAGNOSIS

These questions are about your type of cancer, your diagnosis and your treatment.

A1. When was your cancer diagnosed?
Please write in the month and year if you know:

Month: **Year:**

A2. What type of cancer were you diagnosed with?
Tick (✓) all that apply

☐1 Anus
☐2 Bladder
☐3 Cervix
☐4 Endometrium (womb)
☐5 Ovary
☐6 Prostate
☐7 Rectum
☐8 Testes
☐9 Vagina
☐10 Vulva
☐0 Other *(please specify)*

A3. What treatment(s) are you having/have you had?
Tick (✓) all that apply

☐1 Radiotherapy
☐2 Chemotherapy
☐3 Surgery
☐0 Other *(please specify)*

A4. Which of the following best describes your current situation regarding radiotherapy treatment?

☐1 I am currently receiving treatment
How many weeks have you been on treatment? ________ *weeks*
How many weeks will your treatment last in total? ________ *weeks*

☐2 I have finished treatment
When did you finish treatment?
Month: **Year:**

A5. Is this your first cancer diagnosis? ☐1 Yes ☐2 No

SECTION B: TREATMENT EFFECTS

These questions are about gastrointestinal symptoms and appetite issues that you may experience as a result of your treatment.

B1. Are you currently experiencing any of the following effects as a result of your treatment?
(Tick (✓) all that apply)

☐1 Loss of appetite
☐2 Changes in taste
☐3 Changes in smell
☐4 Wind/bloating
☐0 Other *(please specify)*
☐13 No effects
☐5 Nausea/Vomiting
☐6 Diarrhoea
☐7 Constipation
☐8 Fatigue/Lack of energy
☐9 Dry mouth
☐10 Incontinence
☐11 Mouth sores
☐12 Difficulty swallowing

B2.	***In your opinion, how important is the role of diet in:*** *Please tick (✓) in the appropriate box for each question.*	Not important at all (1)	A little important (2)	Important (3)	Very important (4)
	i. Reducing gastrointestinal symptoms, such as wind, constipation, diarrhoea & nausea?	☐	☐	☐	☐
	ii. Reducing appetite symptoms, such as changes in smell/taste & lack of appetite?	☐	☐	☐	☐
	iii. Reducing the feeling of fatigue?	☐	☐	☐	☐

SECTION C: YOUR DIETARY HABITS

These questions are about your diet since diagnosis, including dietary habits and use of supplements.

C1.	Have you changed your diet since diagnosis?	☐(1) Yes *Please go to question C2*	☐(2) No *Please go to question C5*

C2. Why did you change your diet?

(Tick (✓) all that apply)

☐(1) To reduce the risk of cancer recurrence/spread
☐(2) To assist with treatment side-effects
☐(3) To maintain general health
☐(4) To support therapy/recovery
☐(0) Other *(please specify)*

C3.	***In which of the following food groups have you increased/decreased consumption?*** *Please tick (✓) in the appropriate box for each question.*	Increased (1)	Decreased (2)	No change (3)
	i. Whole grains *e.g. whole wheat bread or pasta, brown or wild rice, whole oats, whole rye, whole barley, quinoa, millet, bulgur, popcorn, buckwheat*	☐	☐	☐
	ii. Refined grains *e.g. white bread, pasta & rice, cornbread, sourdough bread, white flour or corn flakes*	☐	☐	☐
	iii. Fruit	☐	☐	☐
	iv. Vegetables	☐	☐	☐
	v. Low fat milk and dairy products	☐	☐	☐
	vi. Full fat milk and dairy products	☐	☐	☐
	vii. Lean, low fat meat and poultry	☐	☐	☐
	viii. Oily fish *e.g. salmon, tuna, trout or mackerel*	☐	☐	☐
	ix. White fish *e.g. cod, haddock or sea bass*	☐	☐	☐
	ix. Sugary foods and drinks	☐	☐	☐
	x. Processed meats *e.g. bacon, salami, sausage, ham, corned beef, beef jerky, hotdog and canned meat*	☐	☐	☐
	xi. Alcohol	☐	☐	☐

C4. Is there anything else you changed in your diet after your diagnosis?

C5.	***How familiar are you with the following dietary recommendations?*** *Please tick (✓) in the appropriate box for each question.*	Never heard of it (1)	Slightly familiar (2)	Mostly familiar (3)	Very familiar (4)
	i. Be a healthy weight – Keep your weight as low as you can within the healthy range.	☐	☐	☐	☐
	ii. Limit high-calorie foods and avoid sugary drinks.	☐	☐	☐	☐
	iii. Eat a wide variety of wholegrains, vegetables, fruit and pulses, such as beans.	☐	☐	☐	☐
	iv. Aim for at least 5 portions of fruit and vegetables a day.	☐	☐	☐	☐
	v. Eat no more than 500 grams of red meat a week and avoid processed meat.	☐	☐	☐	☐
	vi. Don’t drink alcohol. If you do, limit alcoholic drinks and follow national guidelines (up to 14 units per week). *A pint of beer or a large glass of wine is approximately 2 units of alcohol. A single gin & tonic (25 ml gin) corresponds to 1 unit of alcohol, whereas a double gin & tonic is 2 units.*	☐	☐	☐	☐
	vii. Limit your salt intake to less than 6 grams a day.	☐	☐	☐	☐
	viii. Eat a healthy diet rather than relying on supplements.	☐	☐	☐	☐

C6.	***In your opinion, how important is the role of diet in:*** *Please tick (✓) in the appropriate box for each question.*	Not important at all (1)	A little important (2)	Important (3)	Very important (4)
	i. Preventing cancer recurrence/spread?	☐	☐	☐	☐
	ii. Improving overall health?	☐	☐	☐	☐
	iii. Supporting therapy and recovery?	☐	☐	☐	☐

C7.	Since diagnosis, have you been taking any vitamin/mineral supplements?	☐(1) Yes *Please go to question C8* ☐(2) No *Please go to question C10* ☐(3) Used to, but not anymore *Please go to question C10*
C8.	If yes, which vitamin/mineral supplements have you been taking? *(Tick (✓) all that apply)*	☐(1) Multivitamin ☐(2) Vitamin D ☐(3) Omega 3/Fish oils ☐(4) B vitamins ☐(5) Vitamin C ☐(6) Lycopene ☐(7) Selenium ☐(8) Zinc ☐(0) Other *(please specify)*
C9.	Why have you been taking vitamin/mineral supplements? *(Tick (✓) all that apply)*	☐(1) To reduce the risk of cancer recurrence/spread ☐(2) To assist with treatment side-effects ☐(3) To maintain general health ☐(4) To support therapy/recovery ☐(0) Other *(please specify)*
C10.	How much water/fluids do you generally consume daily? *A glass of water/fluids is 250 ml, as shown in the picture. Fluids include milk, coffee, tea and juice.* 	☐(1) 0-2 glasses/day ☐(2) 3-5 glasses/day ☐(3) 6-8 glasses/day ☐(4) >9 glasses/day
C11.	Who do you usually have meals with? *(Tick (✓) all that apply)*	☐(1) Spouse/partner ☐(2) Family members ☐(3) Friends ☐(4) No one ☐(0) Other *(please specify)*

C12.	Who prepares your meals? *(Tick (✓) all that apply)*	☐(1)	Spouse/partner
		☐(2)	Family members
		☐(3)	Friends
		☐(4)	No one – I prepare my own meals and/or the family meals
		☐(0)	Other *(please specify)*
C13.	During the past 4 weeks, how often did you cook your meals from scratch or were offered home-made meals? *Please tick (✓) one*	☐(1)	Never
		☐(2)	1-3 times/month
		☐(3)	1-4 times/week
		☐(4)	5 times/week or more
C14.	During the past 4 weeks, how often did you eat ready-to-eat meals? *Ready-to-eat meals include salads, soups, sandwiches and cooked meals that only require adding water or heating up. You can get all these from supermarkets or grocery stores.* *Please tick (✓) one*	☐(1)	Never
		☐(2)	1-3 times/month
		☐(3)	1-4 times/week
		☐(4)	5 times/week or more

SECTION D: DIET AND NUTRITION SUPPORT

These questions are about support you may have received from different sources regarding your diet. Please fill in **sub-sections (I)** – 'Diet and Nutrition support from a healthcare professional', **(II)** – 'Diet and Nutrition support from an online or other source' **and (III)** – 'General questions'.

(I): Diet and Nutrition support from a healthcare professional

D1.	Have you received **any** nutrition support in relation to your cancer **from your healthcare team**?	☐(1)	Yes *Please answer questions D2-D9*	☐(2)	No *Please go to question D10*

D2.	Who did you receive diet and nutrition information from? *(Tick (✓) all that apply)*	☐(1)	Dietitian/Cancer specialist dietitian *A dietitian provides diet and nutrition support for the management of your disease. They provide special diets for cancer. They are part of a healthcare team and work in the NHS and in private clinics.*
		☐(2)	Cancer or Radiotherapy Specialist Nurse
		☐(3)	Radiographer/Clinical Oncologist
		☐(4)	Nutritionist *A nutritionist provides information about food and healthy eating for disease prevention. A nutritionist usually works as a freelance outside the NHS setting.*
		☐(5)	General Practitioner (GP)
		☐(0)	Other *(please specify)*

D3. What diet and nutrition information were you provided?

(Tick (✓) all that apply)

☐(1) General healthy eating
☐(2) Nutritional management of symptoms
☐(3) Weight management
☐(4) Healthy Recipes
☐(5) Survivorship courses/classes/workshops
☐(6) Vitamin/mineral supplements
☐(7) Other supplements
☐(0) Other *(please specify)*

D4. I received diet and nutrition information in the form of:

Tick (✓) all that apply

☐(1) Written information/leaflets
☐(2) Links for websites
☐(3) Face to face assistance
☐(4) Telephone assistance
☐(0) Other *(please specify)*

D5. In your opinion, how well were your nutrition needs met?

☐(1) Not at all well ☐(2) Not very well ☐(3) Neutral ☐(4) Well ☐(5) Very well

D6. In your opinion, how consistent was the advice you received?

☐(1) Very inconsistent ☐(2) Inconsistent ☐(3) Neither inconsistent nor consistent ☐(4) Consistent ☐(5) Very consistent

D7. In your opinion, how easy was the advice to follow?

☐(1) Very difficult ☐(2) Difficult ☐(3) Neither difficult nor easy ☐(4) Easy ☐(5) Very easy

D8. Did dietary information/advice influence you to change dietary habits? ☐(1) Yes ☐(2) No

Please explain why:

D9. What, if any, additional nutrition support would you like to receive/have received?

Please go to Question D12.

*If you answered **No** to D1, please answer Questions D10-D11.*

D10. Why didn't you receive any support?

(Tick (✓) all that apply)

☐(1) I chose not to receive any
☐(2) I was not offered any
☐(3) I did not know it existed
☐(4) I did not think nutrition was important
☐(0) Other *(please specify)*

D11. What, if any, diet and nutrition information would you like to have received from your healthcare team?

(Tick (✓) all that apply)

☐(1) General healthy eating
☐(2) Nutritional management of symptoms
☐(3) Weight management
☐(4) Recipes
☐(5) Survivorship courses/classes/workshops
☐(6) Vitamin/mineral supplements
☐(7) Other supplements
☐(8) I did not want any information
☐(0) Other *(please specify)*

(II): Diet and Nutrition support from an online or other source

D12. Did you seek **any** information or support on diet and nutrition in relation to your cancer **online or from another source**?

☐(1) Yes
Please answer questions D13-D18

☐(2) No
Please go to question D19

D13. Which source did you receive diet and nutrition information from?

(Tick (✓) all that apply)

☐(1) A cancer charity website
(e.g. Macmillan Cancer Support, Cancer Research UK)
☐(2) A medical website
(e.g. NHS choices)
☐(3) A blog/social media webpage
☐(4) A newspaper/magazine/book
☐(5) A recipe book
☐(6) Family member/friend
☐(7) Other patient
☐(0) Other *(please specify)*

D14. What diet and nutrition information were you provided?

(Tick (✓) all that apply)

☐(1) General healthy eating
☐(2) Nutritional management of symptoms
☐(3) Weight management
☐(4) Healthy Recipes
☐(5) Survivorship courses/classes/workshops
☐(6) Vitamin/mineral supplements
☐(7) Other supplements
☐(0) Other *(please specify)*

D15. In your opinion, how well were your nutrition needs met?

☐(1) Not at all well ☐(2) Not very well ☐(3) Neutral ☐(4) Well ☐(5) Very well

D16. In your opinion, how consistent was the advice you received?

☐(1) Very inconsistent ☐(2) Inconsistent ☐(3) Neither inconsistent nor consistent ☐(4) Consistent ☐(5) Very consistent

D17. In your opinion, how easy was the advice to follow?

☐(1) Very difficult ☐(2) Difficult ☐(3) Neither difficult nor easy ☐(4) Easy ☐(5) Very easy

D18. Did dietary information/advice influence you to change dietary habits? ☐(1) Yes ☐(2) No

Please explain why:

(III): General questions

D19. Would you be interested in receiving more information about your diet in relation to your cancer?

☐(1) Not interested at all ☐(2) A little interested ☐(3) Somewhat interested ☐(4) Very interested ☐(5) Extremely interested

D20. What mode(s) of delivery would you prefer?

(Tick (✓) all that apply)

☐(1) Face to face by a healthcare professional
☐(2) Posted or e-mailed brochures
☐(3) Internet
☐(4) DVD
☐(5) Telephone
☐(0) Other *(please specify)*

D21.	At which time point(s) would you prefer to receive information about your diet? *(Tick (✓) all that apply)*	☐(1) At diagnosis or soon after ☐(2) During treatment ☐(3) At the end of treatment ☐(4) On a follow up visit ☐(5) Any time

SECTION E: ABOUT YOU

This section contains questions about your background and domestic circumstances. This information is sought for the purpose of analysing and organising our results, and to help us to be confident that our results are representative.

E1.	What is your date of birth?	*DD/MM/YYYY*
E2.	What is your height? ***If unsure, please give your closest estimation.***	______*ft* _____ *in OR* _______ *cm*
E3.	What is your current weight? ***If unsure, please give your closest estimation.***	________ *lb OR* _______ *kg*
E4.	Has your weight changed since diagnosis? *Please tick (✓) one*	☐(1) Yes, I have gained weight ☐(2) Yes, I have lost weight ☐(3) No, my weight has not changed
E5.	Which of the following groups regarding smoking would you say you belong to? *Please tick (✓) one*	☐(1) I am a current smoker ☐(2) I used to smoke, but not anymore When did you quit smoking? *YYYY* ☐(3) I never smoked
E6.	Have you been diagnosed with any of the following conditions? *Please tick (✓) all that apply*	☐(1) Heart problems *e.g. angina, heart failure, prior heart attack or stroke* ☐(2) Diabetes ☐(3) High blood pressure ☐(4) Asthma/other chronic chest problem ☐(5) Arthritis ☐(6) Osteoporosis ☐(7) Problems with your pancreas ☐(15) Other *(please specify)* ☐(8) Problems with your stomach or gallbladder ☐(9) Kidney disease ☐10 Liver disease ☐11 Alzheimer's disease or dementia ☐12 Epilepsy ☐13 Other long standing neurological problem ☐(0) I do not have any of these health conditions

E7.	What is your current marital status? *Please tick (✓) one*	☐(1)	Married or living as married
		☐(2)	Divorced or separated
		☐(3)	Widowed
		☐(4)	Single
		☐(0)	Other *(please specify)*
E8.	Which of these best describes your current employment status? *Please tick (✓) one*	☐(1)	In paid work (including self-employment) – full or part time
		☐(2)	Temporarily off sick from my job
		☐(3)	Unemployed
		☐(4)	Retired from paid work
		☐(5)	Unable to work because of long-term disability or ill health
		☐(6)	In full-time education, training or work experience
		☐(0)	Other *(please specify)*
E9.	Which of the following ethnic groups would you say you belong to? *Please tick (✓) one and circle as required*	☐(1)	White: British / other white groups
		☐(2)	Black: British / African / Caribbean / other black groups
		☐(3)	Asian: British / Indian / Pakistani / Bangladeshi / other Asian groups
		☐(4)	Chinese: British / other Chinese groups
E10.	What is your highest formal qualification? *Please tick (✓) one*	☐(1)	‘O’ level, GCSE or equivalent
		☐(2)	‘A’ level or equivalent
		☐(3)	Clerical or commercial qualification
		☐(4)	Professional qualification
		☐(5)	College or university degree, HND or HNC
		☐(6)	Postgraduate qualification *e.g. MA, MSc*
		☐(7)	None of these

Anything we missed?

Are there any other issues about your diet that you think might be important for us to know about? Please use this space to have your say. Feel free to continue on a separate sheet if you need to.

Please tell us about any other issues that affect your health and wellbeing:

We *very much appreciate the time and thought you have put into completing this survey. If reflecting on your diet has caused anxiety or uncertainty in any way, please do not hesitate to contact a member of your clinical team.*

You can also call Macmillan Cancer Support at ***0808 808 0000*** *or Cancer Research UK at* ***0808 800 4040*** *(free from UK landlines). Specialist nurses are there to listen to your concerns, and*

Office use only – detach on receipt to retain confidentiality

SECTION F: FURTHER WORK

Can we contact you again?

Thank you for your participation in this survey. The results will help us to better understand some of the important nutrition issues pelvic cancer patients face after cancer diagnosis.

We would like to conduct some informal interviews with a number of patients who have completed the questionnaire to explore nutrition issues and concerns in greater depth. If you are interested in taking part in an interview, please fill in your contact details below and we will be in touch.

Completing this expression of interest does not commit you to anything - Eligible patients will be given full details of the interview to allow them to decide whether or not they wish to take part.

Your contact details will be detached from the questionnaire and kept securely and **strictly confidential**. They will **not** be passed on to anyone else. We will keep a record to enable us to contact you about this study only. If you have any questions about this, please contact George Saltaouras on **tel: 01865 483283 or 01865 482669** or **email: 16021065@brookes.ac.uk.**

Would you be interested in taking part in an interview? *Please tick (✓) one*	☐(1) **No, I am not interested** *Do not complete the section below.*
	☐(2) **Yes, I am happy to be contacted for an interview** *Please complete contact details below.* ⇩

Please give your contact details:

Name			
Address		Home telephone	
		Work telephone	
		Mobile telephone	
Postcode		Email address	

Unique study ID *Completed by researcher*	

Please return in the envelope supplied to:

George Saltaouras
Faculty of Health and Life Sciences
Oxford Brookes University
Jack Straws Lane, Marston
Oxford, OX3 0FL

2d. Pre-determined script

Study title: Nutrition & Pelvic Cancer

Would you like to hear about a nutrition research project?

(If yes/maybe)

The project is conducted by researchers at Oxford Brookes University. They would like to invite you to fill in a survey about your experiences of diet and nutrition in relation to cancer. This is a study pack with all necessary information, a copy of the survey and a FREEPOST envelope. Please read the information carefully and if you are interested, fill in the survey and send it back in the envelope provided. There is no time limit on when to complete the survey by, although the research team would be grateful if you can complete and return it within a week. If you have any further questions about the study, there is a number you can call in the information provided in the pack. Thank you.

(If no)

Thank you.

2e: Study Invitation Letter to post-treatment participants

Oxford University Hospitals NHS
NHS Foundation Trust

OXFORD BROOKES UNIVERSITY

FREC study number: 2016/43
REC Reference: 17/ES/0112

01 March 2018

Reference: Nutrition and pelvic cancer: A study to explore dietary habits, nutritional awareness and patient experiences.

I am writing to invite you to consider taking part in a research study being conducted by researchers at Oxford Brookes University, in collaboration with the Radiotherapy Department, Cancer and Haematology Centre, Oxford University Hospitals NHS Foundation Trust.

The study aims to explore dietary and nutrition experiences and concerns in people who have been treated with radiotherapy for cancer in the pelvic area. Cancer in the pelvic area includes cancers of the anus, bladder, rectum, gynaecological cancers (cervix, womb, ovaries, vulva and vagina) and male cancers (prostate and testes). We are inviting people who completed treatment between 6 -24 months ago.

The research team would like to know about your current dietary habits, what you have heard about dietary guidelines, and what information and support you may have received in this area, or would like to have received. Taking part in the study would involve completing the questionnaire enclosed with this letter and returning it in the reply paid envelope provided. The study findings will help us to understand how we can best support patients in this area.

A patient information sheet is included with this letter, which contains more details about this study**. Involvement in the study is entirely voluntary. If you decide not to participate in the study your care will not be affected in any way. If you do decide to participate you can withdraw at any time without giving any reason.**

If you have any further questions that have not been answered in the patient information sheet, please do not hesitate to contact the research team for further information (George Saltaouras – email: 16021065@brookes.ac.uk, tel: 01865 482669 or Professor Eila Watson – email: ewatson@brookes.ac.uk, tel: 01865 482665).

Thank you for taking the time to read this letter.

Yours sincerely,

Dr Amanda Horne, MB BCH BAO MRCP FRCR

Consultant in Clinical Oncology

2f: Consent form (interviews)

Oxford University Hospitals NHS
NHS Foundation Trust

OXFORD
BROOKES
UNIVERSITY

Participant Consent Form

Nutrition and pelvic cancer: A study to explore dietary habits, nutritional awareness and patient experiences **– the patient's view.**

Please initial if you agree with the following statements:	**Please initial**
1. I confirm that I have read and understood the information sheet for the above study, that I have had the opportunity to ask questions and have had these answered satisfactorily as required.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.	☐
3. I agree to be interviewed.	☐
4. I understand that the interview will be audio-recorded.	☐
5. I agree to take part in the above study.	☐

Please circle yes or no in response to the following statements:	**Please circle**	
6. I understand that by taking part, I am agreeing that the researchers may use anonymous extracts from the transcripts of my audio recording in publications and presentations about the findings of this study.	Yes	No
7. I agree that my data gathered in this study will be stored (after it has been anonymised) at Oxford Brookes University and may be used for future research purposes such as publications related to this study after the completion of the study.	Yes	No
8. I give consent for the research team to share anonymised written and recorded material collected in this study with other researchers.	Yes	No

Name of participant (please print): ______________________________ **Date:** __________

Signature: ____

Name of researcher (please print): ______________________________ **Date:** __________

Signature: ____

<u>Contact details</u>:

George Saltaouras, PhD student

tel: 01865 482669, 01865 483283, email: 16021065@brookes.ac.uk.

2g: Topic guide (interviews)

Study Title: Nutrition and pelvic cancer patients: a mixed-methods study to explore dietary habits, nutritional awareness and patient experiences

The following broad topic guide addresses the objectives of the study:

- Current dietary habits and changes since diagnosis
- Beliefs and views of the role of diet in the management of symptoms and keeping healthy
- Patient experiences of nutrition support during and after cancer treatment.

Interview Topic Guide with participants

Topics		**Prompts**
Introduction	Introduction	Who I am Aim of study/interview Get verbal consent
	Cancer history(1)	**Would you like to tell me a bit about yourself?** When diagnosed Type of cancer Type of treatment
Dietary habits	Current dietary habits	Any food groups, particular foods/supplements/dietary patterns?
	Have you changed your diet since diagnosis? (+Pre-cancer eating patterns)	Any food groups, particular foods/supplements added/removed?
	Dietary supplements (2)	Do you consume? What is your opinion about them?
	Cooking and shopping practices (2)	Who cooks? How do you cook? Who shops? Where do you shop?
	Weight changes	Weight gain/loss?
Beliefs about diet and managing symptoms and keeping healthy in the future	Management of treatment-related symptoms	Any food groups, particular foods/supplements/dietary patterns?
	Keeping healthy (for example – reducing the risk of cancer recurrence or development of other conditions)	**What is your understanding of "keeping healthy"? What does it mean to you?** Any food groups, particular foods/supplements/dietary patterns?
Sources of information regarding diet	Who from	Clinic team/other health professional/anyone else Any other sources?
	How received	How did you feel about getting this information?

	Other information wanted	Any other information you wanted or that you have tried to access?
		If so, what type of information, when and from whom would you prefer it?
I think I got all the information I need. Is there anything else you would like to add?		
Conclusion	Resources of nutrition information	**I have a few sources of information that you may find useful. Would you like me to discuss this with you?** Inform participants of reliable online sources for nutrition advice (Macmillan Cancer Support, Cancer Research UK and, if applicable, a cancer-specific site such as Prostate Cancer UK)
	Conclusion	Thank participants for their time and contribution.

(1) Question removed as it was found to make participants feel uncomfortable in the first two interviews (pilot interviews).

(2) Question added after reflection of the content of the first two interviews (pilot interviews).

2h: Ethics approval (on-treatment group)

Georgios Saltaouras
PhD Student Researcher
Marston Road Campus
Jack Straws Lane
Marston
Oxon
OX3 0FL

15 June 2017

Dear Georgios

Re. Nutrition and pelvic cancer patients: a mixed-methods study to explore dietary habits, nutritional awareness and patient experiences

Thank you for your email correspondence, further to the review of your application by the Faculty Research Ethics Committee.

I can confirm that all the points raised in my letter dated 23 May 2017 have been satisfactorily addressed. I am therefore pleased to approve the research by Chair's Action, on behalf of the Faculty Research Ethics Committee.

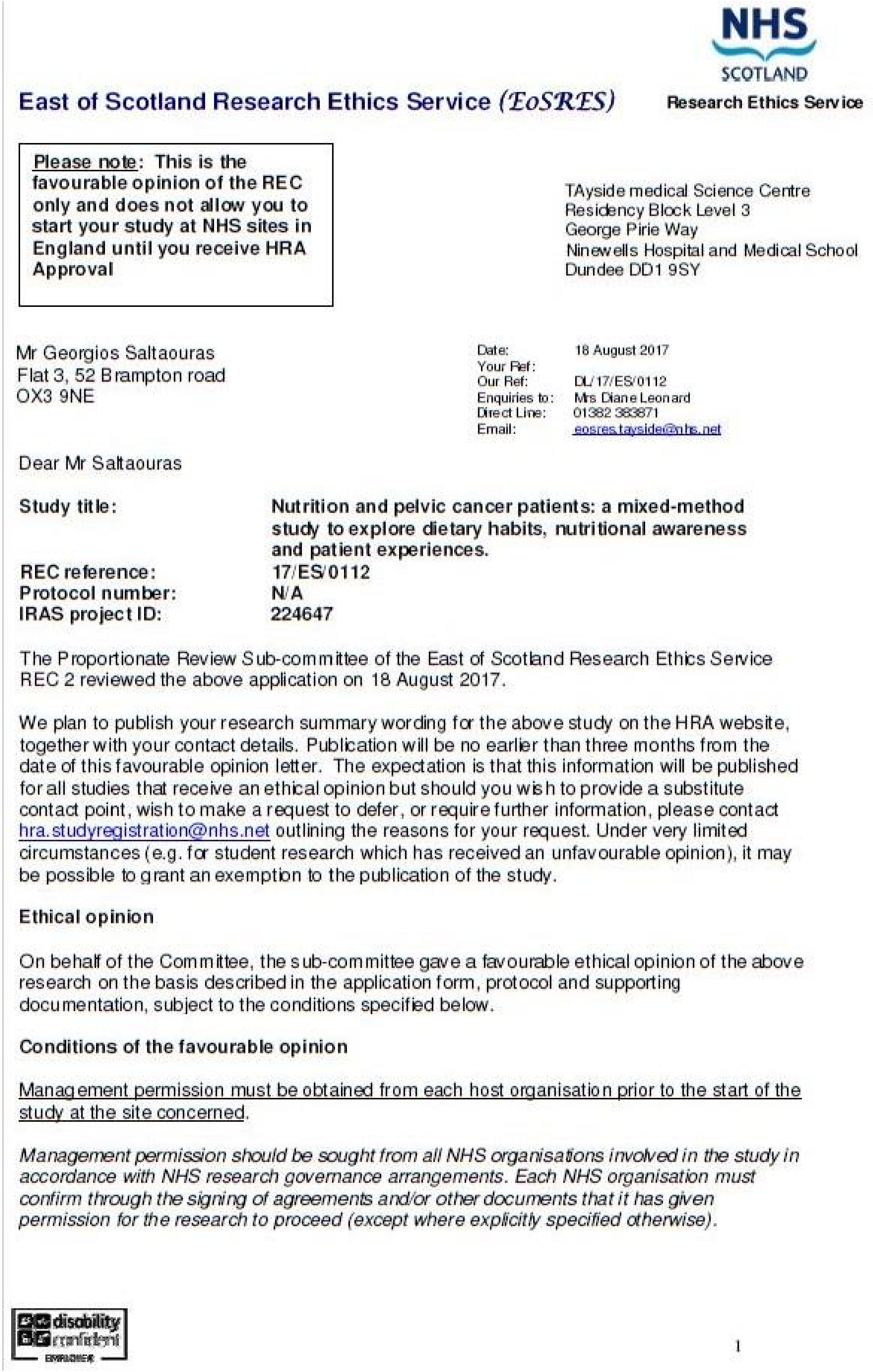
I am including with this letter the necessary correspondence for forwarding with your application for NRES and HRA approval.

Good luck with the data collection.

Yours sincerely

Hazel Abbott
Chair, Faculty of Health and Life Sciences Research Ethics Committee

Cc. Professor Eila Watson, Director of Studies



East of Scotland Research Ethics Service (EoSRES)

NHS SCOTLAND
Research Ethics Service

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

TAyside medical Science Centre
Residency Block Level 3
George Pirie Way
Ninewells Hospital and Medical School
Dundee DD1 9SY

Mr Georgios Saltaouras
Flat 3, 52 Brampton road
OX3 9NE

Date: 18 August 2017
Your Ref:
Our Ref: DL/17/ES/0112
Enquiries to: Mrs Diane Leonard
Direct Line: 01382 383871
Email: eosres.tayside@nhs.net

Dear Mr Saltaouras

Study title:	**Nutrition and pelvic cancer patients: a mixed-method study to explore dietary habits, nutritional awareness and patient experiences.**
REC reference:	**17/ES/0112**
Protocol number:	**N/A**
IRAS project ID:	**224647**

The Proportionate Review Sub-committee of the East of Scotland Research Ethics Service REC 2 reviewed the above application on 18 August 2017.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.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 management permissions 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 publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

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 request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion").

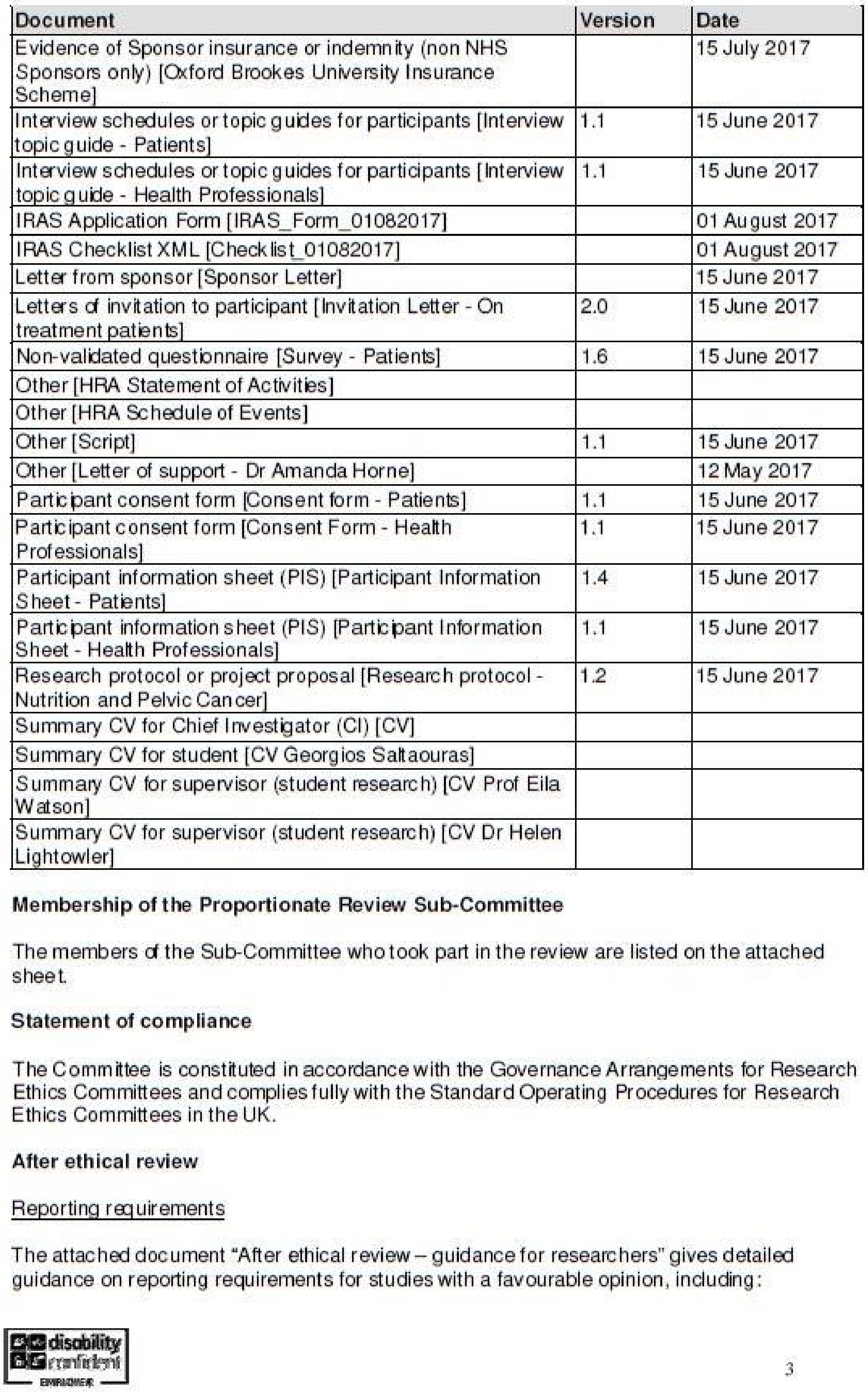
Summary of discussion at the meeting

The PR Sub-Committee agreed that this was a well presented study with no material ethical issues.

Approved documents

The documents reviewed and approved were:

Document	Version	Date
Contract/Study Agreement template		15 June 2017
Covering letter on headed paper		15 June 2017



Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Oxford Brookes University Insurance Scheme]		15 July 2017
Interview schedules or topic guides for participants [Interview topic guide - Patients]	1.1	15 June 2017
Interview schedules or topic guides for participants [Interview topic guide - Health Professionals]	1.1	15 June 2017
IRAS Application Form [IRAS_Form_01082017]		01 August 2017
IRAS Checklist XML [Checklist_01082017]		01 August 2017
Letter from sponsor [Sponsor Letter]		15 June 2017
Letters of invitation to participant [Invitation Letter - On treatment patients]	2.0	15 June 2017
Non-validated questionnaire [Survey - Patients]	1.6	15 June 2017
Other [HRA Statement of Activities]		
Other [HRA Schedule of Events]		
Other [Script]	1.1	15 June 2017
Other [Letter of support - Dr Amanda Horne]		12 May 2017
Participant consent form [Consent form - Patients]	1.1	15 June 2017
Participant consent form [Consent Form - Health Professionals]	1.1	15 June 2017
Participant information sheet (PIS) [Participant Information Sheet - Patients]	1.4	15 June 2017
Participant information sheet (PIS) [Participant Information Sheet - Health Professionals]	1.1	15 June 2017
Research protocol or project proposal [Research protocol - Nutrition and Pelvic Cancer]	1.2	15 June 2017
Summary CV for Chief Investigator (CI) [CV]		
Summary CV for student [CV Georgios Saltaouras]		
Summary CV for supervisor (student research) [CV Prof Eila Watson]		
Summary CV for supervisor (student research) [CV Dr Helen Lightowler]		

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

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/

With the Committee's best wishes for the success of this project.

17/ES/0112	**Please quote this number on all correspondence**

Yours sincerely

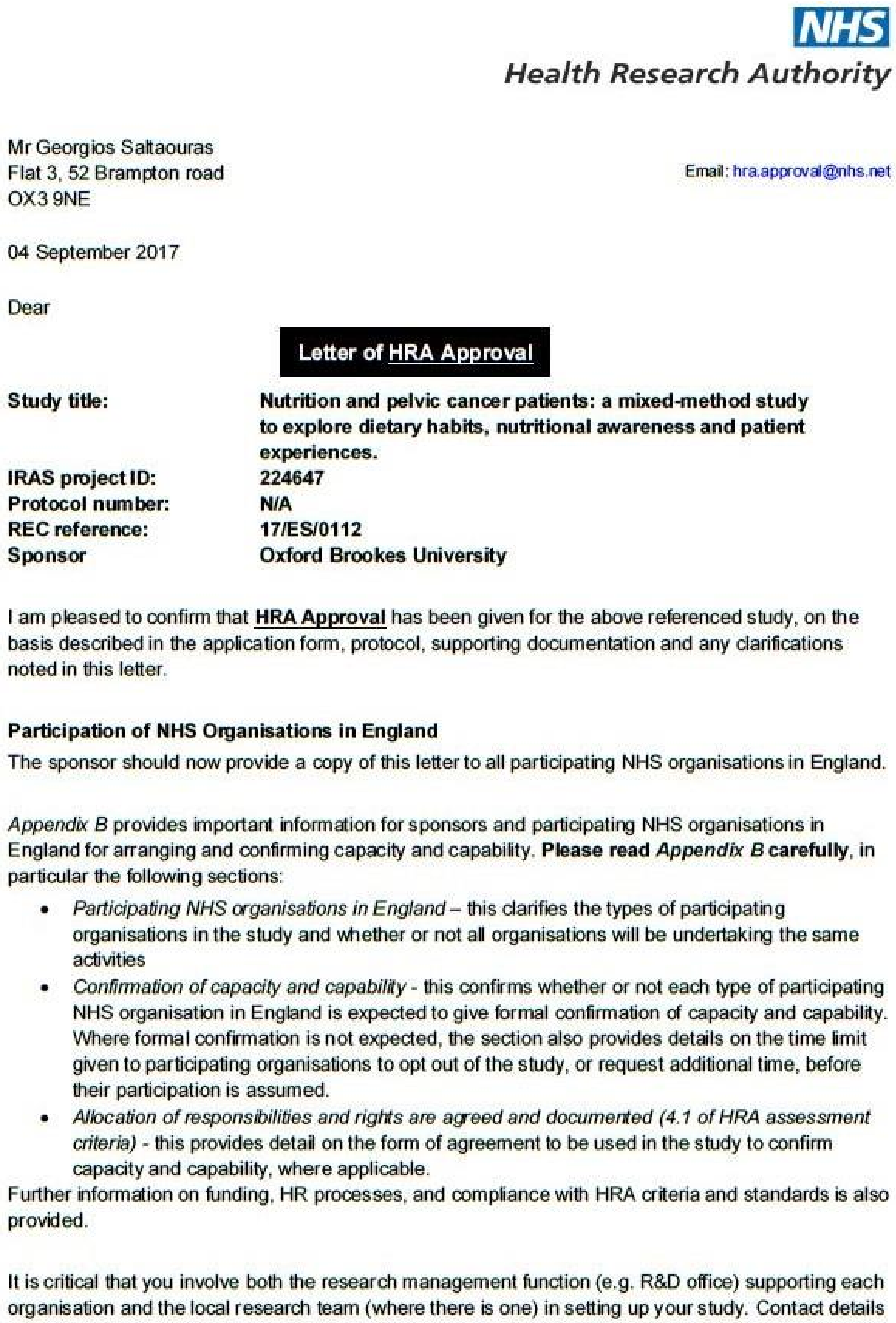
D Leonard.

for Dr Stuart Paterson
Alternate Vice-Chair

Email: eosres.tayside@nhs.net

Enclosures: List of names and professions of members who took part in the review
"After ethical review – guidance for researchers"

Copy to: Ms Hazel Abbott
Ms Heather House, Oxford University Hospitals NHS Trust



NHS
Health Research Authority

Mr Georgios Saltaouras
Flat 3, 52 Brampton road
OX3 9NE

Email: hra.approval@nhs.net

04 September 2017

Dear

Letter of HRA Approval

Study title:	**Nutrition and pelvic cancer patients: a mixed-method study to explore dietary habits, nutritional awareness and patient experiences.**
IRAS project ID:	**224647**
Protocol number:	**N/A**
REC reference:	**17/ES/0112**
Sponsor	**Oxford Brookes University**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

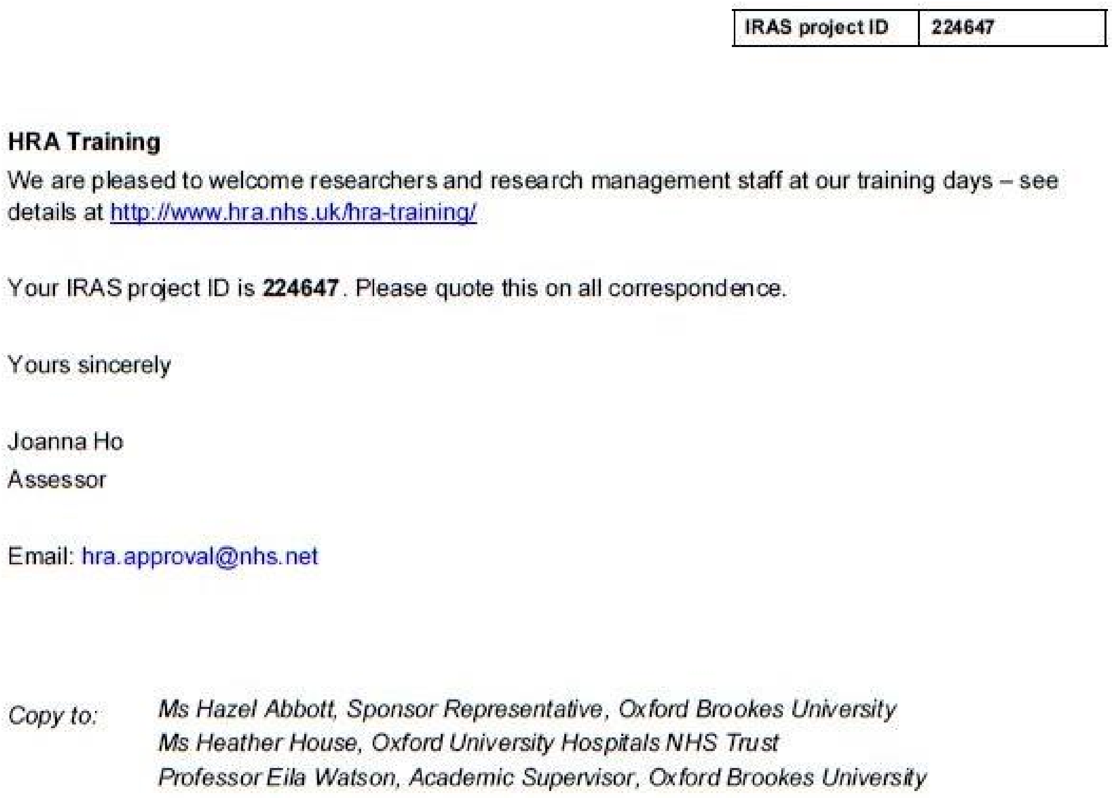
HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

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/.



IRAS project ID	**224647**

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **224647**. Please quote this on all correspondence.

Yours sincerely

Joanna Ho
Assessor

Email: hra.approval@nhs.net

Copy to: *Ms Hazel Abbott, Sponsor Representative, Oxford Brookes University*
Ms Heather House, Oxford University Hospitals NHS Trust
Professor Eila Watson, Academic Supervisor, Oxford Brookes University

NHS
Oxford University Hospitals
NHS Foundation Trust

FP/ANS/13101

From the Head of Research Governance
OUH Research & Development
Joint Research Office
Second Floor, OUH Cowley
Unipart House Business Centre
Garsington Road
Oxford
OX4 2PG

Tel: (01865) 572239
Ailis.NiShuilleabhain@ouh.nhs.uk

Mr Georgios Saltaouras
Flat 3,
52 Brampton road
Oxford
OX3 9NE

Date: 19th September 2017

Dear Mr Saltaouras,

Re: Nutrition and pelvic cancer patients: a mixed-method study to explore dietary habits, nutritional awareness and patient experiences
IRAS Reference: 224647
Research and Development Reference: 13101
Research Ethics Committee Reference: 17/ES/0112

Confirmation of Trust Management Approval
On behalf of the Oxford University Hospitals NHS Foundation Trust, I am pleased to confirm Trust Management Approval and Indemnity for the above research on the basis described in the application, protocol and other supporting documents.

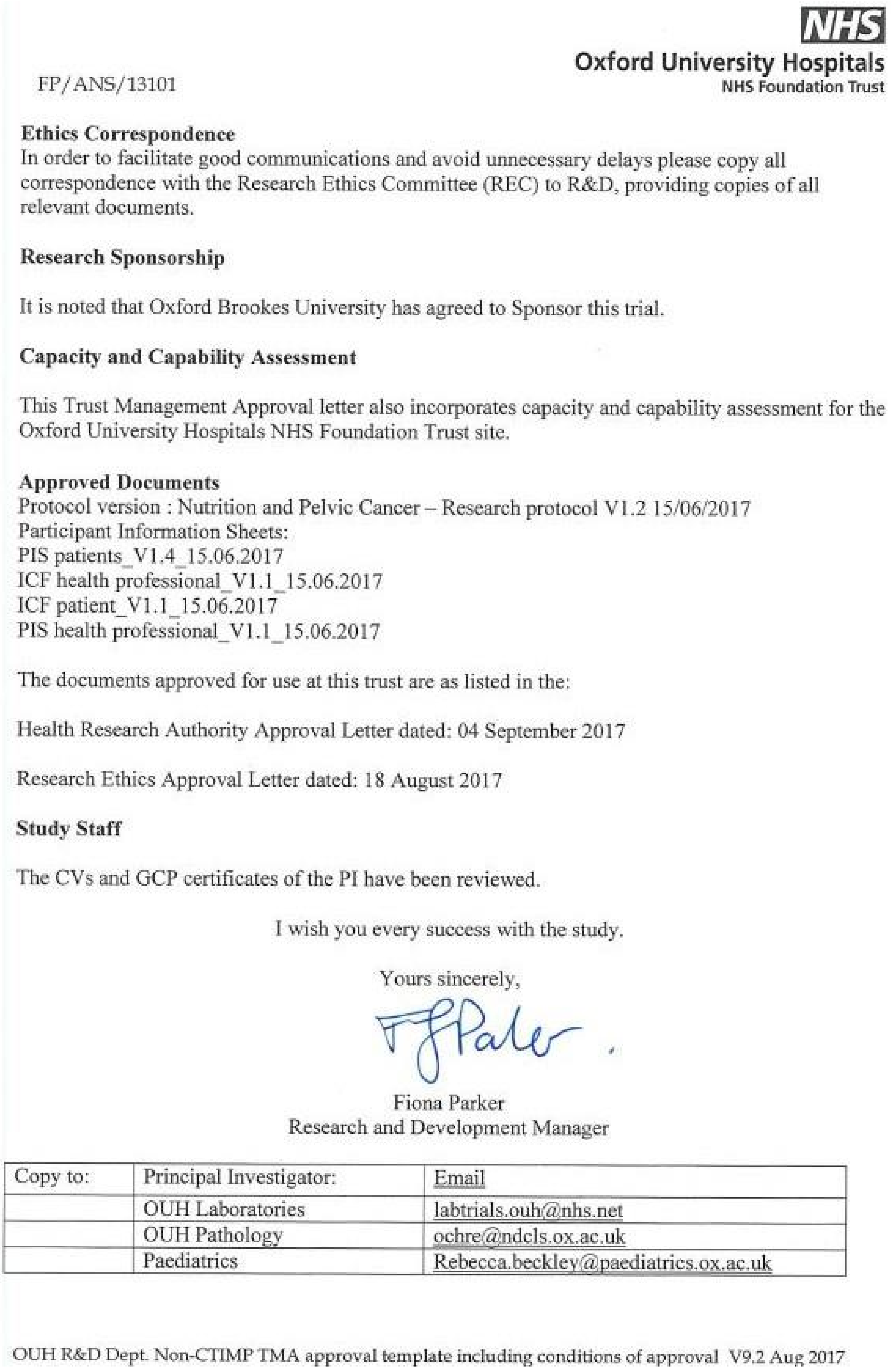
Conditions of Approval
Your attention is drawn to the attached conditions of approval. Breach of these conditions may result in Trust Management Approval being revoked.

Recruitment

The agreed total recruitment target for your study at the OUH site is 100 participants by 28/02/2019 as specified in the Contract/Statement of Activities.

Your first participant recruitment target date is 23/11/2017.

To support OUH Trust and national recruitment targets, R&D will monitor and publish recruitment for your study: 1. Performance against the 70 calendar day period benchmark from the time of receipt of a valid research application in R&D to the date of recruitment of first participant to your study; and for interventional trials; 2. Recruiting planned participants to time and target. The R&D office will contact you to request recruitment progress against both targets. If you recruit your first participant into the study then please send the date to researchrecruitment@ouh.nhs.uk. If you miss this target you will be required to give reasons that can be reported to the DOH/NIHR.



NHS
Oxford University Hospitals
NHS Foundation Trust

FP/ANS/13101

Ethics Correspondence
In order to facilitate good communications and avoid unnecessary delays please copy all correspondence with the Research Ethics Committee (REC) to R&D, providing copies of all relevant documents.

Research Sponsorship

It is noted that Oxford Brookes University has agreed to Sponsor this trial.

Capacity and Capability Assessment

This Trust Management Approval letter also incorporates capacity and capability assessment for the Oxford University Hospitals NHS Foundation Trust site.

Approved Documents
Protocol version : Nutrition and Pelvic Cancer – Research protocol V1.2 15/06/2017
Participant Information Sheets:
PIS patients_V1.4_15.06.2017
ICF health professional_V1.1_15.06.2017
ICF patient_V1.1_15.06.2017
PIS health professional_V1.1_15.06.2017

The documents approved for use at this trust are as listed in the:

Health Research Authority Approval Letter dated: 04 September 2017

Research Ethics Approval Letter dated: 18 August 2017

Study Staff

The CVs and GCP certificates of the PI have been reviewed.

I wish you every success with the study.

Yours sincerely,

Fiona Parker
Research and Development Manager

Copy to:	Principal Investigator:	Email
	OUH Laboratories	labtrials.ouh@nhs.net
	OUH Pathology	ochre@ndcls.ox.ac.uk
	Paediatrics	Rebecca.beckley@paediatrics.ox.ac.uk

2i: Ethics approval (amendment; post-treatment group)

NHS
SCOTLAND
Research Ethics Servic

East of Scotland Research Ethics Service (*EoSRES*)

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

TAyside medical Science Centre
Residency Block Level 3
George Pirie Way
Ninewells Hospital and Medical School
Dundee DD1 9SY

Mr Georgios Saltaouras
Flat 3,
52 Brampton road
OX3 9NE

Date: 14th February 2018
Your Ref:
Our Ref: LR/AG17/ES/0112
Enquiries to: Arlene Grubb
Direct Line: 01382 383848
Email: eosres.tayside@nhs.net

Dear Mr Saltaouras

Study title: **Nutrition and pelvic cancer patients: a mixed-method study to explore dietary habits, nutritional awareness and patient experiences.**
REC reference: **17/ES/0112**
Protocol number: **N/A**
Amendment number: **AM01(REC Reference only)**
Amendment date: **01 February 2018**
IRAS project ID: **224647**

The above amendment was reviewed at the meeting of the Sub-Committee held on 14 February 2018 in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Letters of invitation to participant	1.0	10 January 2018
Notice of Substantial Amendment (non-CTIMP)	AM01	01 February 2018

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

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.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

17/ES/0112: Please quote this number on all correspondence

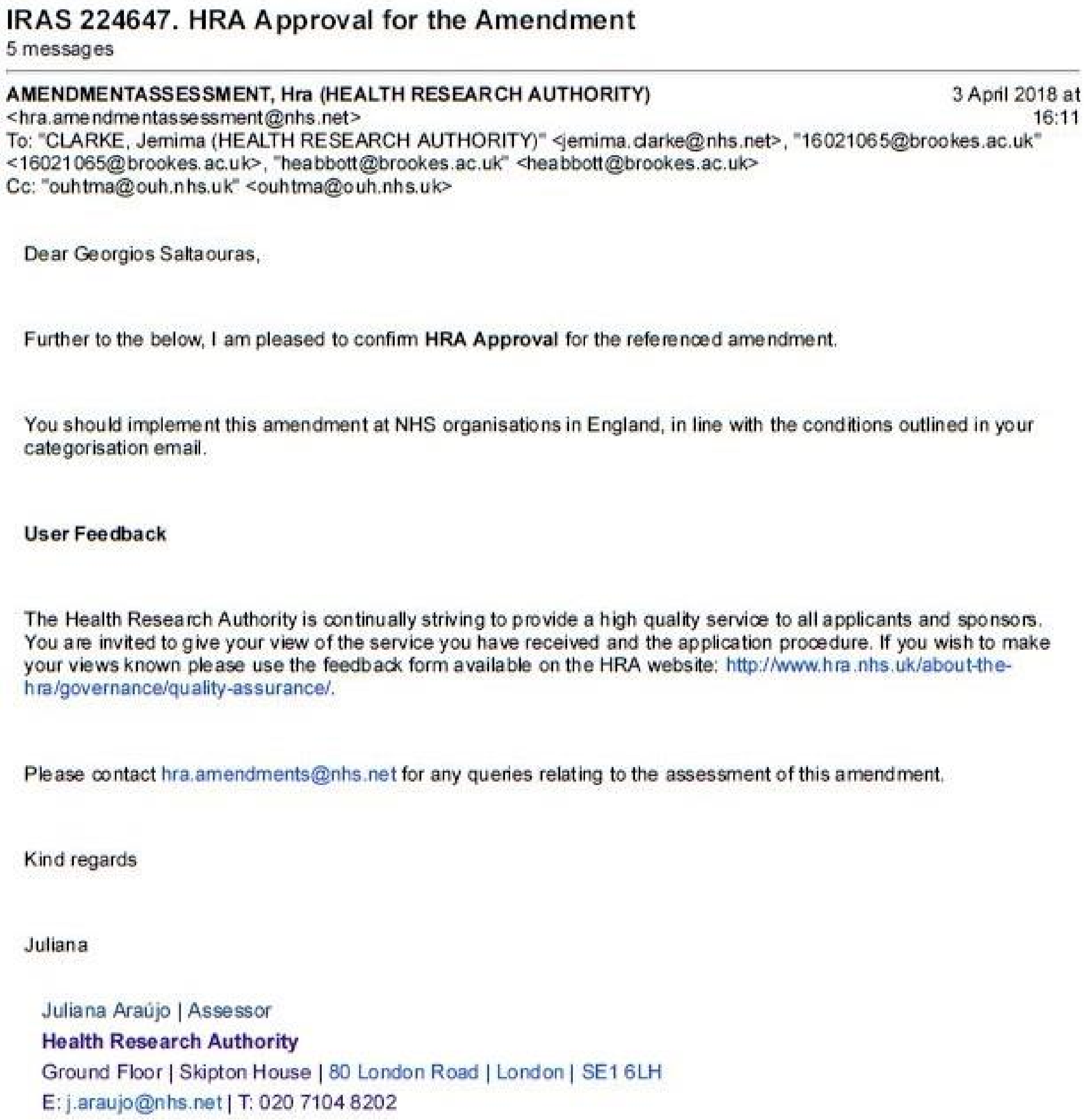
Yours sincerely

Arlene Grubb

PP **Ms Petra Rauchhaus**
Alternative vice Chair

E-mail: eosres.tayside@nhs.net

Enclosures: List of names and professions of members who took part in the review



IRAS 224647. HRA Approval for the Amendment

5 messages

AMENDMENTASSESSMENT, Hra (HEALTH RESEARCH AUTHORITY) <hra.amendmentassessment@nhs.net>

3 April 2018 at 16:11

To: "CLARKE, Jemima (HEALTH RESEARCH AUTHORITY)" <jemima.clarke@nhs.net>, "16021065@brookes.ac.uk" <16021065@brookes.ac.uk>, "heabbott@brookes.ac.uk" <heabbott@brookes.ac.uk>
Cc: "ouhtma@ouh.nhs.uk" <ouhtma@ouh.nhs.uk>

Dear Georgios Saltaouras,

Further to the below, I am pleased to confirm **HRA Approval** for the referenced amendment.

You should implement this amendment at NHS organisations in England, in line with the conditions outlined in your categorisation email.

User Feedback

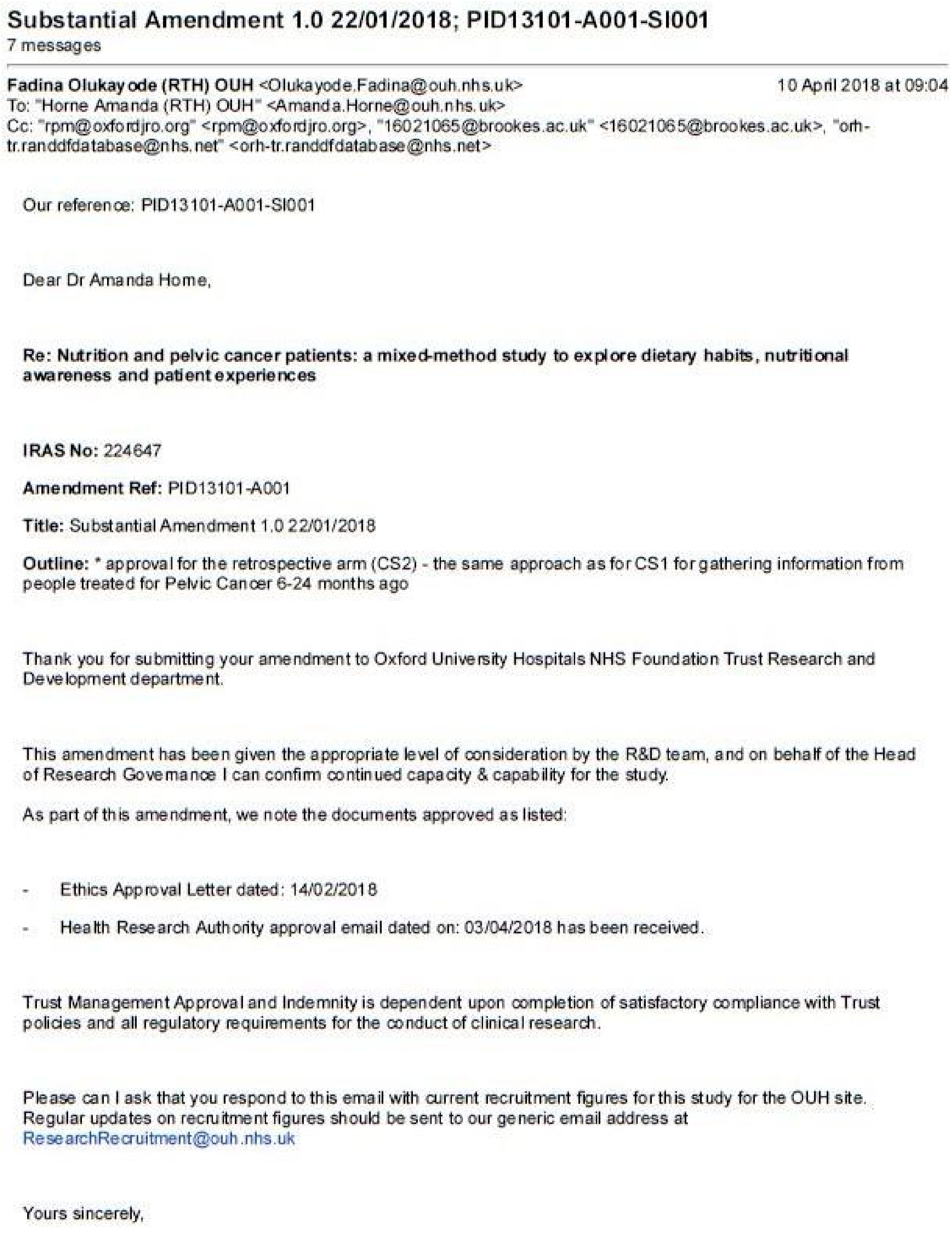
The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

Please contact hra.amendments@nhs.net for any queries relating to the assessment of this amendment.

Kind regards

Juliana

Juliana Araújo | Assessor
Health Research Authority
Ground Floor | Skipton House | 80 London Road | London | SE1 6LH
E: j.araujo@nhs.net | T: 020 7104 8202



Substantial Amendment 1.0 22/01/2018; PID13101-A001-SI001

7 messages

Fadina Olukayode (RTH) OUH <Olukayode.Fadina@ouh.nhs.uk> 10 April 2018 at 09:04
To: "Horne Amanda (RTH) OUH" <Amanda.Horne@ouh.nhs.uk>
Cc: "rpm@oxfordjro.org" <rpm@oxfordjro.org>, "16021065@brookes.ac.uk" <16021065@brookes.ac.uk>, "orh-tr.randdfdatabase@nhs.net" <orh-tr.randdfdatabase@nhs.net>

Our reference: PID13101-A001-SI001

Dear Dr Amanda Home,

Re: Nutrition and pelvic cancer patients: a mixed-method study to explore dietary habits, nutritional awareness and patient experiences

IRAS No: 224647

Amendment Ref: PID13101-A001

Title: Substantial Amendment 1.0 22/01/2018

Outline: * approval for the retrospective arm (CS2) - the same approach as for CS1 for gathering information from people treated for Pelvic Cancer 6-24 months ago

Thank you for submitting your amendment to Oxford University Hospitals NHS Foundation Trust Research and Development department.

This amendment has been given the appropriate level of consideration by the R&D team, and on behalf of the Head of Research Governance I can confirm continued capacity & capability for the study.

As part of this amendment, we note the documents approved as listed:

- Ethics Approval Letter dated: 14/02/2018
- Health Research Authority approval email dated on: 03/04/2018 has been received.

Trust Management Approval and Indemnity is dependent upon completion of satisfactory compliance with Trust policies and all regulatory requirements for the conduct of clinical research.

Please can I ask that you respond to this email with current recruitment figures for this study for the OUH site. Regular updates on recruitment figures should be sent to our generic email address at ResearchRecruitment@ouh.nhs.uk

Yours sincerely,

On behalf of the Head of Research Governance

PID13101-A001-SI001

NHS
Oxford University Hospitals
NHS Foundation Trust
Joint Research Office
Oxford University Hospitals NHS Foundation Trust
Second Floor, OUH Cowley
Unipart House Business Centre, Garsington Road
Oxford, OX4 2PG

Kayode Fadina
Research Support Specialist
Research & Development (Governance)

☎ Tel: 01865 223714
✉ Email: Olukayode.Fadina@ouh.nhs.uk

APPENDIX 3: Collinearity statistics – Chapter 3 (Methodology and methods)

3a: Collinearity statistics for the variables included in the logistic regression model for dietary change and detailed multivariate logistic regression data.

Variables	Tolerance	VIF
Treatment status	.887	1.127
Diagnosis dummy 1 (prostate cancer)	.482	2.073
Diagnosis dummy 2 (lower GI cancer)	.474	2.109
Age	.430	2.324
Body Mass Index	.898	1.114
Qualifications	.890	1.124
Employment	.497	2.011
Marital status	.894	1.118
Presence of a comorbidity	.795	1.258
Presence of a side effect	.913	1.095
Supplement use	.876	1.141
Nutrition support from health professional	.908	1.101

3b: Collinearity statistics for the variables included in the logistic regression model for supplement use and detailed multivariate logistic regression data.

Model	Tolerance	VIF
Treatment status	.915	1.093
Diagnosis dummy 1 (prostate cancer)	.491	2.035
Diagnosis dummy 2 (lower GI cancer)	.504	1.983
Age	.432	2.313
Body Mass Index	.900	1.111
Qualifications	.903	1.107
Employment	.498	2.010
Marital status	.894	1.118
Presence of a comorbidity	.795	1.258
Presence of a side effect	.933	1.072
Nutritional support by health professional	.919	1.088

3c: Collinearity statistics for the variables included in the logistic regression model for support from health professionals.

(Constant)	Tolerance	VIF
Treatment status	.895	1.118
Diagnosis dummy 1 (prostate cancer)	.482	2.076
Diagnosis dummy 2 (lower GI cancer)	.475	2.103
Age	.432	2.317
Body Mass Index	.896	1.116
Qualifications	.881	1.135
Employment	.502	1.991
Marital status	.903	1.108
Presence of a comorbidity	.796	1.256
Presence of a side effect	.905	1.105
Supplement use	.884	1.131
Report of a dietary change	.917	1.091

Appendix 3d: Collinearity statistics for the variables included in the logistic regression model for support from other sources.

Constant	Tolerance	VIF
Treatment status	.892	1.121
Diagnosis dummy 1 (prostate cancer)	.482	2.076
Diagnosis dummy 2 (lower GI cancer)	.469	2.130
Age	.431	2.318
Body Mass Index	.891	1.122
Qualifications	.872	1.147
Employment	.499	2.006
Marital status	.892	1.122
Presence of a comorbidity	.796	1.256
Presence of a side effect	.891	1.123
Supplement use	.867	1.153
Report of a dietary change	.849	1.177
Nutrition support from health professional	.841	1.190

APPENDIX 4: Chapter 4 (Survey results)

4a: Demographic, clinical and health characteristics of the study sample (n=251).

Demographic characteristics	**All participants n=251**	**On-treatment n=102**	**Post-treatment n=149**
Age			
Mean (SD)	68.8 (10.5)	68.1 (9.8)	69.3 (11.0)
Median (IQR)	70.0 (62-77)	70.0 (62-76)	71.0 (62-77)
Range	30-92	43-84	30-92
Missing (n (%))	12 (5)	4 (4)	8 (5)
Gender	**n (%)**	**n (%)**	**n (%)**
Male	153 (61)	66 (65)	87 (58)
Female	76 (30)	28 (27)	48 (32)
Missing	22 (9)	8 (8)	14 (10)
Chi-squared test (treatment status): $x^2(1)=1.052$, *P*=0.305			
Marital status	**n (%)**	**n (%)**	**n (%)**
Married or living as married	186 (74)	74 (73)	112 (75)
Divorced or separated	17 (7)	8 (8)	9 (6)
Widowed	21 (8)	8 (8)	13 (9)
Single	23 (9)	11 (11)	12 (8)
Missing	4 (2)	1 (1)	3 (2)
Chi-squared test (treatment status): Married Vs all other categories: $x^2(1)=0.381$, *P*=0.537 ***Chi-squared test (cancer diagnosis):*** Married Vs all other categories: $x^2(2)=6.514$, *P*=0.038 *Chi-squared tests were performed between groups “married” and “not married”. All categories except “married” were combined as the numbers were very small.*			
Employment status	**n (%)**	**n (%)**	**n (%)**
In paid work (full-time or part-time)	51 (20)	20 (20)	31 (21)
Retired	165 (66)	65 (64)	100 (67)
Other	30 (12)	16 (16)	14 (9)
Missing	5 (2)	1 (1)	4 (3)
Chi-squared test (treatment status): Retired Vs all other categories: $x^2(1)=0.204$, *P*=0.652 ***Chi-squared test (cancer diagnosis):*** Retired Vs all other categories: $x^2(2)=41.188$, ***P*<0.001** *Chi-squared tests were performed between groups “retired” and “not retired”. All categories except “retired” were combined as the numbers were very small.*			
Ethnicity	**n (%)**	**n (%)**	**n (%)**
White	242 (96)	99 (97)	143 (96)
Black/Asian/Other	5 (2)	2 (2)	3 (2)
Missing	4 (2)	1 (1)	3 (2)
Education	**n (%)**	**n (%)**	**n (%)**
O level/GCSE	36 (14)	17 (17)	19 (13)
A level	19 (8)	5 (5)	14 (9)
Clerical or commercial qualification	13 (5)	4 (4)	9 (6)
Professional qualification	42 (17)	14 (14)	28 (19)
College or University qualification	60 (24)	25 (24)	35 (23)

Postgraduate qualification	21 (8)	9 (9)	12 (8)
None of the above	49 (20)	23 (22)	26 (17)
Missing	11 (4)	5 (5)	6 (4)

Chi-squared tests (treatment status): <=High school Vs > High school: $x^2(1)=0.219$, *P*=0.640

Chi-squared tests (cancer diagnosis): Retired Vs all other categories: $x^2(2)=2.331$, *P*=0.312

Chi-squared tests were performed between groups "<=high school" and "some qualification". The category "<=high school" included O level/GCSE and A level; the category "some qualification" included clerical, commercial, professional, college, university or postgraduate qualification

Other clinical characteristics	**All participants (n=251)**	**On treatment (n=102)**	**Post treatment (n=149)**
Treatment	**n (%)**	**n (%)**	**n (%)**
Radiotherapy only	83 (33)	33 (32)	50 (34)
Radiotherapy and chemotherapy	57 (23)	21 (21)	36 (24)
Radiotherapy and hormone therapy	44 (18)	20 (20)	24 (16)
Radiotherapy and surgery	24 (10)	12 (12)	12 (8)
Radiotherapy, chemotherapy and surgery	47 (19)	18 (18)	29 (19)
Time since the end of treatment	**n (%)**	**n (%)**	**n (%)**
6-12 months	N/A	N/A	66 (44)
13-18 months	N/A	N/A	40 (27)
19-24 months	N/A	N/A	36 (24)
Missing	N/A	N/A	7 (5)
First cancer diagnosis	**n (%)**	**n (%)**	**n (%)**
Yes	209 (83)	77 (75)	132 (89)
No	33 (13)	23 (23)	10 (7)
Missing	9 (4)	2 (2)	7 (5)

Other health characteristics	**All participants (n=251)**	**On treatment (n=102)**	**Post treatment (n=149)**
Smoking status	**n (%)**	**n (%)**	**n (%)**
Current smoker	15 (6)	4 (4)	11 (7)
Ex-smoker	132 (53)	54 (53)	78 (52)
Never smoked	97 (39)	43 (42)	54 (36)
Missing	7 (3)	1 (1)	6 (4)

Chi-squared tests for comorbidities

Chi-squared tests (treatment status):	***Chi-squared tests (cancer diagnosis):***
Heart disease: $x^2(1)=0.350$, *P*=0.554	Heart disease: $x^2(2)=10.679$, ***P*=0.005**
Diabetes: $x^2(1)=0.325$, *P*=0.569	Diabetes: $x^2(2)=1.023$, *P*=0.600
High blood pressure: $x^2(1)=1.891$, *P*=0.169	High blood pressure: $x^2(2)=5.975$, *P*=0.050
Asthma: $x^2(1)=0.017$, *P*=0.896	Asthma: $x^2(2)=3.685$, *P*=0.158
Arthritis: $x^2(1)=1.767$, *P*=0.184	Arthritis: $x^2(2)=0.844$, *P*=0.656
Stomach/gallbladder: $x^2(1)=1.461$, *P*=0.227	Stomach/gallbladder: $x^2(1)=3.424$, *P*=0.181
Osteoporosis: Continuity correction=0.439, *P*=0.507.	Osteoporosis: Fisher's Exact Test=7.242, *P*=0.016.

4b: Treatment side effects (n=251).

Characteristics	All participants n=251	On-treatment n=102	Post-treatment n=149
	n (%)	**n (%)**	**n (%)**
Fatigue	135 (54)	63 (62)	72 (48)
Wind/bloating	103 (41)	52 (51)	51 (34)
Diarrhoea	66 (26)	36 (35)	30 (20)
Incontinence	38 (15)	11 (11)	27 (18)
Dry mouth	44 (18)	22 (22)	22 (15)
Constipation	36 (14)	18 (18)	18 (12)
Change in taste	35 (14)	21 (21)	14 (9)
Loss of appetite	29 (12)	18 (18)	11 (7)
Other gastrointestinal problems	11 (4)	3 (3)	8 (5)
Nausea and vomiting	23 (9)	16 (16)	7 (5)
Changes in smell	9 (4)	3 (3)	6 (4)
Urinary dysfunction	9 (4)	4 (4)	5 (3)
Other side effects (1)	31 (12)	10 (10)	21 (14)
No side effects	45 (18)	13 (13)	32 (21)
Missing	3 (1)	0 (0)	3 (2)

Chi-squared tests (treatment status): Fatigue: $x^2(1)$=3.752, *P*=0.053; wind/bloating: $x^2(1)$=6.369, *P*=0.012; diarrhoea: $x^2(1)$=6.686, *P* =0.010; incontinence: $x^2(1)$=2.750, *P* =0.097; dry mouth: $x^2(1)$=1.738, *P* =0.187; constipation: $x^2(1)$=1.369, *P* =0.242; changes in taste: $x^2(1)$=5.993, *P* =0.014; loss of appetite: $x^2(1)$=5.947, *P* =0.015; nausea and vomiting: $x^2(1)$=8.466, ***P* =0.004**.

Chi-squared tests (cancer diagnosis): Fatigue: $x^2(2)$=0.093, *P*=0.955; wind/bloating: $x^2(2)$=0.613, *P* =0.736; diarrhoea: $x^2(2)$=5.882, *P* =0.053; incontinence: $x^2(2)$=3.691, *P* =0.158; dry mouth: $x^2(2)$=7.896, *P* =0.019; constipation: $x^2(2)$=7.336, *P* =0.026; changes in taste: $x^2(2)$=18.708, ***P* <0.001**; loss of appetite: $x^2(2)$=20.514, ***P* <0.001**; nausea and vomiting: $x^2(2)$=17.568, ***P* <0.001**.

---

(1) Other side effects include hot flushes (n=5), mouth sores (n=5), difficulty swallowing (n=5), weight changes (n=3), pain (n=3), itching (n=1), erectile dysfunction (n=1), mucus (n=1), irritable bladder (n=1), radiation induced cystitis (n=1), lymphoedema (n=1), blood in urine (n=1), depression (n=1), lack of concentration (n=1), infection of the buttocks (n=1).

4c: Weight changes (n=251).

Characteristics	All participants n=251	On-treatment n=102	Post-treatment n=149
Weight changes (1)	**n (%)**	**n (%)**	**n (%)**
Weight gain	82 (33)	28 (27)	54 (36)
Weight loss	65 (26)	33 (32)	32 (21)
No weight changes	98 (39)	38 (37)	60 (40)
Missing	10 (4)	3 (3)	7 (5)

Chi-squared tests (treatment status): Weight gain: $x^2(1)$=2.634, *P*=0.105; weight loss: $x^2(1)$=3.271, *P*=0.071; no weight changes: $x^2(1)$=0.441, *P* =0.507.

Chi-squared tests (cancer diagnosis): Weight gain: $x^2(2)$=3.102, *P*=0.212; weight loss: $x^2(2)$=8.587, *P* =0.014; no weight changes: $x^2(2)$=3.102, *P* =0.210.

---

(1) Four participants reported weight gain and weight loss. The percentage values exceed 100%.

4d: Dietary habits and dietary changes since diagnosis (n=251).

Characteristics	**All participants n=251**	**On-treatment n=102**	**Post-treatment n=149**
Have you changed your diet since diagnosis?	**n (%)**	**n (%)**	**n (%)**
Yes	170 (68)	70 (69)	100 (67)
No	81 (32)	32 (31)	49 (33)
Why have you changed your diet? [1,2]	**n=170** **n (%)**	**n=70** **n (%)**	**n=100** **n (%)**
To reduce the risk of recurrence	52 (31)	18 (26)	34 (34)
To assist with treatment side effects	77 (45)	43 (61)	34 (34)
To maintain general health	99 (58)	35 (50)	64 (64)
To support therapy and recovery	70 (41)	36 (51)	34 (34)
Other [3]	11 (6)	1 (1)	10 (10)
Missing	35 (21)	15 (22)	20 (20)

Chi-squared tests (treatment status): Reduce the risk of recurrence: $x^2(1)=1.314$, *P*=0.252; to assist with treatment side effects: $x^2(1)=16.934$, ***P* <0.001**; to maintain general health: $x^2(1)=4.463$, *P* =0.035; to support therapy and recovery: $x^2(1)=6.879$, ***P* =0.009**.

Chi-squared tests (cancer diagnosis): Reduce the risk of recurrence: $x^2(2)=0.250$, *P*=0.882; to assist with treatment side effects: $x^2(2)=0.138$, *P* <0.933; to maintain general health: $x^2(2)=3.022$, *P* =0.221; to support therapy and recovery: $x^2(2)=0.515$, *P* =0.773.

---

[1] This question was answered only by participants who responded "Yes" in the question "Have you changed your diet since diagnosis?. N=100 for the post-treatment group, N=70 for the on-treatment group".

[2] More than one answers possible. The percentage values exceed 100%.

[3] Other responses included losing weight (n=4), diagnosis of diabetes (n=3), gaining weight (n=1), inability to eat specific foods after operation (n=1) and maintenance of consistency of faeces for ostomy (n=1).

4d: Dietary changes and chi-squared tests according to treatment status.

***Dietary changes*.**	**Increased consumption**		**Decreased consumption**	
	On treatment	***Post treatment***	***On treatment***	***Post treatment***
Whole grains	23/98	38/144	16/98	15/144
	$x^2(1)=0.264$, *P*=0.608		$x^2(1)=1.824$, *P*=0.177	
Refined grains	16/97	7/142	18/97	45/142
	$x^2(1)=8.863$, *P*=0.003		$x^2(1)=5.121$, *P*=0.024	
Fruit	31/101	51/147	14/101	9/147
	$x^2(1)=0.433$, *P*=0.511		$x^2(1)=4.261$, *P*=0.039	
Vegetables	25/98	55/148	9/98	5/148
	$x^2(1)=3.648$, *P*=0.056		$x^2(1)=3.702$, *P*=0.054	
Low fat milk and dairy products	12/99	19/141	10/99	12/141
	$x^2(1)=0.095$, *P*=0.758		$x^2(1)=0.177$, *P*=0.674	
Full fat milk and dairy products	6/94	5/140	25/94	43/140
	$x^2(1)=0.992$, *P*=0.319		$x^2(1)=0.463$, *P*=0.496	
Lean, low fat meat and poultry	24/100	26/143	8/100	14/143
	$x^2(1)=1.219$, *P*=0.270		$x^2(1)=0.229$, *P*=0.632	
Oily fish	22/99	48/145	7/99	1/145
	$x^2(1)=3.405$, *P*=0.065		Continuity correction 5.676, *P*=0.017	
White fish	24/99	39/145	2/99	2/145
	$x^2(1)=0.216$, *P*=0.642		Continuity correction <0.001, *P*=1.000	
Sugary foods and drinks	6/101	0/145	50/101	68/145
	Continuity correction 6.509, *P*=0.011		$x^2(1)=0.162$, *P*=0.687	
Processed meats	2/100	0/145	39/100	60/145
	Continuity correction 0.975, *P*=0.323		$x^2(1)=0.139$, *P*=0.709	
Alcohol	0/102	2/143	53/102	47/143
	Continuity correction 0.230, *P*=0.632		**$x^2(1)=8.985$, *P*=0.003**	

4d: Dietary changes and chi-squared tests according to diagnosis.

Dietary changes	**Increased consumption**			**Decreased consumption**		
	Urological	Lower GI	Gynaecological	Urological	Lower GI	Gynaecological
Whole grains	33/124	18/78	7/27	2/124	20/78	6/27
	$x^2(2)=0.322$, *P*=0.851			**$x^2(2)=28.608$, *P*<0.001**		
Refined grains	6/122	12/77	4/28	26/11	22/77	11/28
	$x^2(2)=6.907$, *P*=0.032			$x^2(2)=4.228$, *P*=0.121		
Fruit	34/129	32/78	11/28	5/129	15/78	2/28
	$x^2(2)=5.361$, *P*=0.069			**$x^2(2)=13.691$, *P*=0.001**		

Vegetables	38/129	30/75	9/29	4/129	8/75	2/29
	$x^2(2)=2.443$, *P*=0.295			Fisher's Exact Test=4.890, *P*=0.073		
Low fat milk and dairy products	19/127	8/72	3/28	9/127	6/72	4/28
	$x^2(2)=0.768$, *P*=0.681			$x^2(2)=1.552$, *P*=0.461		
Full fat milk and dairy products	4/122	6/74	1/25	33/122	22/74	9/25
	Fisher's Exact Test=2.258, *P*=0.310			$x^2(2)=0.840$, *P*=0.657		
Lean, low fat meat and poultry	23/127	17/76	6/27	6/127	9/76	5/27
	$x^2(2)=0.633$, *P*=0.729			$x^2(2)=6.752$, *P*=0.034		
Oily fish	31/126	25/77	8/28	3/126	3/77	2/28
	$x^2(2)=1.488$, *P*=0.475			Fisher's Exact Test=2.019, *P*=0.323		
White fish	24/127	26/76	8/28	0/127	4/76	0/28
	$x^2(2)=6.132$, *P*=0.047			Fisher's Exact Test=6.408, *P*=0.026		
Sugary foods and drinks	2/127	2/77	2/29	58/127	37/77	17/29
	Fisher's Exact Test=2.765, *P*=0.214			$x^2(2)=1.586$, *P*=0.452		
Processed meats	1/127	0/76	1/29	42/127	38/76	15/29
	Fisher's Exact Test=2.722, *P*=0.341			$x^2(1)=7.227$, *P*=0.027		
Alcohol	2/127	0/77	0/29	48/127	33/77	15/29
	Fisher's Exact Test=1.188, *P*=0.638			$x^2(2)=2.021$, *P*=0.364		

4d: Other dietary habits (n=251).

	All participants n=251	**On-treatment n=102**	**Post-treatment n=149**
How much water or fluids do you consume daily?	**n (%)**	**n (%)**	**n (%)**
0-2 glasses/day	12 (5)	1 (1)	11 (7)
3-5 glasses/day	69 (27)	25 (25)	44 (30)
6-8 glasses/day	126 (50)	54 (53)	72 (48)
>9 glasses/day	40 (16)	21 (21)	19 (13)
Missing	4 (2)	1 (1)	3 (2)
Who do you usually have meals with? (1)	**n (%)**	**n (%)**	**n (%)**
Spouse/partner	181 (72)	77 (75)	104 (70)
Family members	63 (25)	24 (24)	39 (26)
Friends	26 (10)	9 (9)	17 (11)
No one	57 (23)	24 (24)	33 (22)
Missing	2 (1)	0 (0)	2 (1)

Chi-squared tests (treatment status): Spouse/partner: $x^2(1)=0.682$, *P*=0.409; family members: $x^2(1)=0.287$, *P*=0.592; friends: $x^2(1)=0.484$, *P* =0.487; no one: $x^2(1)=0.040$, *P* =0.842.

Chi-squared tests (cancer diagnosis): Spouse/partner: $x^2(2)=6.316$, *P*=0.043; family members: $x^2(2)=9.485$, *P*=0.011; friends: $x^2(2)=9.279$, *P* =0.012; no one: $x^2(2)=0.833$, *P* =0.659.

Who prepares your meals? (1)	**n (%)**	**n (%)**	**n (%)**
Spouse/partner only	93 (37)	44 (43)	49 (33)
I prepare my own meals – only me	94 (37)	39 (39)	55 (37)
Shared task with spouse/partner	60 (24)	17 (17)	43 (29)
Family members	23 (9)	10 (10)	13 (9)
Friends	6 (2)	1 (1)	5 (3)
Other (2)	2 (1)	0 (0)	2 (1)

Chi-squared tests (treatment status): Spouse/partner: $x^2(1)$=2.372, *P*=0.123; own meals: $x^2(1)$=0.045, *P*=0.832; shared task: : $x^2(1)$=4.928, *P*=0.026; family members: $x^2(1)$=0.085, *P*=0.771.

Chi-squared tests (cancer diagnosis): Spouse/partner only: $x^2(2)$=24.628, ***P*<0.001**; own meals: $x^2(2)$=19.952, ***P*<0.001**; shared task: : $x^2(1)$=2.252, *P*=0.324; family members: $x^2(1)$=1.216, *P*=0.545.

How often have you had homemade meals during the past 4 weeks?	**n (%)**	**n (%)**	**n (%)**
Never	13 (5)	4 (4)	9 (6)
1-3 times/month	13 (5)	5 (5)	8 (5)
1-4 times/week	61 (24)	31 (30)	30 (20)
5 times/week or more	160 (64)	59 (58)	101 (68)
Missing	3 (1)	2 (2)	1 (1)

Chi-squared tests (treatment status): $x^2(1)$=5.575, *P*=0.233.

Chi-squared tests (cancer diagnosis): $x^2(2)$=7.586, *P*=0.475.

How often have you had ready meals during the past 4 weeks?	**n (%)**	**n (%)**	**n (%)**
Never	79 (31)	30 (29)	49 (33)
1-3 times/month	109 (43)	42 (41)	67 (45)
1-4 times/week	51 (20)	25 (24)	26 (17)
5 times/week or more	9 (4)	3 (3)	6 (4)
Missing	3 (1)	2 (2)	1 (1)

Chi-squared test (treatment status): $x^2(1)$=2.112, *P*=0.549

Chi-squared test (cancer diagnosis): $x^2(2)$=22.379, ***P*=0.001**.

(1) More than one answers possible. The percentage values exceed 100%.

(2) Other responses included food being prepared by a nursing home (n=1) and eating meals out (n=1).

4d: Logistic regression (dietary changes).

Whole sample – multivariate logistic regression stepwise method

				95% CI for Exp (B)	
	B	P value	Exp (B)	Lower	Higher
Age	-0.026	0.094	0.974	0.944	1.005
Nutritional support by health professional	1.289	<0.001	3.631	1.823	7.230

Urological cancers – multivariate logistic regression stepwise method					
				95% CI for Exp (B)	
	B	P value	Exp (B)	Lower	Higher
Body Mass Index	0.140	0.039	1.150	1.007	1.313
Qualifications	-0.974	0.104	0.378	0.117	1.223
Nutritional support by health professional	1.229	0.017	3.418	1.243	9.403

Lower GI cancers – multivariate logistic regression stepwise method					
				95% CI for Exp (B)	
	B	P value	Exp (B)	Lower	Higher
Age	-0.059	0.041	0.943	0.891	0.997
Body Mass Index	-0.136	0.076	0.873	0.751	1.014
Nutritional support by health professional	1.555	0.028	4.737	1.180	19.009

4e: Supplement use (n=251).

Characteristics	**All participants n=251**	**On-treatment n=102**	**Post-treatment n=149**
Have you been taking any supplements since diagnosis?	**n (%)**	**n (%)**	**n (%)**
Yes	77 (31)	26 (25)	51 (34)
No	172 (68)	76 (75)	96 (64)
Missing	2 (1)	0 (0)	2 (2)
Why have you been taking supplements? (1,2)	**n=77** **n (%)**	**n=26** **n (%)**	**n=51** **n (%)**
To reduce the risk of recurrence	8 (10)	2 (8)	6 (12)
To assist with treatment side effects	18 (23)	8 (31)	10 (20)
To maintain general health	54 (70)	19 (73)	35 (79)
To support therapy and recovery	21 (27)	7 (27)	14 (27)
Other (3)	10 (13)	4 (15)	10 (20)
Missing	2 (3)	0 (0)	2 (4)

Chi-squared tests (treatment status): Reduce the risk of recurrence: Continuity correction=0.046, *P*=0.830; to assist with treatment side effects: $x^2(1)=1.000$, *P* =0.317; to maintain general health: $x^2(1)=0.023$, *P* =0.880; to support therapy and recovery: $x^2(1)=0.023$, *P* =0.880.

Chi-squared tests (cancer diagnosis): Reduce the risk of recurrence: Fisher's Exact Test=4.365, *P*=0.094; to assist with treatment side effects: Fisher's Exact Test=3.491, *P* =0.178; to maintain general health: Fisher's Exact test=0,218, *P* =0.937; to support therapy and recovery: Fisher's Exact Test=15.637, *P* <0.001.

Which supplements have you been taking? [(2)]	**n (%)**	**n (%)**	**n (%)**
Vitamin D	38 (49)	14 (54)	24 (47)
Omega 3	32 (42)	9 (35)	23 (45)
Multivitamins	27 (35)	10 (38)	17 (33)
Vitamin C	22 (29)	7 (27)	15 (29)
Glucosamine sulphate	9 (12)	1 (4)	8 (16)
B vitamins	10 (13)	5 (19)	5 (10)
Iron	6 (8)	1 (4)	5 (10)
Calcium	9 (12)	4 (16)	5 (10)
Zinc	6 (8)	2 (8)	4 (8)
Other [(4)]	34 (44)	9 (35)	25 (50)

Chi-squared tests (treatment status): Vitamin D: $x^2(1)=0.317$, *P* =0.573; Omega-3: $x^2(1)=0.779$, *P* =0.377; Multivitamins: $x^2(1)=0.199$, *P* =0.656; Vitamin C: $x^2(1)=0.052$, *P* =0.819.

Chi-squared tests (cancer diagnosis): Vitamin D: $x^2(2)=0.491$, *P* =0.782; Omega-3: $x^2(2)=0.309$, *P*=0.857; Multivitamins: $x^2(2)=2.171$, *P* =0.338; Vitamin C: $x^2(2)=1.265$, *P* =0.531.

[(1)] This question was answered only by participants who responded “Yes” in the question “Have you been taking supplements since diagnosis?”.

[(2)] More than one answers possible. The percentage values exceed 100%.

[(3)] Other responses included vitamin D deficiency (n=4), bone health (n=3), problems with joints (n=2), mobility problems (n=1), finger nails splitting (n=1), General Practitioner instructions (n=1), reduction of the risk of illness (n=1) and use before diagnosis (n=1).

[(4)] Other responses included magnesium (n=4), selenium (n=3), evening primrose (n=3), vitamin B12 (n=3), coenzyme Q10 (n=2), probiotics (n=2), garlic (n=2), iodine (n=2), turmeric (n=2), folic acid (n=1), chromium (n=1), vitamin K (n=1), dietary fibre (n=1), cranberry (n=1), boron (n=1), quercetin (n=1), milk thistle (n=1), berberine (n=1), evening primrose (n=1) and peppermint capsules (n=1).

4e: Logistic regression (supplement use).

Whole sample – multivariate logistic regression stepwise method

				95% CI for Exp (B)	
	B	P value	Exp (B)	Lower	Higher
Treatment status	0.626	0.085	1.871	0.916	3.820
Report of side effect	0.900	0.049	2.459	1.005	6.021
Nutritional support from health professional	0.567	0.095	1.764	0.906	3.433

Urological cancers – multivariate logistic regression stepwise method

				95% CI for Exp (B)	
	B	P value	Exp (B)	Lower	Higher
Report of a side effect	1.313	0.053	3.718	0.984	14.051

Lower GI cancers – multivariate logistic regression stepwise method

				95% CI for Exp (B)	
	B	P value	Exp (B)	Lower	Higher
Body Mass Index	-0.199	0.046	0.820	0.674	0.997

4f: Nutritional awareness (n=251).

How familiar are you with each of the following dietary recommendations?	**Never heard of it**	**Slightly familiar**	**Mostly familiar**	**Very familiar**
	n (%)	**n (%)**	**n (%)**	**n (%)**
Be a healthy weight (*n*=247)	4 (2)	18 (7)	53 (21)	172 (70)
Limit high calorie foods (*n*=245)	6 (2)	16 (7)	51 (21)	172 (70)
Eat a variety of wholegrains, vegetables, fruit and pulses (*n*=247)	7 (3)	15 (6)	53 (21)	172 (70)
Aim for at least 5 portions of fruit and vegetables a day (*n*=248)	3 (1)	10 (4)	41 (17)	194 (78)
Limit red meat and avoid processed meats (*n*=247)	18 (7)	53 (21)	73 (30)	103 (42)
Do not drink alcohol (*n*=245)	3 (1)	16 (7)	49 (20)	177 (72)
Limit salt intake (*n*=247)	10 (4)	32 (13)	63 (26)	142 (57)
Do not rely on supplements (*n*=247)	5 (2)	9 (4)	45 (18)	188 (76)

4g: Perceptions of the role of diet after diagnosis (n=251).

How important is the role of diet in…	Not important	A little important	Important	Very important	Missing
	n (%)	**n (%)**	**n (%)**	**n (%)**	**n (%)**
Reducing GI side effects?	12 (5)	34 (14)	85 (34)	109 (43)	11 (4)
Chi-squared test (Treatment status): x^2(3)=1.805, *P*=0.614					
Chi-squared test (Cancer diagnosis): Fisher's Exact test=4.063, *P*=0.669					
	n (%)	**n (%)**	**n (%)**	**n (%)**	**n (%)**
Reducing appetite side effects?	45 (18)	46 (18)	76 (30)	51 (20)	33 (13)
Chi-squared test (Treatment status): x^2(3)=1.972, *P*=0.578					
Chi-squared test (Cancer diagnosis): x^2(6)=5.629, *P*=0.466					
	n (%)	**n (%)**	**n (%)**	**n (%)**	**n (%)**
Reducing the feeling of fatigue?	38 (15)	30 (12)	71 (28)	93 (37)	19 (8)
Chi-squared test (Treatment status): x^2(3)=2.273, *P*=0.518					
Chi-squared test (Cancer diagnosis): x^2(6)=6.644, *P*=0.355					
	n (%)	**n (%)**	**n (%)**	**n (%)**	**n (%)**
Preventing cancer recurrence?	19 (8)	39 (16)	82 (33)	102 (41)	9 (4)
Chi-squared test (Treatment status): x^2(3)=1.346, *P*=0.718					
Chi-squared test (Cancer diagnosis): x^2(6)=1.565, *P*=0.955					
	n (%)	**n (%)**	**n (%)**	**n (%)**	**n (%)**
Improving overall health?	1 (<1)	10 (4)	73 (29)	163 (65)	4 (2)
Chi-squared test (Treatment status): Fisher's Exact test=4.171, *P*=0.201					
Chi-squared test (Cancer diagnosis): Fisher's Exact test=2.257, *P*=0.970					
	n (%)	**n (%)**	**n (%)**	**n (%)**	**n (%)**
Supporting therapy and recovery?	4 (2)	22 (9)	82 (33)	135 (54)	7 (3)
Chi-squared test (Treatment status): Fisher's Exact test=4.657, *P*=0.185					
Chi-squared test (Cancer diagnosis): Fisher's Exact test=4.745, *P*=0.553					

4h: Support from health professionals (n=251)

Participants who received support by a health professional (n=108)

	All participants n=108	On treatment n=48	Post treatment n=60
Source of information	**n (%)**	**n (%)**	**n (%)**
Dietitian	18 (17)	5 (10)	13 (22)
Cancer or Radiotherapy specialist nurse	64 (59)	34 (71)	30 (50)
Radiographer/Oncologist	21 (19)	15 (31)	6 (10)
Nutritionist	6 (6)	1 (2)	5 (8)
General Practitioner	10 (9)	4 (8)	6 (10)
Other [(1)]	8 (7)	2 (4)	6 (10)
Missing	7 (6)	1 (2)	6 (10)

Chi-squared tests (treatment status): Dietitian: $x^2(1)=3.097$, *P*=0.078; Nurse: $x^2(1)=3.050$, *P*=0.081; Radiographer/oncologist: $x^2(1)=6.604$, *P*=0.010; Nutritionist: Continuity Correction=1.189, *P*=0.276; General Practitioner: Continuity Correction=0.011, *P*=0.918.

Chi-squared tests (cancer diagnosis): Dietitian: $x^2(2)=6.904$, *P*=0.032; Nurse: $x^2(2)=5.442$, *P*=0.066; Radiographer/oncologist: $x^2(2)=3.580$, *P*=0.167; Nutritionist: Fisher's exact Test=0.696, *P*=0.821; General Practitioner: Fisher's Exact Test=3.162, *P*=0.168.

Content of information	**n (%)**	**n (%)**	**n (%)**
General healthy eating	81 (75)	33 (69)	48 (80)
Nutritional management of side effects	33 (31)	19 (40)	14 (23)
Weight management	17 (16)	7 (15)	10 (17)
Recipes	10 (9)	3 (7)	7 (12)
Vitamin/mineral/other supplements	9 (8)	4 (8)	5 (8)
Other [(2)]	11 (10)	7 (15)	4 (7)
Missing	1 (1)	0 (0)	1 (1)

Chi-squared tests (treatment status): General healthy eating: $x^2(1)=2.286$, *P*=0.131; Nutritional management of side effects: $x^2(1)=3.119$, *P*=0.077; Weight management: $x^2(1)=0.111$, *P*=0.739; Healthy recipes: Continuity correction=0.434, *P*=0.510; Vitamin and mineral supplements: Continuity correction<0.001, *P*=1.000.

Chi-squared tests (cancer diagnosis): General healthy eating: $x^2(2)=0.453$, *P*=0.797; Nutritional management of side effects: $x^2(2)=1.134$, *P*=0.567; Weight management: $x^2(2)=2.976$, *P*=0.226; Healthy recipes: Fisher's exact test=1.966, *P*=0.317; Vitamin and mineral supplements: Fisher's Exact Test=0.262, *P*=1.000.

Format of information	**n (%)**	**n (%)**	**n (%)**
Written information/leaflets	77 (71)	35 (73)	42 (70)
Links for websites	9 (8)	5 (10)	4 (7)
Face to face assistance	54 (50)	27 (56)	27 (45)
Telephone assistance	7 (6)	2 (4)	5 (8)
Survivorship courses	3 (3)	2 (4)	1 (2)
Missing	3 (3)	2 (4)	1 (2)

Chi-squared tests (treatment status): Leaflets: $x^2(1)=0.317$, *P*=0.573; Websites: Continuity correction=0.153, *P*=0.695; Face to face assistance: $x^2(1)=1.731$, *P*=0.188; Telephone assistance: Continuity correction=0.200, *P*=0.655.

Chi-squared tests (cancer diagnosis): Leaflets: $x^2(2)=1.341$, *P*=0.512; Websites: Fisher's Exact Test=0.836, *P*=0.658; Face to face assistance: $x^2(2)=1.462$, *P*=0.481; Telephone assistance: Fisher's Exact Test=4.130, *P*=0.127.

[(1)] Other responses include collection of publications (n=3), stoma specialist nurse (n=2), physiotherapist (n=1), Maggies centre (n=1), nursing home (n=1).

(2) Other information include fluid intake (n=2), foods to avoid during treatment (n=2), nutritional management of diabetes (n=2), nutritional management of heart disease (n=1), management of ileostomy bag (n=1), instructions to consume carbohydrates during treatment (n=1), food safety (n=1) and avoiding dairy products (n=1).

Satisfaction with information (n=108)

	All participants n=108	**On-treatment n=48**	**Post-treatment n=60**
How well were your needs met?	**n (%)**	**n (%)**	**n (%)**
Not at all well	0 (0)	0 (0)	0 (0)
Not very well	6 (6)	2 (4)	4 (7)
Neutral	30 (28)	10 (21)	20 (33)
Well	47 (44)	27 (56)	20 (33)
Very well	25 (23)	9 (19)	16 (27)
How consistent was the advice you received?	**n (%)**	**n (%)**	**n (%)**
Very inconsistent	1 (1)	0 (0)	1 (2)
Inconsistent	7 (6)	3 (6)	4 (7)
Neither inconsistent nor consistent	22 (20)	7 (15)	15 (25)
Consistent	52 (48)	23 (48)	29 (48)
Very consistent	26 (24)	15 (31)	11 (18)
How easy was the advice to follow?	**n (%)**	**n (%)**	**n (%)**
Very difficult	0 (0)	0 (0)	0 (0)
Difficult	5 (5)	2 (4)	3 (5)
Neither difficult nor easy	29 (27)	11 (23)	18 (31)
Easy	49 (45)	23 (48)	26 (45)
Very easy	23 (21)	12 (25)	11 (19)
Did information influence you to change your diet?	**n (%)**	**n (%)**	**n (%)**
Yes	73 (67)	38 (79)	35 (58)
No	33 (31)	10 (21)	23 (38)
Missing	2 (2)	0 (0)	2 (3)

Participants who did not receive support by a health professional (n=143)

	All participants n=143	**On-treatment n=54**	**Post-treatment n=89**
Why didn't you receive any support? (1)	**n (%)**	**n (%)**	**n (%)**
I chose not to receive any	13 (9)	8 (15)	5 (6)
I was not offered any	101 (71)	35 (65)	66 (74)
I did not know it existed	46 (32)	16 (30)	30 (34)
I did not think nutrition was important	5 (3)	2 (4)	3 (3)
Other (2)	6 (4)	3 (6)	3 (4)
Missing	5 (3)	1 (2)	4 (4)

Chi-squared tests (treatment status): I chose not to receive any: Continuity correction=2.257, *P*=0.133; I was not offered any: $x^2(1)=2.242$, *P* =0.134; I did not know support existed: $x^2(1)=0.383$, *P* =0.536

Chi-squared tests (cancer diagnosis): I chose not to receive any: Fisher's Exact Test=4.397, *P*=0.083; I was not offered any: $x^2(2)=0.193$, *P* =0.908; I did not know support existed: $x^2(2)=1.868$, *P* =0.393.

What, if any, diet and nutrition information would you like to have received from your healthcare team? (1)	**n (%)**	**n (%)**	**n (%)**
Healthy eating	53 (37)	22 (41)	31 (35)
Nutritional management of side effects	39 (27)	19 (35)	20 (22)
Weight management	37 (26)	11 (20)	26 (29)
Healthy recipes	23 (16)	11 (20)	12 (13)
Survivorship classes/courses/workshops	7 (5)	0 (0)	7 (8)
Nutritional supplements	30 (21)	11 (20)	19 (25)
I did not want any information	40 (28)	12 (22)	28 (33)
Other (3)	8 (6)	1 (2)	7 (8)
Missing	8 (6)	3 (6)	5 (6)

Chi-squared tests (treatment status): General healthy eating: $x^2(1)=0.517$, *P*=0.472; Nutritional management of side effects: $x^2(1)=2.793$, *P*=0.095; Weight management: $x^2(1)=1.404$, *P*=0.236; Healthy recipes: $x^2(1)=1.191$, *P*=0.275, *P*=0.510; Supplements: $x^2(1)=0.049$, *P*=0.824.

Chi-squared tests (cancer diagnosis): General healthy eating: $x^2(2)=5.537$, *P*=0.063; Nutritional management of side effects: $x^2(2)=1.909$, *P*=0.385; Weight management: $x^2(2)=9.564$, *P*=0.008; Healthy recipes: $x^2(2)=4.995$, *P*=0.082; Supplements: Fisher's Exact Test=1.613, *P*=0.416.

---

(1) More than one answers possible. The percentage values exceed 100%.

(2) Other responses included increased awareness on diet and nutrition (n=4) and perception of having a healthy diet (n=2).

(3) Other responses included perception of having a healthy diet (n=2), receipt of information related to other diseases (n=2), need for tailored information (n=2), information related to stoma reversal (n=1) and information about medical cannabis (n=1).

4h: Logistic regression (support from health professionals).

Whole sample – logistic regression stepwise method

				95% CI for Exp (B)	
	B	P value	Exp (B)	Lower	Higher
Report of a dietary change	1.326	<0.001	3.766	1.902	7.458

Urological cancers – logistic regression stepwise method

				95% CI for Exp (B)	
	B	P value	Exp (B)	Lower	Higher
Age	-0.129	0.009	0.879	0.797	0.968
Report of dietary change	1.215	0.017	3.370	1.239	9.166

Lower GI cancers – logistic regression stepwise method

				95% CI for Exp (B)	
	B	P value	Exp (B)	Lower	Higher
Marital status	-1.311	0.117	0.270	0.052	1.388
Report of a dietary change	1.368	0.040	3.929	1.064	14.510

4i: Support from another source (n=251).

Participants who received support by other sources (n=79)

	All participants n=79	On-treatment n=28	Post-treatment n=51
Source of information [1]	**n (%)**	**n (%)**	**n (%)**
Cancer charity website	46 (58)	22 (79)	24 (47)
Medical website	28 (35)	12 (43)	16 (31)
Blog/social media webpage	7 (9)	2 (7)	5 (10)
Newspaper/magazine/book	17 (22)	7 (25)	10 (20)
Recipe book	15 (19)	6 (21)	9 (18)
Family member/friend	19 (24)	7 (25)	12 (24)
Other patient	5 (6)	3 (11)	2 (4)
Other [2]	6 (8)	0 (0)	6 (12)
Missing	5 (6)	0 (0)	5 (10)
Content of information [1]	**n (%)**	**n (%)**	**n (%)**
General healthy eating	61 (77)	22 (79)	39 (76)
Nutritional management of side effects	19 (24)	10 (36)	9 (18)
Weight management	15 (19)	7 (25)	8 (16)
Recipes	22 (28)	8 (29)	14 (27)
Vitamin/mineral/other supplements	13 (16)	5 (18)	8 (16)
Other [3]	5 (6)	1 (4)	4 (8)
Missing	4 (5)	1 (4)	3 (6)

(1) More than one answers possible. The percentage values exceed 100%.

(2) Other responses included medical programmes (n=1), a supplement-specific website (n=1), a weight loss company website (n=1), the World Health Organisation website (n=1), other websites (not specified; n=1) and a Macmillan booklet (n=1)

(3) Other responses included information tailored to cancer (n=1), rainbow diet (n=1), reduction of sugar (n=1) and information related to chemotherapy treatment (n=1).

Satisfaction with information (n=79)

	All participants n=79	**On-treatment n=28**	**Post-treatment n=51**
How well were your needs met?	**n (%)**	**n (%)**	**n (%)**
Not at all well	3 (4)	1 (4)	2 (4)
Not very well	6 (8)	2 (7)	4 (8)
Neutral	28 (35)	10 (36)	18 (35)
Well	31 (39)	12 (43)	19 (37)
Very well	11 (14)	3 (11)	8 (16)
How consistent was the advice you received?	**n (%)**	**n (%)**	**n (%)**
Very inconsistent	1 (1)	0 (0)	1 (2)
Inconsistent	3 (4)	1 (4)	2 (4)
Neither inconsistent nor consistent	23 (29)	7 (25)	16 (32)
Consistent	36 (46)	15 (54)	21 (41)
Very consistent	11 (14)	4 (14)	7 (14)
Missing	5 (6)	1 (4)	4 (8)
How easy was the advice to follow?	**n (%)**	**n (%)**	**n (%)**
Very difficult	1 (1)	0 (0)	1 (2)
Difficult	5 (10)	2 (7)	3 (6)
Neither difficult nor easy	22 (28)	10 (36)	12 (24)
Easy	33 (42)	10 (36)	23 (45)
Very easy	14 (18)	4 (14)	10 (20)
Missing	4 (5)	2 (7)	2 (4)

4i: Logistic regression (support from other sources).

Whole sample – logistic regression stepwise method

				95% CI for Exp (B)	
	B	P value	Exp (B)	Lower	Higher
Body Mass Index	-0.081	0.054	0.923	0.850	1.001
Report of a dietary change	1.324	0.001	3.759	1.668	8.471
Support from HP	0.775	0.031	2.171	1.071	4.402

Urological cancers – logistic regression stepwise method

				95% CI for Exp (B)	
	B	P value	Exp (B)	Lower	Higher
Support from HP	1.019	0.045	2.769	1.024	7.492
Report of dietary change	1.097	0.047	2.995	1.013	8.854

Lower GI cancers – logistic regression stepwise method

				95% CI for Exp (B)	
	B	P value	Exp (B)	Lower	Higher
Age	-0.053	0.081	0.948	0.894	1.006
BMI	-0.244	0.012	0.783	0.648	0.947

4j: Interest in getting more information (n=251).

Characteristics	All participants n=251	On treatment n=102	Post treatment n=149
Would you be interested in receiving more information about your diet in relation to your cancer?	**n (%)**	**n (%)**	**n (%)**
Not interested at all (1)	35 (14)	10 (10)	25 (17)
A little interested (1)	37 (15)	15 (15)	22 (15)
Somewhat interested (2)	43 (17)	14 (14)	29 (19)
Very interested (2)	75 (30)	37 (36)	38 (26)
Extremely interested (2)	53 (21)	23 (23)	30 (20)
Missing	8 (3)	3 (3)	5 (3)

Chi-squared test (treatment status): Yes (somewhat, very or extremely interested) Vs No (not or little interested): x^2(1)=1.535, *P*=0.215

Chi-squared test (cancer diagnosis): Yes (somewhat, very or extremely interested) Vs No (not or little interested): x^2 (2)=3.832, *P*=0.147

What mode(s) of delivery would you prefer? (3)	**n (%)**	**n (%)**	**n (%)**
Face to face by a healthcare professional	71 (28)	30 (29)	41 (28)
Brochures	145 (58)	64 (63)	81 (54)
Internet	56 (22)	19 (19)	37 (21)
DVD	13 (5)	7 (7)	6 (4)
Telephone	25 (10)	5 (5)	20 (13)
Missing	45 (18)	16 (16)	29 (19)

Chi-squared tests (treatment status): Face to face: x^2(1)=0.011, *P*=0.915; brochures x^2(1)=1.150, *P*=0.283; internet x^2(1)=1.933, *P*=0.164; DVD: x^2(1)=0.835, *P*=0.361; telephone: x^2(1)=5.534, *P*=0.019.

Chi-squared test (cancer diagnosis): Face to face: x^2(2)=0.547, *P*=0.761; brochures x^2(2)=0.891, *P*=0.640; internet x^2(2)=5.849, *P*=0.054; DVD: x^2(2)=3.583, *P*=0.167; telephone: x^2(2)=2.528, *P*=0.283.

At which time point(s) would you prefer to receive information about your diet? (1)	**n (%)**	**n (%)**	**n (%)**
At diagnosis	57 (23)	30 (29)	27 (18)
During treatment	59 (24)	30 (29)	29 (19)
At the end of treatment	53 (21)	23 (23)	30 (20)
On a follow up visit	31 (12)	12 (12)	19 (13)
Any time	88 (35)	29 (28)	59 (40)
Missing	34 (14)	13 (13)	21 (14)

(1) Categorised as No for the chi-squared test

(2) Categorised as Yes for the chi-squared test

(3) More than one answers possible. The percentage values exceed 100%.

APPENDIX 5: Chapter 5 – Findings from interviews

Coding Framework

One overarching concept: Managing diet post-diagnosis

Seven themes:

1. **Impact of diagnosis and treatments on dietary choices**
    a. Managing altered gastrointestinal function: Any dietary changes related to the presence of bowel problems, techniques to manage and support bowel issues, level of support from healthcare team or other sources
    b. Managing altered appetite: Same as above, but in relation to altered appetite (increasing or reduced)
    c. Impact of an ostomy: Same as above, but focussed on the presence of an ostomy
    d. Treatment related adjustments: Any comments on dietary changes to adjust to radiotherapy or other treatments' requirements e.g. water, coffee, alcohol
    e. The "teachable moment": Any changes that are result the "teachable moment" of a cancer diagnosis e.g. reduced red meat and alcohol, more fruit and vegetables. Also, any comments on support from healthcare team or other sources to support future wellbeing.
    f. Impact of treatments on body weight: Any information on weight changes, gain, loss, fluctuations and the level of support from health professionals or other sources in relation to weight management. Body weight changes due to treatments or any other reason.
    g. Perceptions of weight status and changes: Emotions, thoughts, concerns and attitudes in relation to body weight, body image. Acknowledging weight issues and requesting support.
    h. Need for healthcare professional support: Description of requests on support in diet and nutrition, past experiences, comments on credibility of health professionals as resources of information.
2. **Personal resources**
    a. Pre-existing knowledge: Understanding the link between diet and health, describing healthy eating habits, knowledge of healthy and less healthy foods (whether they practice these habits or not), having knowledge (e.g. nurse background), health literacy, awareness of research, interest in lifestyle, general beliefs- *e.g in body's awareness of what it needs?*
    b. Ability to cook*:* Any comments on cooking practices, managing to cook for the household, preparing fresh food from scratch as opposed to ready meals.
    c. Ability to access healthy foods: Having a garden, being able/unable to afford higher quality/more expensive food, access to markets.
3. **Social resources**
    a. Spousal support: Role of spouse in preparing food, describing sharing task with spouse, experiences of spouse contributing to recovery (esp. during treatment) in relation to food and impact of living alone. Also any

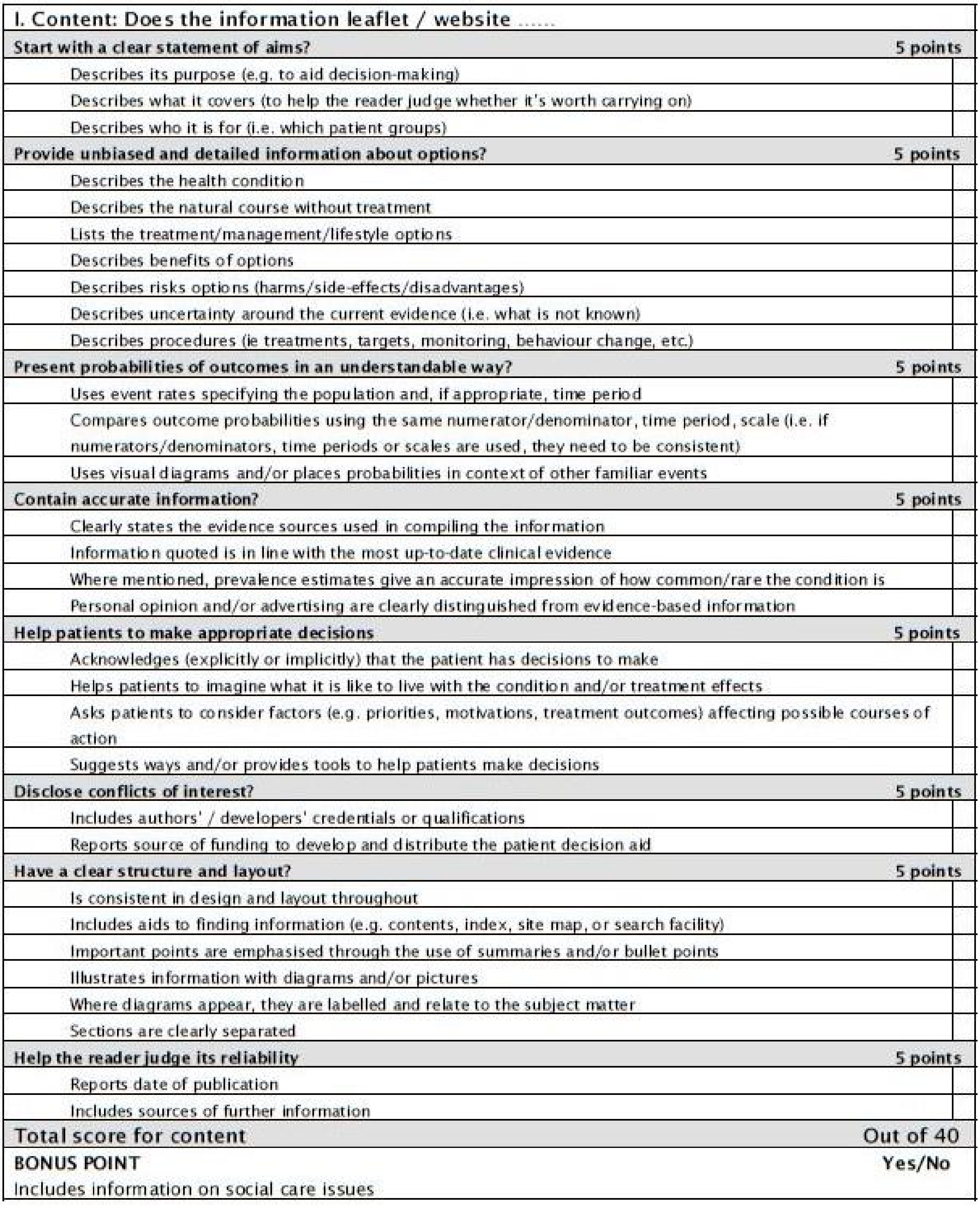
advice/motive/suggestions in relation to food from spouse to contribute to participant's health.

   b. Dietary habits of family: Spouse/partner/children's dietary habits affecting participant's dietary habits.

4. **Comorbidities and disabilities:** Examples of managing comorbidities nutritionally, having disabilities and how it affects food preparation
5. **Influence of work:** Any description of work or traveling commitments affecting dietary management of cancer, weight management, side effects.
6. **Being active and mobile:** Describing sense of "going back to normal", keep active, keep mobile to carry on with everyday activities, how diet can assist to keeping active, going back to pre-diagnosis habits, general comments about diet keeping them healthy from now on.
7. **Barriers for change:** Any barriers towards implementing changes in diet; includes lack of interest, lack of time, lack of evidence, perceived ineffectiveness, perceived healthy habits with no need to change, perceived lack of link between diet and cancer.

APPENDIX 6: (Chapter 8 – Online sources)

6a. Content checklist (Coulter et al. 2006)



I. Content: Does the information leaflet / website	
Start with a clear statement of aims?	**5 points**
Describes its purpose (e.g. to aid decision-making)	
Describes what it covers (to help the reader judge whether it's worth carrying on)	
Describes who it is for (i.e. which patient groups)	
Provide unbiased and detailed information about options?	**5 points**
Describes the health condition	
Describes the natural course without treatment	
Lists the treatment/management/lifestyle options	
Describes benefits of options	
Describes risks options (harms/side-effects/disadvantages)	
Describes uncertainty around the current evidence (i.e. what is not known)	
Describes procedures (ie treatments, targets, monitoring, behaviour change, etc.)	
Present probabilities of outcomes in an understandable way?	**5 points**
Uses event rates specifying the population and, if appropriate, time period	
Compares outcome probabilities using the same numerator/denominator, time period, scale (i.e. if numerators/denominators, time periods or scales are used, they need to be consistent)	
Uses visual diagrams and/or places probabilities in context of other familiar events	
Contain accurate information?	**5 points**
Clearly states the evidence sources used in compiling the information	
Information quoted is in line with the most up-to-date clinical evidence	
Where mentioned, prevalence estimates give an accurate impression of how common/rare the condition is	
Personal opinion and/or advertising are clearly distinguished from evidence-based information	
Help patients to make appropriate decisions	**5 points**
Acknowledges (explicitly or implicitly) that the patient has decisions to make	
Helps patients to imagine what it is like to live with the condition and/or treatment effects	
Asks patients to consider factors (e.g. priorities, motivations, treatment outcomes) affecting possible courses of action	
Suggests ways and/or provides tools to help patients make decisions	
Disclose conflicts of interest?	**5 points**
Includes authors' / developers' credentials or qualifications	
Reports source of funding to develop and distribute the patient decision aid	
Have a clear structure and layout?	**5 points**
Is consistent in design and layout throughout	
Includes aids to finding information (e.g. contents, index, site map, or search facility)	
Important points are emphasised through the use of summaries and/or bullet points	
Illustrates information with diagrams and/or pictures	
Where diagrams appear, they are labelled and relate to the subject matter	
Sections are clearly separated	
Help the reader judge its reliability	**5 points**
Reports date of publication	
Includes sources of further information	
Total score for content	**Out of 40**
BONUS POINT Includes information on social care issues	**Yes/No**

6b: Invitation letter to gatekeepers (example)

OXFORD
BROOKES
UNIVERSITY

My name is George and I am a PhD student at Oxford Brookes University supervised by Professor Eila Watson, Dr Helen Lightowler and Dr Shelly Coe. I am writing because I seek feedback on written literature in order to inform my project.

My project is about diet and nutrition after cancer diagnosis in the pelvis. As part of it, I aim to assess the quality of existing leaflets that provide information about diet and nutrition after cancer treatment. I am inviting you to read two of those leaflets and give me your opinion about them by answering the following questions:

- How would you rate the information provided in this leaflet?
- How easy was for you to understand the information?
- How helpful was the leaflet for you?

The materials I would like you to read and comment on are:

- ***Eating well when you have cancer – provided by The Royal Marsden NHS Foundation Trust***
- ***Managing weight gain after cancer treatment – provided by Macmillan Cancer Support***

We appreciate there is time involved in reading the leaflets. Your involvement is entirely voluntary and you are free to withdraw without any explanation. If you decide not to participate, your care will not be affected in any way. No personal information will be recorded and your feedback will be kept confidential.

If you are interested in getting involved, please let us know and we will send you the materials. My contact details and those of Professor Eila Watson are available at the end of this letter.

Your help will be greatly appreciated. Thank you for taking the time to read this letter.

Yours sincerely,

George Saltaouras
PhD researcher
Oxford Brookes University
Jack Straw's Lane, OX3 0FL
Tel: 01865 322669
Mobile: 07592 995370
Email: 16021065@brookes.ac.uk

Prof Eila Watson
Professor in Supportive Care
Oxford Brookes University
Jack Straw's Lane, OX3 0FL
Tel: 01865 322665
Email: ewatson@brookes.ac.uk

6c: Questionnaire for PPI feedback

OXFORD
BROOKES
UNIVERSITY

Assessing the face validity of patient information leaflets – Diet, nutrition and pelvic cancers

<u>Title of the leaflet:</u>

If you need more space, please feel free to continue on a separate sheet.

How would you rate the information provided in this leaflet? *Did you learn more about diet and nutrition by reading the leaflet?*

How easy was it for you to understand the information? *How did you find the format? Any comments on how the leaflet looks like (e.g. pictures, graphs) or how it is worded?*

How helpful was the leaflet for you? *Would it help you make an informed decision about your diet? Would it answer your questions?*

Would you change anything? *Would you want any other information in this booklet? Would you prefer e.g. a different format?*

For any question, please contact George Saltaouras.

Tel: 01865 482669

Mobile: 07592 995370

Email: 16021065@brookes.ac.uk.