NHS
National Institute for Health Research

Cancer and Nutrition

NIHR infrastructure collaboration

Improving cancer prevention and care.
For patients. For Clinicians. For researchers.

Report of Phase One July 2015

ISBN: 9780854329878

Contact us

NIHR Southampton Biomedical Research Centre
Mail point 113
Southampton General Hospital
Tremona Road
Southampton
SO16 6YD
United Kingdom

Website: www.cancerandnutrition.nihr.ac.uk
Email: cancer_nutrition@nihr.ac.uk
Tel: +44 (0)23 8120 6317

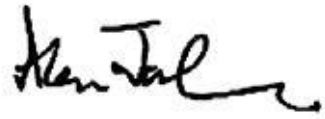

300 mL
± 5%
250
200
150
100
50

Preface

It is predicted that cancer will increasingly be the most frequent cause of death and a major cost to the delivery of health care over the next 30 to 40 years[1]. Good nutritional state is integral to the prevention of cancer, as well as to the treatment of the disease and end of life care. The general public look to doctors and other health professionals for clear guidance on how they can help themselves. Doctors in turn look to researchers for the evidence that will enable clear answers to the difficult questions they are asked. There are superb researchers studying many aspects of cancer and its treatment, but they seldom worry themselves about nutritional considerations. There are outstanding researchers exploring aspects of food, nutrition and physical activity, but cancer does not feature as a main concern on their agenda. We would like these two groups of researchers to draw on each other's skill and experience to enable insight and add value to their respective efforts. The availability of this greater knowledge and understanding can then be the basis of better advice and support to those who deliver, and receive, services.

The past 10 to 15 years have seen increasing concern about the need to build better links between these two areas of scientific endeavour. This concern has resonance not only for the prevention of cancer but also for its treatment, and for those people living with, or having survived, cancer. In 2014, the World Cancer Research Fund began a dialogue with the National Institute for Health Research (NIHR) infrastructure about the need for better management of the scattered research efforts in the overlapping area of cancer and nutrition. Out of this developed the Cancer and Nutrition infrastructure collaboration NIHR, facilitated by the NIHR Office for Clinical Research Infrastructure (NOCRI) and the NIHR Southampton Biomedical Research Centre (BRC). During the past year a small team has sought to bring together existing experience and expectations as the basis for a better organised attack on a disease process that touches the lives of virtually every person in the country, directly or indirectly. This report represents the first product of that effort.

I am especially grateful to those colleagues who have put in considerable effort and thought to produce this text and also to those who have provided constructive criticism. This has been a challenging task, and there has been much to learn in the process. It has been a pleasure to work with such a committed and enthusiastic group of people. I hope that their efforts will help to establish a base of activity that will in time bring wide benefit to all. We firmly believe that by better organising and coordinating our efforts it will be possible to achieve considerable progress for a modest investment, but substantial return in a relatively short period of time.



Professor Alan Jackson, June 2015
Former Director,
NIHR Southampton Biomedical Research Centre

* International Agency for Research on Cancer and Cancer Research UK. World Cancer Factsheet. Cancer Research UK, London, 2014.

List of figures

Cancer and Nutrition
NIHR infrastructure collaboration

Improving cancer prevention and care.
For patients. For Clinicians. For researchers.

Executive summary

The prevalence of cancers is increasing worldwide and in the UK, and this is particularly true for the burden of preventable cancers related to nutrition. Nutritional factors are increasingly recognised as a growing cause of morbidity and mortality, including from cancers, and there are substantial research efforts directed to a better understanding of how cancer might both be prevented, and treated, and the lifestyle factors which contribute to cancer development. The disciplines of cancer and nutrition each draw on a wide range of science, skills, and expertise but are not well coordinated and the sharing of knowledge, information and expertise between them is poor.

In early 2014 the need to bring coherence to existing activities and provide a coordinated framework for future research in the areas of cancer and nutrition was identified. In discussion with the NIHR Office for Clinical Research Infrastructure (NOCRI), it was agreed that Professor Alan Jackson, with the team at the NIHR Southampton BRC, would lead this initiative. This report provides a summary of the first phase of the initiative, including a patient experience survey and a clinicians' survey, a mapping of the cancer and nutrition research activities in the UK, other activities of the initiative and recommendations for the way forward.

In recognition of the importance of translational research and the need to deliver quality nutritional care to cancer patients, we conducted a patient experience survey. We sought to assess whether patients are being given consistent, evidence-based advice; what other nutritional support, advice and care patients would like to receive; and what are the major gaps perceived in service provision at diagnosis, treatment and after treatment. The survey was open and online. It was available for eight weeks during which time ninety-six patients (suffering from a range of cancers) responded. Many patients reported unsatisfactory experiences of nutritional care in relation to their cancer and inconsistent or unhelpful dietary advice. They identified a need for more reliable nutritional and dietetic information for cancer patients, particularly how to deal with side-effects of chemotherapy, weight changes, specific foods to eat and diets that patients can follow.

We also conducted a survey of UK clinicians working in cancer and/or nutrition to understand what they considered to be the biggest gaps in terms of evidence, research, support and care in relation to nutrition and cancer. This provided a comparison with the gaps identified by patients and those identified from the mapping. Clinicians indicated that getting the medical community to recognise the importance of nutrition in cancer care is challenging, that nutritional assessment is not carried out in a systematic way and there is insufficient training for dietitians wishing to specialise in cancer. More large-scale interventional trials are needed to produce data which can be translated into meaningful advice and recommendations for patients.

The mapping exercise looked at data from the National Cancer Research Institute (NCRI) from

2009 to 2013 to characterise the extent of cancer and nutrition research in the UK. Although this database excludes several smaller but important funders, it was thought that it would be able to sufficiently indicate the broad nature of nutrition and cancer research. The mapping included all cancer sites, study types (e.g. human, animal and in vitro) and stages of cancer or cancer research categories (e.g. prevention, treatment and diagnosis). A total of 6,579 unique awards from the NCRI data were added to a custom-made Access database. Searching in the Access database using a comprehensive list of predefined nutrition keywords identified 1,408 unique awards, of which 158 (11%) were included for mapping analysis. The analysis looked at spend on nutrition-related research within the NCRI database, the most commonly studied nutrition themes, cancer sites and cancer research categories.

Of the 158 awards that were included, the majority were human studies (80%). The focus of these human studies was to support large cohort studies to collect dietary data and specimens, or conduct statistical data analysis; to understand the effects of nutrients or nutritional status on cancer risk using observational or interventional data; and for surveillance of, or intervention on, cancer risk factors such as dietary patterns, body weight and physical activity. More than a third of these human studies did not specify a cancer site or nutrition theme. Of those that did specify a cancer site, the most frequently studied were colon and rectal cancer, breast cancer, lung and oesophageal cancer. These are the cancers sites with higher potential preventability through improved diet and physical activity.

This collaboration has started to bring together a network of stakeholders who work in cancer and/or nutrition from across the NIHR clinical research infrastructure and more widely (including research charities and patient representatives) to develop a community of practice. A very positive response has been received from patients, clinicians and researchers. A work plan under five workstreams has been identified, and this Report concludes with recommendations on future actions. The collaboration will continue to build this network in the next phase of its work to encourage greater integration between the disciplines of nutrition and cancer.

Acknowledgements

This report was written by the Cancer and Nutrition NIHR infrastructure collaboration Phase One Task and Finish Group. Special thanks go to the NIHR Southampton Biomedical Research Centre for funding staff to work on this initiative. Thanks also go to the National Cancer Research Institute (NCRI) for providing access to the NCRI data, NOCRI for extensive efforts in supporting and facilitating communication and engagement with national stakeholders, and all survey participants and other individuals who have contributed to the initiative.

Abbreviations

BRC	*Biomedical Research Centre*
BRU	*Biomedical Research Unit*
CRN	*Clinical Research Network*
CRUK	*Cancer Research UK*
DH	*Department of Health*
ECMC	*Experimental Cancer Medicine Centre*
ICRP	*International Cancer Research Partnership*
NCRI	*National Cancer Research Institute*
NIHR	*National Institute for Health Research*
NOCRI	*NIHR Office for Clinical Research Infrastructure*
WCRF	*World Cancer Research Fund*

1 Introduction

The prevalence of cancers is increasing in the UK and worldwide, and this is particularly true for the burden of preventable cancers related to diet, nutrition and physical activity (see paragraph 1.4 for the working definition of nutrition and cancer). These factors are increasingly recognised as a growing cause of morbidity and mortality in general, as well as from cancers. There are substantial research efforts directed to a better understanding of how cancer might both be prevented, and treated, and the lifestyle factors which contribute to cancer development. The disciplines of cancer and nutrition each draw on a wide range of science, skills and expertise but are not well coordinated and the sharing of knowledge, information and expertise between them is poor. The Cancer and Nutrition NIHR infrastructure collaboration seeks to bring greater coherence to these two disciplines.

1.1 Purpose of the report

This report provides a summary of the initiative from its conception (Spring 2014) to the completion of the first phase (March 2015).

The objectives of the first phase were to:

- Establish the initiative and its management structure
- Bring together key stakeholders and begin to build a community of practice
- Undertake an initial scoping exercise of existing UK cancer and nutrition research

The long-term aim is to bring coherence to existing activities in nutrition and cancer. This includes the following objectives:

- Create a framework as a basis for future research
- Establish better networks for sharing knowledge between stakeholders.

1.2 Inception of the initiative

In early 2014, Professor Alan Jackson and his team at the NIHR Southampton BRC, together with the World Cancer Research Fund (WCRF UK), supported by NOCRI, recognised the need to bring coherence to existing activities in the area of cancer and nutrition and provide a coordinated framework for future research into these areas.

An initial exploratory meeting involving prominent leaders in nutrition and cancer research, from the charity sector and across the NIHR clinical research infrastructure was held in March 2014. At this meeting, the NIHR Southampton BRC agreed to scope the current level and nature of research activities in the country, in order to determine where the main effort is focused and to identify gaps that might need addressing (see Appendices 1 and 2 for minutes of the meeting and a list of attendees). The purpose of this initiative is to enable and support translational research, with the primary objective to use basic science to improve the delivery of clinical practice and patient benefits. The initiative aims to help improve the quality of research to be better able to address questions relating to nutrition and to bring together expertise from these two disciplines to secure future funding.

1.3 Background

Cancer is an increasing proportion of the total numbers of deaths in the UK and is now a cause of more deaths than cardiovascular diseases. Nutritional factors including obesity and physical inactivity are estimated to be responsible for about a quarter to a third of incident cancers in the UK, and nutritional support in its widest sense is important in the management of patients with cancer. Furthermore, poor nutrition is recognised as an adverse prognostic factor at diagnosis. The UK has international strength in both cancer and nutrition research, from basic biology to clinical management. Nevertheless, there is little interaction between the two disciplines, and better coordination and cooperation are needed to bring gains in knowledge that could translate to better prevention and care. This collaboration offers the opportunity to develop a coherent translational research agenda in cancer and nutrition, from prevention and public health to patient care and therapeutic management.

[2] CRUK, analysis on the 10 Most Common Causes of Death in 2011, available from http://www.cancerresearchuk.org/cancer-info/cancerstats/mortality/all-cancers-combined/newpagetemp Last accessed March 2015.

The biology of cancer has been increasingly understood over past decades, and considerable advances in pharmacotherapy have come from this understanding of the molecular biology of cancer cells and tumours. Epidemiology implicates nutritional factors as key to the patterns of cancer incidence around the globe. However, less attention has been paid to the mechanisms underpinning the transformation of normal cells into cancer cells, and their acquisition of the genetic and epigenetic variations that are necessary for the malignant cancer phenotype to develop, in contrast to the description of the characteristics of already transformed cancer cells.

Hanahan and Weinberg have characterised the cancer phenotype as a set of six (plus two emerging) hallmarks of cancer, underpinned by two enabling characteristics. They relate to cancer cell behaviour in relation to cell growth and replication; survival and death; cell relations with neighbouring cells and tissues (invasion and metastasis); angiogenesis; energy metabolism; and resistance to immune destruction. The enabling characteristics are genomic instability and inflammation. It is notable that there is a greater or lesser nutritional component to all of these characteristics.

Experimental models of cancer have mainly focused on exposing experimental animals to synthetic chemical compounds that are known carcinogens, with different chemicals responsible for phases of initiation, promotion and progression. However the accumulation of the changes responsible for these phases is not necessarily ordered in the same way in human cancer. More recently, experimental models use animals modified genetically to predispose them to various cancers. However, there is always a question as to the degree to which such models reflect human cancer.

Some cancers in humans are caused by external agents overwhelming the normal cell and DNA repair mechanisms, but increasingly the common cancers are not principally caused by external agents but arise endogenously through acquisition of damage during normal cell division and failure of normal repair function. Anthropometric and other nutritional markers are associated with cancer risk, and indicate a metabolic milieu conducive to cancer development. In particular, although most human cancer becomes clinically detectable after the age of 55 years, evidence implicates factors operating throughout the life course from conception through to older age, and the process of acquiring the abnormalities that accumulate to create cancer cells may occur over decades. Critically, the nature of the link between growth and maturation and cancer differs from the link between them and cardiovascular disease - for instance, greater height is a marker of higher risk of several cancers, but lower risk of cardiovascular diseases. Understanding the underpinning biology of this divergence is essential for characterising optimal growth trajectories for children in various environmental contexts.

For patients already diagnosed, there is clear evidence that adiposity and physical inactivity are prognostic indicators of poor outcome, though the mechanisms underpinning these links remain obscure. In addition, adiposity is a factor that is only poorly accounted for in chemotherapeutic dosing regimens. In later stage cancer, cachexia remains a problem, yet the mechanisms underpinning it remain poorly understood.

Clearly there is scope to increase understanding of the role of nutrition in the prevention, management and palliation of cancer, with an opportunity to improve public health and patient care. Better communication and organisation of the research infrastructure will be essential for to this to be delivered. Training of staff to minimal standards of quality-assured skill and competence in nutritional measurement, with more detailed characterisation of nutritional phenotype in routine clinical care, would add considerable value. More intensive investigation should be available as appropriate in specialist centres. Developing agreed standard toolkits for adoption nationally would greatly facilitate existing activities, adding value and better enabling high quality interdisciplinary and multi-centre collaboration, thereby leading directly to improved health and care.

[3] WCRF International, Cancer preventability estimates for diet, nutrition, body fatness and physical activity. Available from: *http://www.wcrf.org/int/cancer-facts-figures/preventability-estimates/cancer-preventability-estimates-diet-nutrition* Last accessed March 2015.
[4] Hanahan, D. & Weinberg, R. A. 2011. Hallmarks of cancer: the next generation. Cell, 144, 646-74.

1.4 Nutrition and cancer: working definitions

The collaboration uses the following definitions of cancer and nutrition:

Nutrition

Nutrition is the set of integrated processes by which cells, tissues, organs and the whole body acquire the energy and nutrients for normal structure and function, which is achieved at body level through dietary supply, and the capacity of the body to transform the substrates and cofactors necessary for metabolism. All of these domains (diet, metabolic capacity, body composition and level of demand for energy and nutrients) are influenced by levels of physical activity and can vary according to different physiological and pathological or disease states.

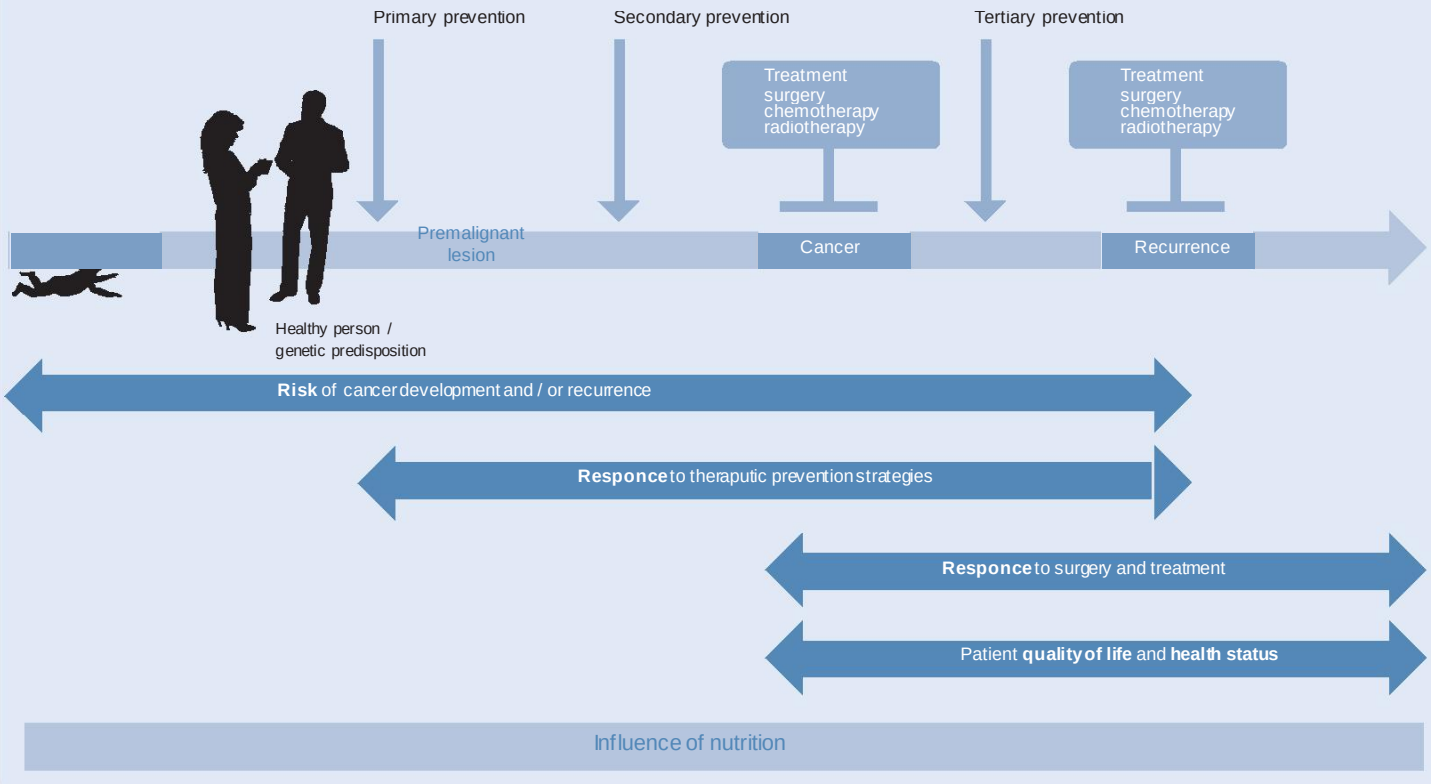
Cancer

All types, sites and stages of cancer are included in the scope of our work. Stages of cancer include prevention, diagnosis, treatment, survivorship and palliative and end of life care.

These definitions were written and agreed by the Task and Finish Group at the start of the mapping activity to ensure the mapping was as comprehensive as possible.

Nutrition is a fundamental environmental exposure at all stages of the life course from pre-conception, through normal growth and development to adulthood and in aging. Nutrition is important for normal function at cell, tissue, organ and whole body level, and is necessary for the proper integration of many complex body systems. The nutritional phenotype (the relation between nutrient and energy demand and supply) is an important determinant of susceptibility to cancer, cancer progression, response to treatment and quality of life after diagnosis (Figure 1).

Figure 1: Influence of nutrition through the life course



1.5 Management of the collaboration

The collaboration is managed by a Steering Committee which is responsible for operational aspects of the work and reports to NOCRI. The first phase of work was implemented by a Task and Finish Group (see Figure 2). Full terms of reference for the two groups are included in Appendix 3.

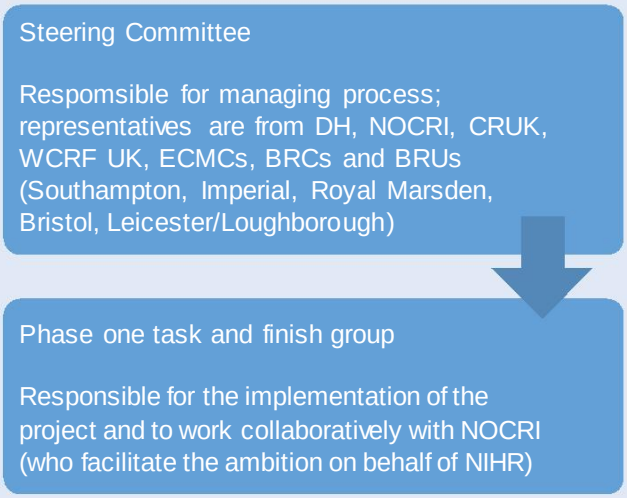


Figure 2: Management structure of the collaboration

1.6 Activity planning

When planning activities in phase one, the Task and Finish Group consulted the James Lind Alliance (JLA)[5], a non-profit making initiative which brings together patients, carers and clinicians to identify and prioritise 'unanswered research questions'. Collaboration with the JLA was explored but not pursued because the JLA's proposed methodology was similar to the collaboration's and therefore it was not considered an appropriate use of resources. The key activities completed in phase one include a mapping of cancer and nutrition research activities in the UK, a patient experience survey and a clinicians' survey. The findings of these three activities were triangulated to identify priorities and recommendations for the way forward.

[5] James Lind Alliance: http://www.lindalliance.org/

1.7 Key organisations

NIHR Office for Clinical Research Infrastructure (NOCRI) works across the NIHR clinical infrastructure to promote, facilitate and develop collaborative working that delivers benefits for patients and the NHS, maximising the impact of the Department of Health's investment in research infrastructure. An important aspect of their infrastructure work is to support the establishment of national collaborations within the NIHR infrastructure, where it is believed that coordinated working can add value and overcome disease and technical challenges.

NIHR Southampton Biomedical Research Centre (BRC) is an international hub for nutrition research, training and policy with key research themes on nutrition, growth and development; and nutrition, lifestyle and healthy ageing. The BRC collaborates with Southampton Experimental Cancer Medicine Centre (ECMC), jointly funded by NIHR and CRUK, to carry out cancer and nutrition research, with the aim of translating research into better health care. It has received an NIHR Infrastructure Award (2012-2017).

World Cancer Research Fund (WCRF UK) champions the latest and most authoritative scientific research from around the world on cancer prevention and survival through diet, weight and physical activity, in order to help people make informed lifestyle choices to reduce their cancer risk.

1.8 Stakeholder engagement

As a collaborative initiative, involving and engaging key stakeholders is integral to our work and has been a focus from the beginning. We have sought to be as inclusive as possible, keeping interested parties informed at each stage. The complex nature of the cancer and nutrition fields has made this a challenging task, but we have maintained regular contact with a range of organisations in order to continue to raise the profile of the collaboration.

As a first activity, we invited expressions of interest from relevant individuals and organisations not represented on the Steering Committee. We contacted major national cancer charities (e.g. Macmillan, Marie Curie Cancer Care), local cancer charities (e.g. Cambridge Cancer Research Fund), site-specific cancer charities (e.g. Pancreatic Cancer UK, Ovarian Cancer Action), research

councils (e.g. Medical Research Council), health departments (e.g. Scottish Health Department), research organisations (e.g. NIHR Biomedical Research Centres and Units, Experimental Cancer Networks), funders (e.g. Wellcome Trust) and professional nutrition bodies (e.g. British Dietetic Association, Association for Nutrition). We also contacted a number of patient organisations (e.g. Involve and the NCRI Consumer Liaison Group). We asked organisations to identify a point of contact, and included an open invitation for all interested parties to attend, participate in, and support our workshop at the NCRI annual conference (November 2014) (a full report of the NCRI workshop, and a list of all who attended, is included in Appendix 3). This list of contacts forms the initial part of a growing network of interested organisations and individuals who want to support, or be involved, in the initiative. We have used these contacts subsequently as a means to disseminate updates from the collaboration to a wider audience.

We have engaged a range of other organisations to give publicity to our work, giving presentations at relevant meetings (e.g. the UK Therapeutic Cancer Prevention Network [UKTCPN], October 2014), and delivering updates via partner newsletters, which in some cases reach thousands at a time (e.g. WCRF UK and CRUK). Both of these approaches have resulted in increased awareness of the collaboration and expressions of interest from stakeholders. This further highlights the importance of and perceived need for this work.

1.8.1 Building a community of practice

A specific aim of this stakeholder engagement is to build (and maintain) a community of practice of researchers and clinicians working in nutrition and cancer and to foster better collaborative working in these important areas. The following methods have been employed to achieve this:

- Named individuals identified as points of contact at major organisations; contacts are asked to disseminate news and updates within their networks to increase publicity further;
- Dedicated website to provide information about the initiative to interested parties;
- Online discussion forum (via website) for interested parties to share ideas; it is the hope that this will grow considerably as the collaboration develops;
- Mailing list to share results of the mapping and additional updates; an invitation to join the mailing list is on the home page and invites all researchers, clinicians and patients to sign up;
- Presentations at stakeholder events to raise awareness and provide updates (e.g. NCRI conference);
- Support from NOCRI communications teams to broadcast news and produce promotional materials.

1.8.2 Public and Patient Involvement

Public and patient involvement (PPI) is an important part of research, and of this initiative. Ultimately, patients are the intended beneficiaries of improved research in nutrition and cancer, and should have an opportunity to voice their concerns and suggestions. Patients are likely to be aware of gaps in clinical care relating to their needs and the collaboration would benefit from their input.

At the beginning of the scoping activity, we consulted the NIHR Southampton BRC PPI officer for advice and suggestions about an appropriate PPI strategy. We also consulted PPI organisations (e.g. Involve, the NCRI Consumer Liaison Group [CLG]) about how best to involve patients in the initiative. The strongest recommendation was to ensure that patients be involved at all stages of our work. We were invited to take part in the CLG's Dragons' Den session at the 2014 NCRI conference; the Dragons' Den is a relatively informal opportunity to run focus groups with patients and consumers who have experience of cancer research (and a potential personal interest in the proposed topic). We used this opportunity to understand the best way to engage patients in the initiative. A full report of the Dragons' Den session can be found in Appendix 5.

The results of this session formed a major part of our PPI strategy, in particular the decision to conduct a patient experience survey (further details on the survey can be found on page 4).

We also subsequently invited a PPI representative to sit on the Steering Committee (from December 2014) to ensure that patients' opinions were represented in all decisions the collaboration makes.

After presenting at the NCRI conference, and circulating updates of our work, we have had a

great deal of positive feedback from patients (seeboxed text). Again, this further highlights the recognition of the need for this work.

"All the lay people I have talked to about the initiative are all very enthusiastic, because as you will know, patients will often examine every aspect of their lifestyle when they receive a cancer diagnosis, and there is a wealth of debatable information out there on the internet. In my opinion, it is time the findings were translated from test tube to public"

Cancer patient, December 2014

"I think this is one of the most exciting new initiatives to happen for some time…this is a long overdue piece of work so bravo to Southampton for taking it on. How can I add my voice to this important work?"

Cancer patient, November 2014

1.8.3 Industry

Industry has the responsibility to plan economic activity with the health of the population in mind and is involved at all stages along the cancer journey through a variety of channels. At this early stage, the initiative has not yet developed concrete proposals to present to industry. However, it is the intention that when the collaboration is more developed, working relationships with industry will be established that may be mutually beneficial to both parties. Considerations for working with industry are included as part of the recommendations on page 31.

2 Patient Experience Survey

2.1 Background

We participated in the Dragons' Den session at the NCRI Conference (November 2014), an informal round-table discussion with patients and carers who have a research interest and either sit on NCRI Clinical Studies Groups (CSGs), are members of the Independent Cancer Patients Voice (ICPV) or are consumers who sit on funding committees.
We asked participants for their opinion on the quality of nutritional care they received during the cancer process and their opinions on the biggest gaps in nutrition and cancer care and research.
The participants suggested conducting a survey to canvass opinion more widely on these issues which we undertook between January and February 2015. The following section provides a summary of this work.

2.2 Methods

2.2.1 Objectives

The overall objective of the survey was to understand perceived gaps in nutritional care and support and compare the opinions offered by patients with the findings from the mapping analysis.

The survey sought to answer the following questions:

1. Are patients being given consistent, evidence-based advice?
2. What other nutritional support, advice and care would patients like to receive?
3. What are the major gaps in service provision at diagnosis, during treatment and after treatment?

For the purposes of the survey, we used the term "nutrition support" to mean any kind of nutritional information, advice and care a patient may have received in relation to cancer. Nutritional support may include anything related to diet, body composition, weight changes, metabolism, feeding (including artificial feeding), and physical activity.

2.2.2 Developing the survey

Based on a priori knowledge and discussions with patients at the NCRI conference, a draft of the survey was developed; the survey included a mixture of multiple choice (quantitative) and free text (qualitative) questions.

We conducted an initial pre-pilot with two patients, using a paper version of the survey, to test the length and acceptability of the survey (allowing for the additional time it would take to fill in the survey by hand). Following this, a number of modifications to the content, language and structure of the survey were made; some sensitive wording was removed and formatting changed. The time taken to complete the survey was deemed to be acceptable (20 minutes by hand, therefore shorter online).

We then created an online version of the survey and to check the usability of the questionnaire it was piloted with a group of 12 people. These were from a leukaemia patient group (n=6), a clinical research nurse, two clinicians, and three members

of a charity for young people affected by cancer. Minor amendments were made. The final version of the survey was reviewed by the Task and Finish Group and a database expert to ensure it would generate useful, reliable results.

2.2.3 Ethics

The NHS REC Ethics Checklist for England was completed; ethical approval was not necessary.

2.2.4 Format of survey

The survey was online and open access. No paper copies were sent out given the short timeframe in which to collect results. Support was offered to any patients unable to complete the survey online who wished to take part; no one took up this offer. The survey was aimed primarily at patients, but carers were also invited to complete the survey on behalf of their patients. A copy of the survey can be found in Appendix 6.

2.2.5 Sample

No target sample size was set; the aim was to collect as many responses as possible within the timeframe. The survey was sent to cancer patient networks (e.g. NCRI Consumer Liaison Group, the Independent Cancer Patients Voice Group), local patient groups, local charities (e.g. Tenovus, the Powys Association of Voluntary Organisations) and the NCRI Clinical Support Groups. We relied on word of mouth through patient networks to share the survey and asked patients completing the survey to share the link with others who might be interested to fill it in. We promoted the survey via social media (WCRF UK and NOCRI both advertised the survey) and information about the survey was sent out in the CRUK newsletter. The survey was available online for 3 weeks (7th - 30th January 2015). During that time, 84 responses were received. The deadline was then extended for an extra week to try to increase the sample size. The final sample size was 96.

2.2.6 Data analysis

Responses were exported into Excel and cleaned. The qualitative and qualitative results were analysed separately, using a methodology appropriate to each type of question. Given the small sample size, no statistical or qualitative analysis software was used.

2.3 Summary of results

2.3.1 Sample

A total of 96 responses were received; 71.9% were female and most participants were aged between 60-69 years (33%) and 50-59 years (29%) (Figure 3). A possible explanation for the high proportion of female respondents might be because the survey was disseminated to a breast cancer support group. The majority of respondents were from South Central (25%), followed by Yorkshire and The Humber (13%) and London (10%). Fifty seven percent of patients had early, potentially curable cancers and 37% had advanced cancers. The most common cancers respondents were suffering from were breast (36%), kidney (20%) and blood (10%).

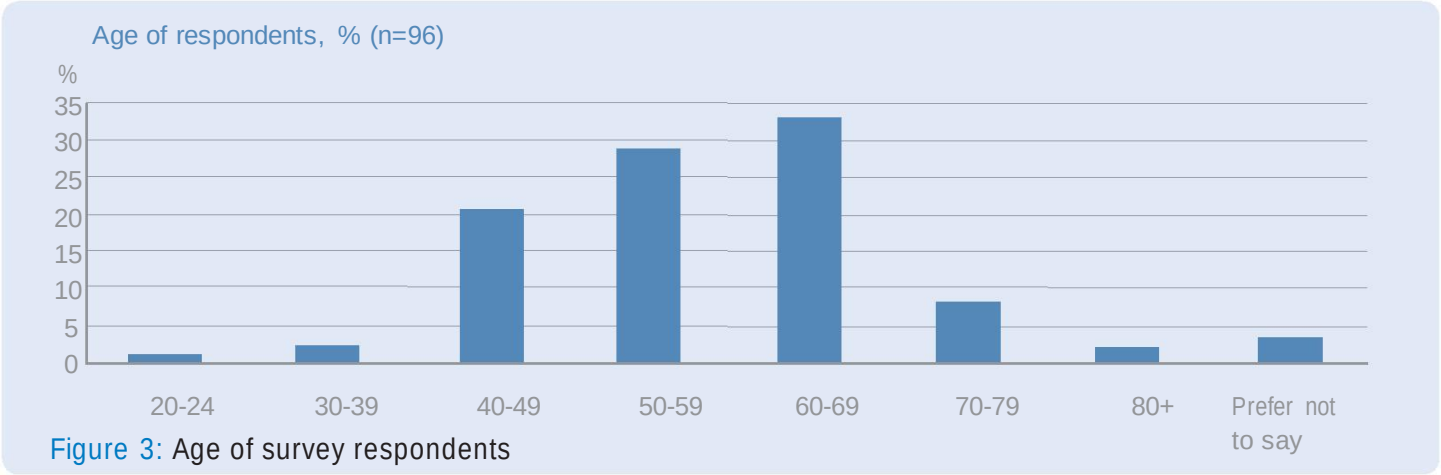


Figure 3: Age of survey respondents

[7] Note: the formatting of the original online version of the survey is not available in offline format - Appendix 6 includes all questions without formatting

Box 1: A summary of perceived nutritional and dietetic needs, organised by theme

Supplements

- Use of vitamins & minerals, supplements and alternative therapies (n=9)
- Supplements to aid healing after surgery
- Food supplements should be prescribed by GP when necessary

Dietetic support

- Automatic referral to a dietitian on diagnosis, rather than when a specific problem arises (e.g. weight changes)
- Earlier screening and identification of nutritional compromise, to ensure more timely nutritional intervention
- Support, education at diagnosis and reviews with each treatment
- In-patient visits from dietitians / support from specialist cancer dietitians
- More monitoring support and follow up after treatment
- Having access to dietitians for advice (n=4), via support groups / by telephone
- Nutritional support at all stages, particularly post-treatment (n=5)

Advice, guidelines and recommendations

- Clear, uncomplicated information
- How to overcome conflicting advice; how to know what and who to trust (n=2); “myth-busting” for all stages of cancer
- Clear research-intensive, fact-based information that offers sound nutritional advice (n=2)
- To be given information, rather than having to spend hours conducting own research
- Tailored advice that is cancer-specific (n=4), e.g. clear evidence of nutrition and breast cancer (n=2)
- Advice based on client experience in overcoming nutritional problems
- Talking to others in a similar position

2.3.2 Nutritional advice

The majority of patients answering the survey reported receiving no nutritional advice from their healthcare team (72%). Three out of four (76%) patients did not receive support because they were not offered it and 10% said they did not know it existed. One person did not think nutrition was important.

Of the 25 patients who did report receiving some kind of nutritional support, 76% received their advice in the form of written information and 56% received it face-to-face. Five patients were given a feeding tube, four were put on a special diet and one required intravenous feeding. Three of these patients had to ask for the support, the rest received it as a matter of course.

The most common advice received by these patients was about general healthy eating, followed by guidance on physical activity and exercise and where to find advice online (see Figure 5). Advice on specific foods to eat or avoid and protein and energy supplements were more commonly given during treatment (44%, 40% and 40% respectively) than at other stages.

Patients seemed to receive inadequate and inconsistent advice, for example being told "eat what you fancy", “just eat healthily…that's all I got”, and were confused by reading conflicting advice in the media. Some patients also reported feeling overwhelmed with information.

2.3.3 Nutritional problems

The most common nutritional-related problems reported by patients were changes in taste and smell (70%), appetite loss (69%), followed by nausea and vomiting (56%), being unsure what to eat (56%) and inability to be physically active (56%). Of these, the most commonly reported nutritional problems were those related to the side effects of chemotherapy.

Reported nutrional problems, % (n=96)

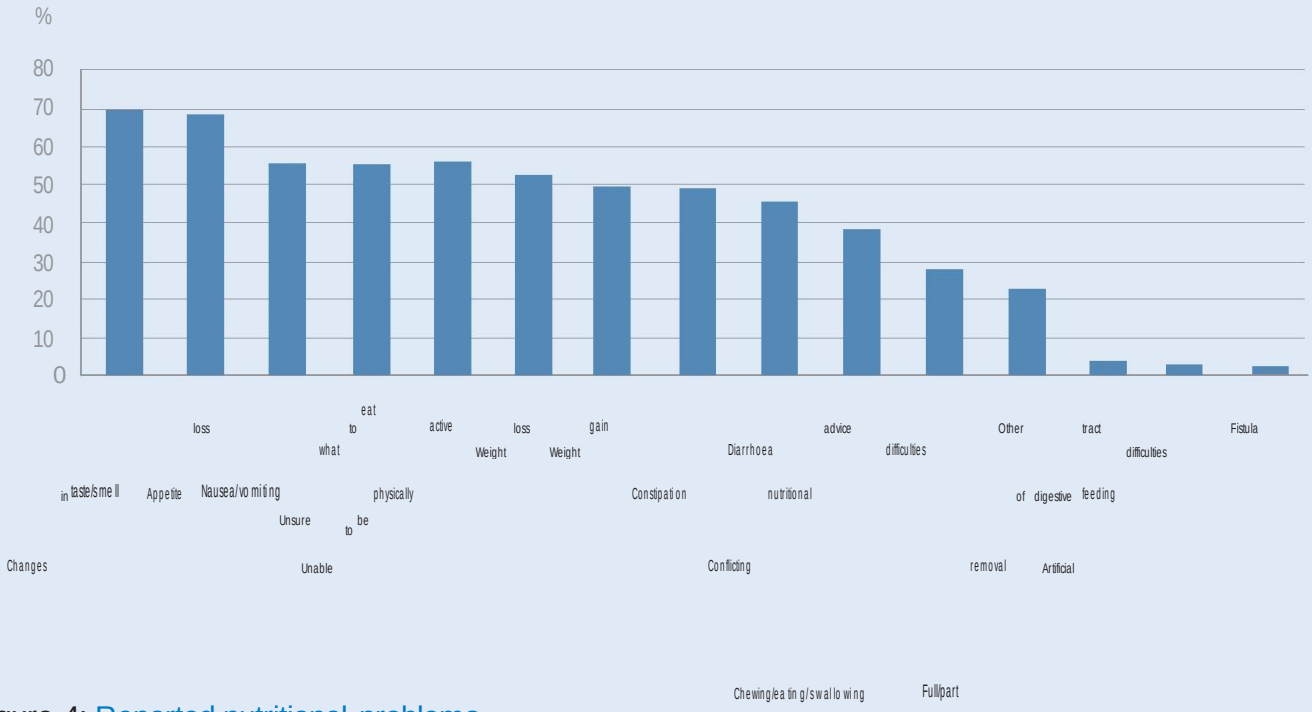


Figure 4: Reported nutritional problems

Respondents were asked what they thought the biggest nutritional and dietetic needs for cancer patients were (Q8c). Box 2 provides an overview of the most commonly cited responses as well as patients' suggestions for additional support they would like to receive.

Box 2: A summary of perceived nutritional and dietetic needs, organised by theme

Guidance on particular foods, meals and recipes

- Foods for specific purposes: to provide iron/to keep energy up (n=6)/to boost immunity (n=9) /to "fight cancer" (sources of lycopene & anthocyanins) (n=3)/vitamin and mineral rich foods (n=3)/non-bloating foods/to aid anxiety/to improve hair and nail health foods of the right consistency
- Recipe books: simple ideas/small meals that are tasty and nutritious/cheap meals (n=9)
- Receiving support to help prepare food when weak
- Foods to avoid (e.g. processed foods) (n=5)
- Access to clean, organic food
- Guidance on portion size (n=4)

Coping with the side effects of chemotherapy

- Food to help with nausea, sickness and diarrhoea (n=10)
- Clear advice on how to maintain eating when appetite fails (n=6)/how to make foods appetising (n=5)
- Foods to eat when suffering from taste changes (n=5)

How to monitor and treat weight changes

- How to combat weight gain (n=6) (especially in reference to breast cancer)
- How to maintain a constant weight (n=7)
- How to gain weight (healthily) (n=3)
- How to be active when not feeling well

Nutritional advice received, according to stages of care, % (n=25)

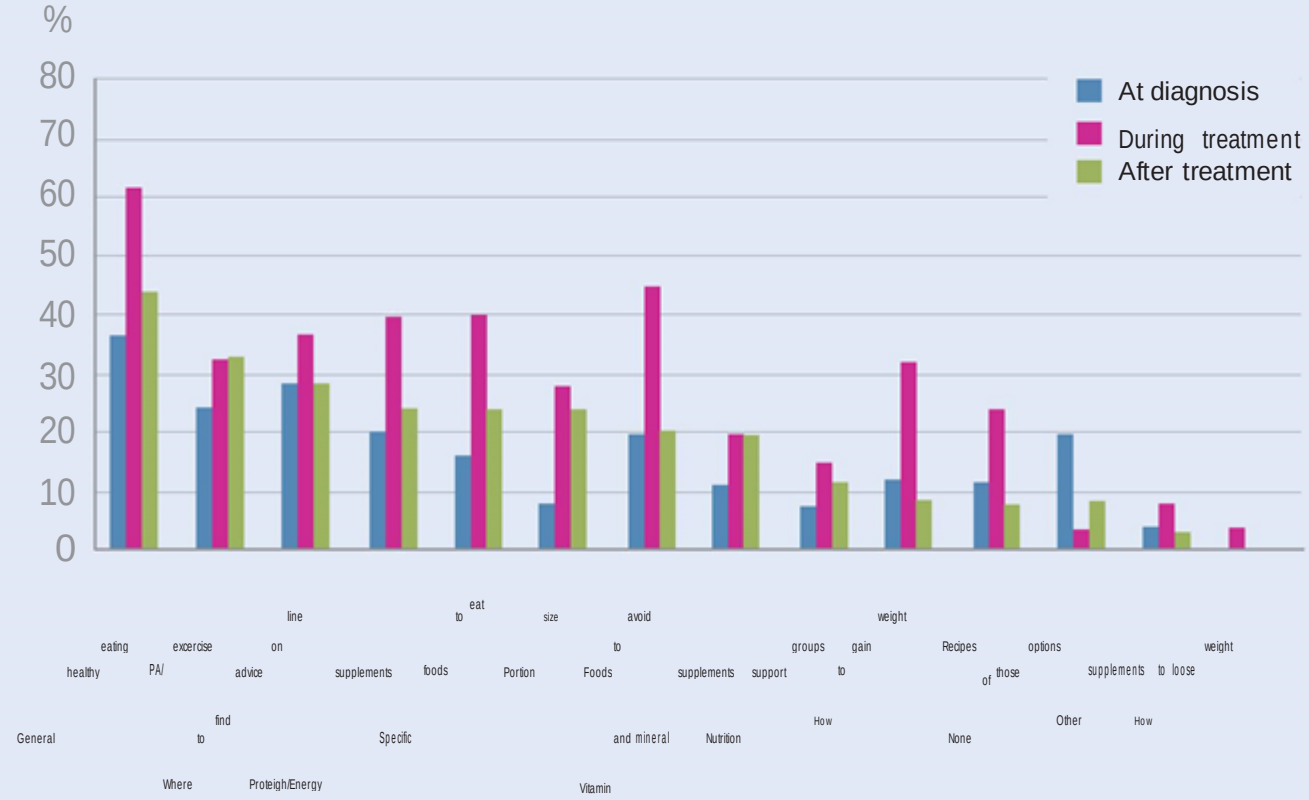


Figure 5: Type of nutritional support received, according to treatment phase, % (n=25)

Ten patients provided examples of specific foods that they were told to avoid. Box 3 provides a summary of these foods.

Box 3: Summary of foods that patients were told to avoid

- Soya foods (due to an oestrogen-receptive cancer); too much caffeine; animal fats (use olive or rape seed oil)
- Food containing raw eggs and unpasteurised foods (risk of infection)
- Takeaway or 'high risk foods' during chemotherapy
- Salads, ice cream, eggs, rice, takeaways, pate and some cheeses
- A list of foods whilst neutropenic - “it seems lettuce is potentially deadly!”
- Grapefruit
- Avoid spicy and very acidic foods
- Items containing live bacteria, e.g. Yakult drinks, yogurts with live cultures, soft cheeses.
- No runny egg yolks or uncooked meat; no items out of date
- Pineapple and ginger to help with nausea; apricots, spinach to help with iron
- Soya margarine, milk and cream, burnt food especially meat (linked to breast cancer). Cut down red meat, sugar and alcohol.

2.3.4 Quality of advice

We asked patients about the quality and consistency of nutritional advice at different stages of cancer. Of the 22 patients who answered, most said that the advice was easy to follow, and it was consistent (more so at treatment and after treatment than at diagnosis). Figure 6 shows how well patients believed their nutritional needs were met, according to the treatment phase.

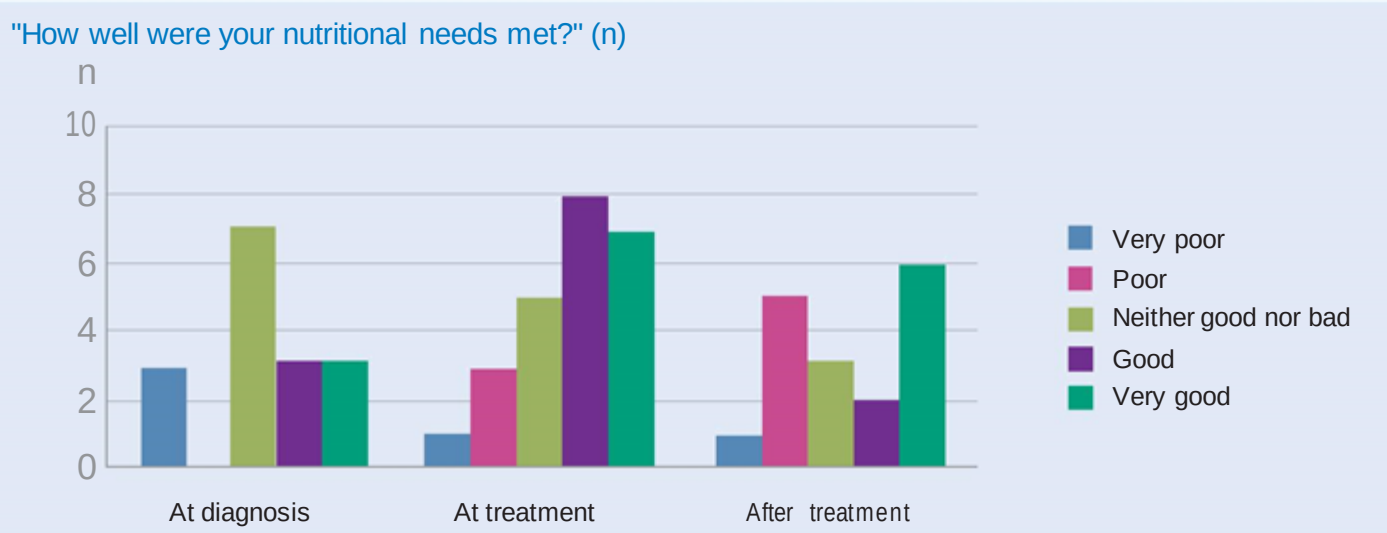


Figure 6: Perceived quality of nutritional advice according to treatment phase, n=22

Only four patients felt they had received incorrect advice. This included: being told to eat more calcium when *"I explicitly told the dietician I was lactose intolerant and was not recommended any non-dairy sources of calcium";* having a PEG inserted after surgery which *"I didn't need for my dietary needs…it was then left in situ for 9 months without needing it";* and *"I was told that "this is as good as it will get" but I found that incorrect. Fortunately I didn't accept that view and now am back to 75% of my original ability to eat and drink".*

2.3.5 Other sources of nutritional information

More than two-thirds of patients (n= 65, 68%) said they looked for written nutritional information online or in a book. Of these patients, 51 (65%) looked at websites for information, cancer charity websites (n=41), medical advice websites (n=22) or another source (n=13). Seventeen patients looked for information in books, 24 in recipe books and nine read leaflets (for example from NHS, a local authority or Macmillan).

2.3.6 Additional support

The majority of patients (n=64) said they would like additional nutritional support at all stages of treatment but did not provide specific examples about what form this support would take. Patients commonly reported feeling confused and vulnerable when suffering from cancer *"I only found out what to eat by trial and error"* and would like more support to overcome these feelings. There was some contradiction with other patients who reported feeling that they had information overload, which made them feel *"ultimately clueless"*.

A number of patients said that specialists were very vague when providing nutritional information, for example *"I was told by my consultant that there was no evidence about nutrition and cancer!"* and *"I asked several times [for advice] and was just told to eat a balanced diet".* Patients said they would like to have someone of whom to ask questions when feeling confused about nutrition. Specifically, one patient said they wanted to be *"treated as individuals, with individual cancers"* and another said they would like help in *"myth-busting".*

2.3.7 Hospital food

Eighty-three patients received food while in hospital and answered questions on the quality of this food (Figure 7). The majority of comments about hospital food were negative. Some patients said their nutritional needs were taken into account, that the food was *"good and appropriate"*, however the majority of comments were that food was of poor nutritional quality, unappealing, and the same as for *"other patients without nutritional needs"*.

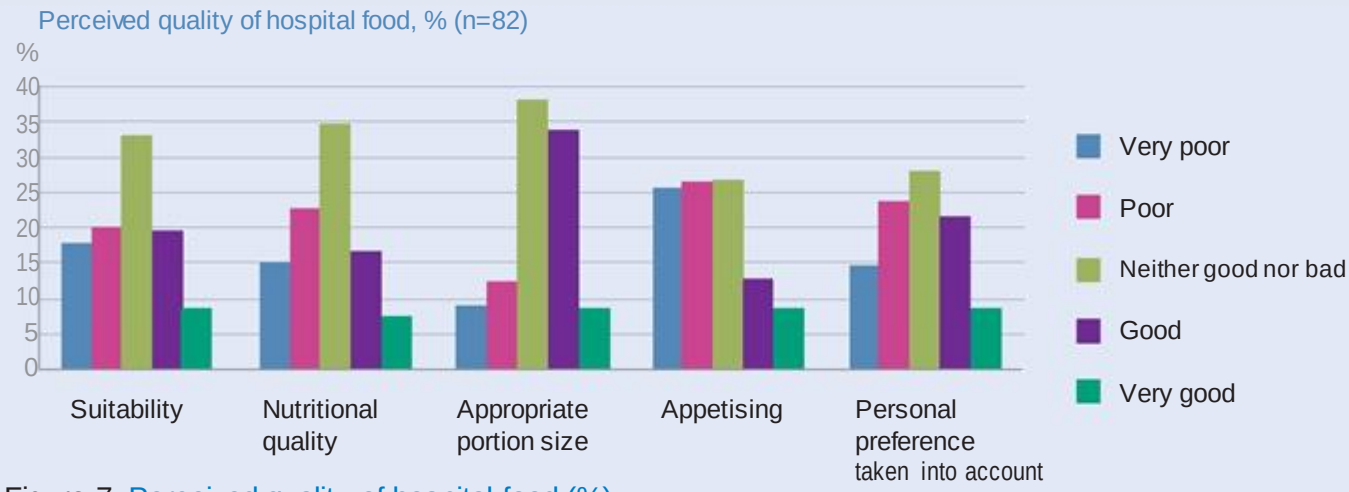


Figure 7: Perceived quality of hospital food (%)

2.3.8 Lifestyle advice

More than half of patients (53%) were given no additional lifestyle advice; 27% of patients were told to reduce sun exposure, 25% to increase (or maintain) physical activity levels, 10% to reduce alcohol, and 8% to stop smoking.

2.3.9 Strengths and limitations

There are limitations to this survey. The survey was small, online and anonymous. It is therefore not possible to validate the information received. We relied on word of mouth to distribute the survey and cannot know the response rate. The survey was shared among a breast cancer support group resulting in the majority of the respondents being female (72%). Limiting the survey to online responses may have prevented some people from completing it (e.g. those without computer literacy, aged, or extremely ill). Within the time available, an online survey was judged to be the best way to reach as many people as possible.

2.4 Key findings

1. Many patients reported unsatisfactory experiences of nutritional care in relation to cancer
2. Particular gaps identified by patients include how to deal with side-effects of chemotherapy, weight changes and specific foods and diets that patients should or should not consume.
3. There is a need for more reliable and consistent nutritional and dietetic information for cancer patients

3 Clinicians' Survey

3.1 Background

To understand clinicians' perceptions of the major gaps in clinical practice and research in nutrition and cancer, we sought the opinions of UK-based clinicians working in either or both of these fields.

3.2 Methods

3.2.1 Objectives

The overall objective of the survey was to understand what clinicians think might be the biggest gaps in terms of evidence, research and support/care in relation to nutrition and cancer. In addition, the survey sought to provide a comparison between the gaps perceived by clinicians and those identified by patients and through the mapping.

Specifically, the survey sought to answer the following questions:

- What kind of nutritional support, care and advice do clinicians give to cancer patients?
- Is nutritional status routinely assessed in cancer patients and if so how?
- What are the top three priorities for cancer and nutrition research in the UK?
- What are the main barriers to conducting nutritional research?

3.2.2 Developing the survey

To develop the questionnaire, a number of practical considerations were taken into account. Firstly as there was only little time available it was most practical to make the survey available online only: the survey was written using Google Forms and hosted on the collaboration's website. Secondly, clinicians generally do not have much time and asking them to complete a long, detailed survey is unrealistic; as a result the survey was kept to one page, with an estimated completion time of 10 minutes or less. The survey was available online for a period of three weeks during February 2015.

A short set of questions was developed based on a priori knowledge. The questions were circulated among the Task and Finish Group for comment; minor revisions were made. The questions were on the following themes:

- Top priorities for cancer and nutrition research in the UK
- Methods for assessing and managing nutritional status in cancer patients
- Nutritional advice and support given to cancer patients

A copy of the survey can be found in Appendix 7.

3.2.3 Sample

No predefined target sample size was set (we estimated that 50 respondents was a realistic response within the time period). Rather than attempting a nationwide survey, we focused our efforts locally in Southampton. The survey was sent to 317 members of the University of Southampton Cancer Sciences mailing list and 343 people from cancer departments across Southampton NHS trust. The link was also circulated to the British Dietetic Association Oncology Group, all those who had expressed interest at the NCRI conference (who were asked to share the survey within their networks) and a few other interested individuals. It is not possible to estimate how many people received the survey as it may have been shared to other networks we are unaware of.

3.2.4 Data analysis

Responses were downloaded automatically from Google Forms and exported into Excel. Due to the relatively small sample size, all analysis was done in Excel; only descriptive analysis was necessary.

3.3 Summary of results

3.3.1 Sample

A total of 77 clinicians completed the survey; the roles of these respondents are listed in Table 1. Nearly half (47%) of respondents were purely clinical work, 47% a mixture of clinical and research work and the remaining 5% purely research-based work. Eighty six per cent of the sample regularly treated cancer patients as part of their job.

Table 1: Types of clinicians among survey sample

Type of clinician	N	%
Dietician	26	34%
Oncologist	19	25%
Surgeon	11	14%
Other	8	10%
Nurse (cancer)	6	8%
Medical specialist (other)	5	6%
Public health consultant	2	3%
Total	77	100%

3.3.2 Assessing nutritional status

Seventy per cent of respondents said they actively assess or manage the nutritional status of their cancer patients. Of the 30% (n=23) who do not actively assess the nutritional status of their patients, six said they do not feel adequately trained to do so, seven said they do not have the infrastructure to do so and the remaining respondents (n=10) said it is not a necessary part of their work (purely research or 'not of primary important to their patients').

3.3.3 Nutritional advice, support and care

Seventy nine per cent of respondents regularly provide nutritional advice, support or care to cancer patients as part of their job; Box 4 provides a summary of the most commonly reported types of support. The most common part of nutritional care is referral to a dietitian, followed by advice on supplementation, general healthy eating, managing chemotherapy side effects and artificial feeding.

Box 4: Clinicians' reported nutritional advice, care and support, by theme

- Dietitian referral (n=20)
- Supplementation (n=14)
- General healthy eating advice (n=9)
- Managing side effects (n=8)
- Parenteral and enteral feeding support (n=7)
- Weight loss/gain/management advice (n=5)
- Food fortification advice (n=4)
- Eat little and often (n=3)
- Food first approach (n=2)
- Use of supportive literature and aids
- Discourage patients from starting 'faddy' diets
- No nutritional advice outside of 'rather specific scenarios'
- Guidance on nutrition in survivorship
- Varied advice

3.3.4 Nutritional assessment

Clinicians were asked to describe how they assess patients' nutritional status. The most commonly reported method was simply by measuring weight, with some using more complex assessments, including body composition (DXA) and waist circumference. Dietitians also use MUST (Malnutrition Universal Screening Tool) if concerned about a patient's weight. Other assessments mentioned included grip strength, muscle function, the Oxford equation and malabsorption indicators (e.g. stool colour). One dietitian said that it is up to nurses to screen in- and outpatients using a validated nutrition-screening tool; it is *"recognised to be inadequately sensitive or specific enough to identify all those at risk"* so they are trained to identify other factors which can impair nutritional status. Two dietitians said they were restricted by time and therefore not able to conduct detailed anthropometric and nutritional assessment of patients, and could also *"only provide very limited service to patients to promote survivorship after treatment"*.

It was also mentioned that there are no robust national training programmes on nutrition and cancer for specialists or for dietitians post registration; competence is based on clinical experience and improvement through self-study, for example journal clubs. This suggests that there are specific training needs within the fields of cancer and nutrition to be able to provide better nutritional support and care.

3.3.5 Barriers to research

Clinicians were asked what barriers exist in undertaking nutrition and cancer research; 61 people answered this question. The most common barrier was the perceived difficulties in securing funding, frequently attributed to an under-appreciation of the problem; one dietitian said there is an *"almost complete failure of the oncology community to take nutrition and lifestyle seriously"*. Getting funders, clinicians and the research community to recognise the importance of nutrition can be *"extremely difficult"*. Money is reportedly being given to small pilot studies that duplicate each other, rather than putting funding into large scale trials that produce high quality epidemiological data on lifestyle factors and outcomes.

One dietitian thought that research is focused too heavily on molecular nutrient changes which are *"difficult to translate into meaningful patient advice, leaving acute practitioners with a poor evidence base"*. According to another dietitian, government research agendas focus too heavily on therapeutic delivery to increase treatment and survival and *"forgets or underplays the importance of nutrition in survival...nutrition has a lower priority in medical treatment as it is less associated with fines, service or contractual requirements"*.

Nutrition and cancer are recognised by clinicians as complex areas: *"cancer is a very multifaceted disease in itself and can affect nutrition in many different ways. One size does not fit all!"* Dietitians recognise that there are a range of external factors

than can impact a patient's nutritional status and therefore deciding priorities for research (for example isolating particular foods or nutritional factors to study) is difficult: *"it would be really important [to research] but difficult to separate out factors leading to malnutrition i.e. disease, depression, swallowing difficulties"*. Added to this, nutritional assessment is challenging and has not been standardised which further acts as a barrier to research (the use of CT scans to assess fat and muscle mass was mentioned specifically).

Clinicians identified a need for better data and more high-quality research. Epidemiological data are *"flawed in cancer patients due to confounding and poor data on treatment and histology and much more work is needed"*, however, funding and conducting interventional studies remains difficult. Interventional studies are hard to conduct given the large numbers of participants needed, adequate blinding, controlling for bias and randomisation. There are also ethical issues in undertaking randomised controlled trials: populations may be too unwell to cope with the demands of participating in a trial, for example the time needed to attend extra appointments. The time it takes to submit ethical and research applications may also prevent clinicians from undertaking research whose clinical commitments occupy their time.

Aside from the lack of funding, clinicians find that there is insufficient national research infrastructure in which to undertake research: *"there is lack of structure and co-operation between different organisations. Whether it's NHS or charities such as Cancer Research, more needs to be done to bring organisations together to help improve nutrition and cancer for patients"*. More personnel with time dedicated to research are needed, for example dietitians specialising in oncology. Clinical dietitians would like support from colleagues to undertake research as well as additional time outside their *"already heavy workloads"* to do so: *"proper collection of patient data and patient education/follow-up with regards to nutritional issues is a laborious process if bias is to be avoided"*.

Industry's involvement in research was also cited as a barrier to research. More money is available from drug and nutritional supplement companies than other sources which one clinician thought would bias the research agenda and study outcomes: *"the greatest focus of research effort seems to lie in pharma-sponsored trials or molecular nutrition. Understanding how to influence prevention (which is not of interest to pharma) has too little funding"*. The food and drinks industry was also deemed to be *"too heavily involved"* in research.

Some people interpreted this question from a patient perspective. There was consensus that cancer patients are generally happy to get involved with research if they feel it will be of benefit to others in the future, therefore this is not considered a barrier to research.

3.4 Key findings

- Incorporation of nutrition in cancer care is challenging
- More large-scale interventional trials are needed, but they are difficult to conduct for practical (funding and infrastructure) and ethical reasons
- Better evidence is needed to produce meaningful advice for patients and recommendations for clinical care
- Nutritional assessment is not carried out in a systematic way
- There is insufficient training for dietitians and other clinicians wishing to specialise in nutrition and cancer

4 Mapping

4.1 Rationale for mapping activity

This mapping exercise seeks to chart the extent of available research in the UK which is explicitly focused on the links between cancer and nutrition (as defined in Section 1.4), including human, animal and in vitro studies. There is a large body of information in the UK (and worldwide) related to these two fields. Suitable databases for mapping were explored, namely the International Cancer Research Partnership (ICRP), National Cancer Research Institute (NCRI), UK Clinical Research Network (CRN) and clinicaltrials.gov. The nature and coverage of these databases, as well as the types of studies included, are summarised in Table 2. The NCRI database was chosen because of its wide coverage, inclusion of all study types and systematically coded information on cancer research areas and cancer sites, although it does not include research commissioned by smaller funders. More information on the collection and coding process of the NCRI data is detailed in Appendix 8. Details on how cancer research areas and cancer sites was coded are available in Appendices 9 and 10 .

Given the limited time available to complete this activity and the extent of cancer and nutrition research activities in the UK, research from the past five years (2009 - 2013) was mapped in the first instance. This could be extended to five to ten years in the future, subject to adequate resourcing.

Table 2: Comparison of the potential databases for the mapping

	ICRP*	NCRI*	UK CRN	Clinicaltrials.gov
Type of data	UK and International cancer research awards	UK cancer research awards (NCRI is an ICRP partner)	UK clinical study portfolio	International clinical study portfolio
Data collection	Award information submitted by ICRP partners annually	Award information submitted by NCRI partner organisations annually, who are the major cancer research funders in UK	Study information submitted by principal investigators	Information submitted by principal investigators on the studies that are required by US law to register at clinicaltrials.gov, and other studies that are registered voluntarily at clinicaltrials.gov
Coverage	90%+ (UK, estimated)	90%+ (UK, estimated)	Unknown	Unknown (likely to have a low coverage of studies in the UK)
Interface	ICRP website	ICRP website (using a GB location filter) Given access to the full data in Excel spreadsheet form via Department of Health/NIHR, which includes detailed financial figures	UK CRN website	Clinicaltrials.gov website
Types of studies included	Human, animal and in vitro	Human, animal and in vitro	Human studies	Human studies
Cancer research information	Systematically coded information on cancer sites and areas of cancer research	Systematically coded information on cancer sites and areas of cancer research	Coded information on cancer sites and some areas of cancer research	Coded information on cancer sites
Information on study design	Limited	Limited	More detailed	More detailed

*The ICRP is a worldwide cancer research partnership and currently has 97 members, including the NCRI. The NCRI, a UK-wide cancer research partnership, is the only ICRP member from the UK. Every year, NCRI collects cancer research award information from its UK partner funders and submits this information to ICRP. All ICRP members use the Common Scientific Outline system to code award information to ensure consistency.

4.2 Methodology

Figure 8 provides an overview of the mapping process. The following section provides further details about each stage.

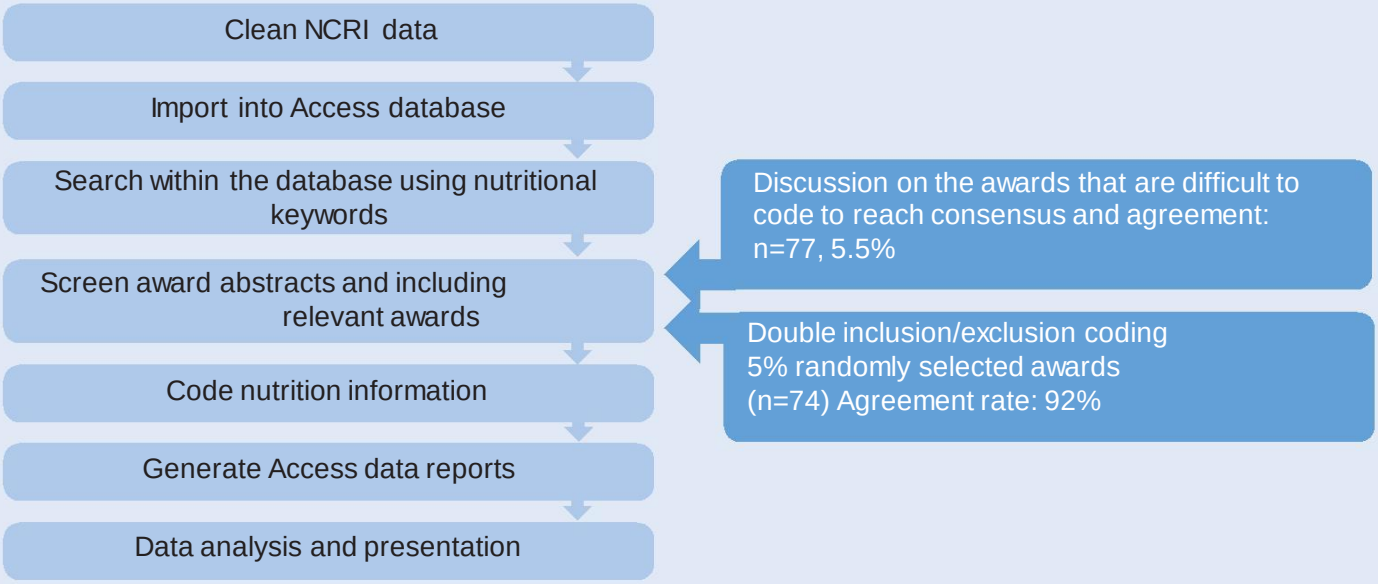


Figure 8: Overview of the mapping methodology

We obtained complete NCRI data for the years 2009 to 2013. If an award is active for more than one year, it appears more than once in the database. We identified and removed any such duplicates, leaving 6,579 unique awards. These were imported into a custom made Access database.

A comprehensive list of nutritional keywords was compiled to find cancer studies within the Access database which had a nutritional component. The nutritional keywords are based on the World Cancer Research Fund's 2007 report, *Food, Nutrition, Physical Activity, and the Prevention of Cancer: a Global Perspective*[8]; to ensure a systematic approach, we included keywords relating to each nutritional topic in the report (for a full list of keywords see Appendix 11). We did not search the database with cancer keywords on the assumption that all awards in the NCRI database are related to cancer.

Titles and abstracts of potentially relevant studies were screened using the inclusion and exclusion criteria listed in Table 3. Awards were then coded for study type (e.g. human interventional, in vitro), study design (e.g. cohort study) and type of nutrition element studied (e.g. nutritional status, supplements).

The nutritional element(s) of each award was coded according to nutrition themes and sub-themes. A complete list of these themes, with examples of each, are shown in Appendix 12. Note, awards may investigate more than one nutritional theme or sub-theme.

[8] World Cancer Research Fund/ American Institute for Cancer Research. Food, Nutrition, Physical Activity, and the Prevention of Cancer: a Global Perspective. Washington DC: AICR, 2007

Table 3: Inclusion and exclusion criteria

Inclusion Criteria

- Nutrition and cancer elements are clearly stated in the abstract.
- Nutrition and cancer are a predefined primary or secondary research aim/outcome.
- The link between nutrition and cancer is obvious and direct.
- Awards made to support infrastructure development are included and labelled as infrastructure related awards.

Exclusion Criteria

- Awards on developing, or using, naturally existing components/substances for chemoprevention or treatment purpose at doses and routes of administration that are not appropriate for human consumption.
- Awards on food technologies/sciences.
- An in vitro study which is unlikely to directly contribute or translate to an increased understanding of the role of nutrition in cancer in human beings (questions to consider: do they use human cells?. Whether appropriate nutrient concentrations are involved?).

4.3 Quality assurance

Awards that were difficult to code were discussed among the Task and Finish Group until consensus was reached (n=77). At the end of the coding, 5% of screened awards were randomly selected and the inclusion and exclusion decisions were cross-checked by a second member of the Task and Finish Group. The two coders initially agreed on 92% of these awards. Where a disagreement was found (8%), awards were discussed among the whole group until an agreement was reached.

The database was also cross-checked to verify if studies known to the Task & Finish group at the start of the mapping exercise (e.g. those shared by stakeholders) were in the database and picked up by the inclusion criteria (Table 4).

Table 4: Additional studies suggested by stakeholders in the NCRI database (2009-2013) and mapping analysis

Study name	Included in NCRI database	Included in mapping
Million Women Study	✔	✘
Bladder Cancer Prognosis Programme	✔	✔
Comparison of a questionnaire and objective measures of chemosensory changes in oncology patients	✘	✘
EPIC (European Prospective Investigation into Cancer and Nutrition)	✔	✔

4.4 Results from the mapping

In total, 14,439 award entries were in the original NCRI database. After removing 7,860 duplicate awards (awards that were active for more than one year and thus had multiple entries), 6,579 unique awards remained and were imported into the Access database. Searching the Access database using the nutrition keywords identified 1,408 unique awards, of which 158 (11%) were included for analysis (see Figure 9 and Figure 10). These awards referred to 111 studies.

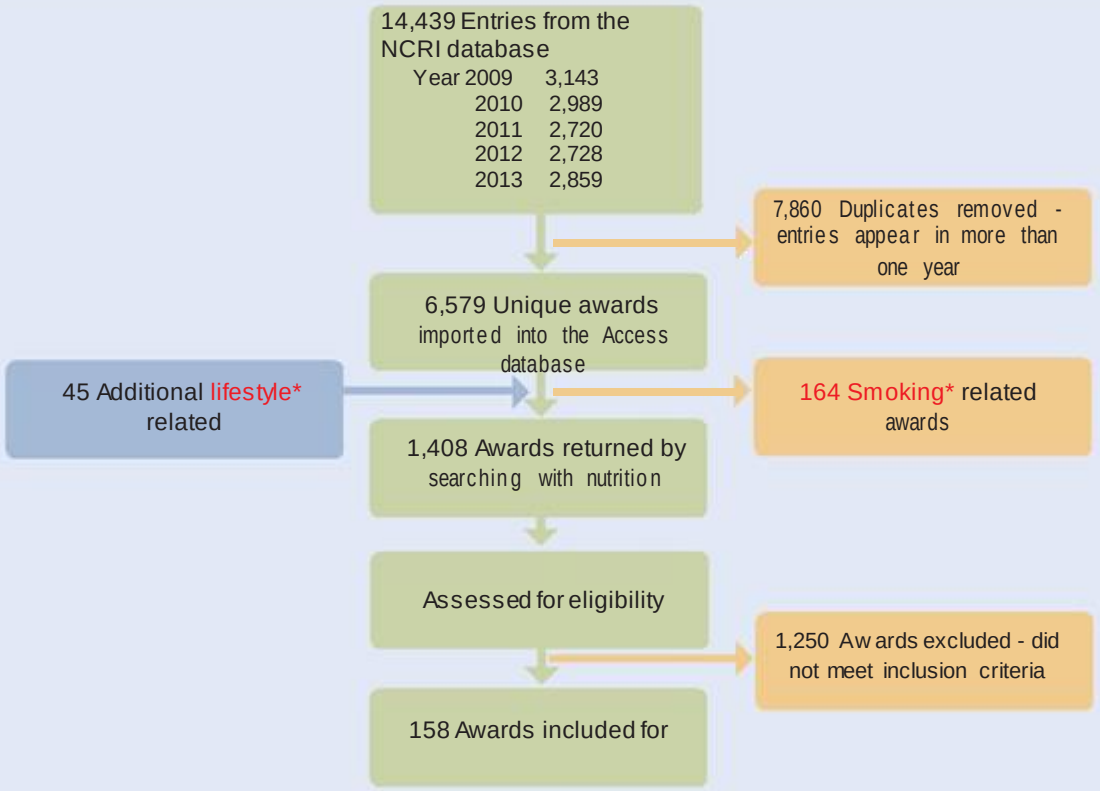


Figure 9: Overview of the mapping results.

* After the mapping started, the group decided to include lifestyle as a keyword and remove smoking: smoking is considered an environment carcinogen rather than a nutritional factor.

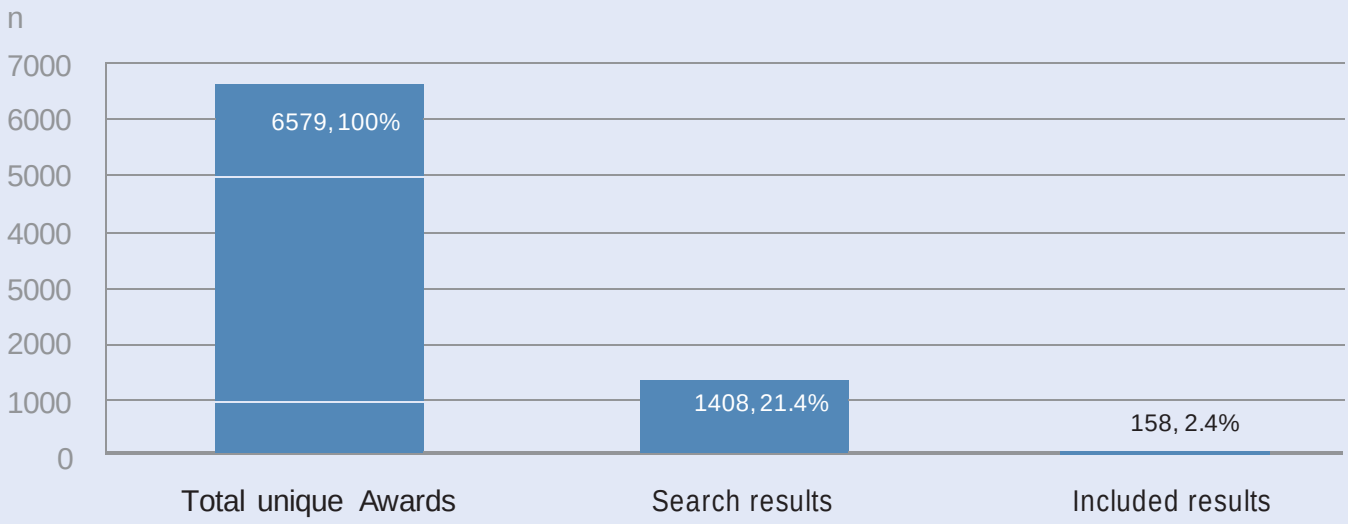


Figure 10: Total awards active between 2009 and 2013, identified using nutritional keywords and included in the mapping (n, % of the total unique awards in 2009-2013)

4.4.1 Overview of spend on cancer and nutrition research

Awards with a nutritional component included in the mapping account for about 1.8% of the total cancer research spend recorded in the NCRI database between 2009 and 2013. While the spend on cancer research doubled between 2002 and 2011[9], investment in cancer and nutrition research was inconsistent (Figure 11). More than 75% of this was spent in England. A small number of nutrition-related cancer research awards were made in Scotland (n=6), Northern Ireland (n=4) and Wales (n=2) between 2009 and 2013. Cancer and nutrition spend in Scotland dropped significantly from £1.9m in 2009 to £268k in 2013 (Figure 12), and increased slightly in Northern Ireland, from £109k in 2009 to £207k in 2013. The variation observed in the spend for Northern Ireland and Scotland may be because there are only small amounts of nutrition-related cancer research awards made each year. Between 2009 and 2013, there were only four and six nutrition-related cancer research awards made to Northern Ireland and Scotland respectively.

Cancer and nutrition spend by UK funders outside the UK has shown an increase from £0 to £220k over the past five years.

Money spent on cancer and nutrition research in the NCRI database is shown per head of the population for the devolved administrations (Table 5). This figure increased in England and Northern Ireland over the period 2009-2013 but decreased in Scotland and Wales. Wales consistently received less funding per head of population than the other devolved administrations.

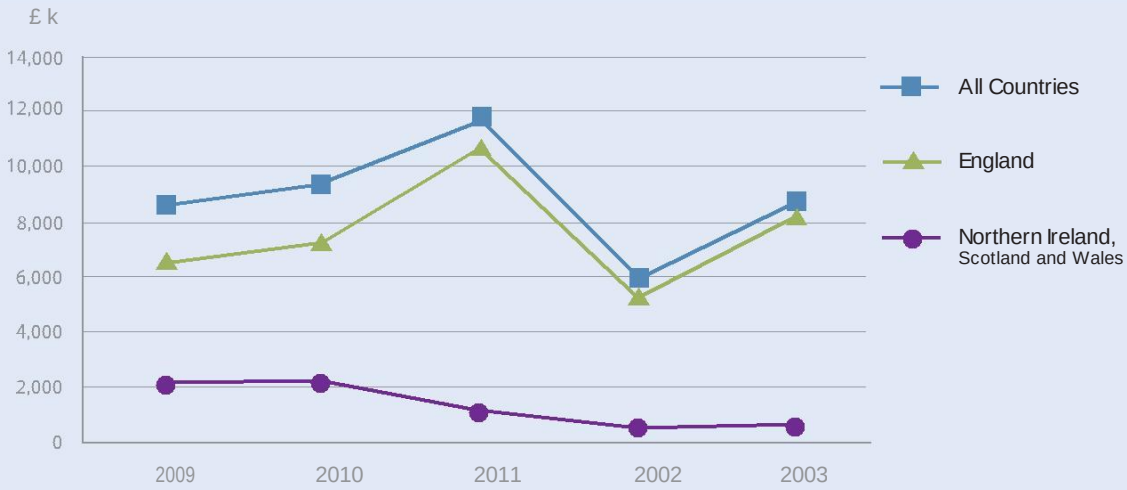


Figure 11: Money spent on cancer and nutrition research by all devolved administrations, 2009-2013

Figure 12: Money[9] spent on cancer and nutrition research by Northern Ireland, Scotland and Wales, 2009-2013

[9] The National Cancer Research Institute (NCRI) Cancer research in the UK 2002-2011: An overview of the research funded by NCRI Partners. 2013.

[10] Money spent on cancer and nutrition research is calculated based on the total value of the awards made to studies or projects that looked at nutrition. Within this amount, it is not possible to specify the proportion attributable to the nutrition component.

Country	2009	2013	Change between 2009 and 2013
England	£0.13	£0.15	22%
Northern Ireland	£0.06	£0.11	86%
Scotland	£0.37	£0.05	-86%
Wales	£0.03	£0.01	-70%

Table 5: Funding awarded for cancer and nutrition research, per head of the population[11], by devolved administrations, 2009 and 2013

4.4.2 Overview of nutrition themes

The most frequently studied nutrition themes, according to the number of awards, were lifestyle exposures and nutrition, included in 44% and 37% of awards respectively (see Figure 13). There were smaller proportions of awards looking at nutritional status (18%), metabolic conditions (18%), nutritional interventions (15%) and metabolism (16%).

According to the number of studies, nutrition was the most popular theme, included in 41% of studies. Notably, cohort studies investigating the associations between lifestyle exposures and cancer risks, and obesity-related interventions or observational studies, often received multiple awards (anecdotal observation).

Figure 14 provides a breakdown of the number of awards by nutrition sub-themes, of which the most commonly studied were micronutrients (vitamins, 11% and minerals, 8%) and other natural substances (8%). Lifestyle exposures (non-specific lifestyle factors, dietary exposures, alcohol consumption and physical activity) were the dominant nutrition sub-themes studied, with each included in at least 14% of awards. An equal proportion of awards studied oral supplements and non-specific nutritional care (9.5%), with only a small percentage of awards investigating parenteral and enteral feeding (2%).

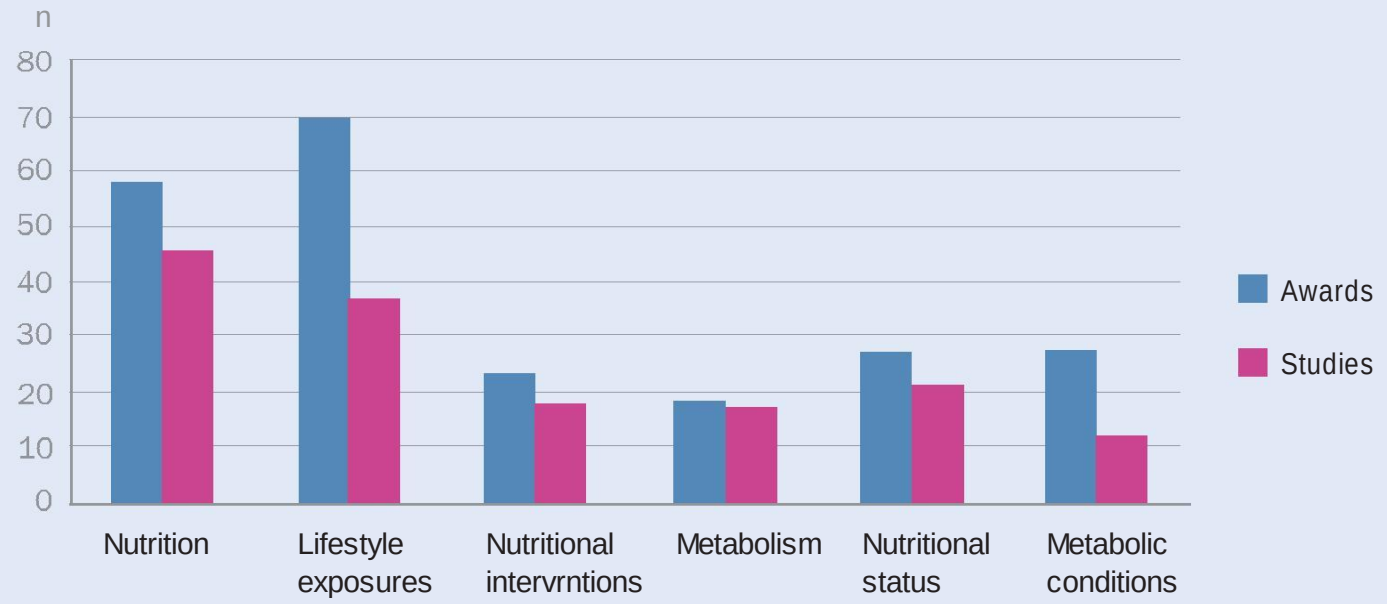


Figure 13: Nutrition themes covered by numbers of cancer research awards and studies, 2009-2013 * Studies may receive more than one award.

[11] Census data for 2009 and 2013 were obtained from the Office for National Statistics http://www.ons.gov.uk/ons/guide-method/census/index.html (last accessed March 2015).

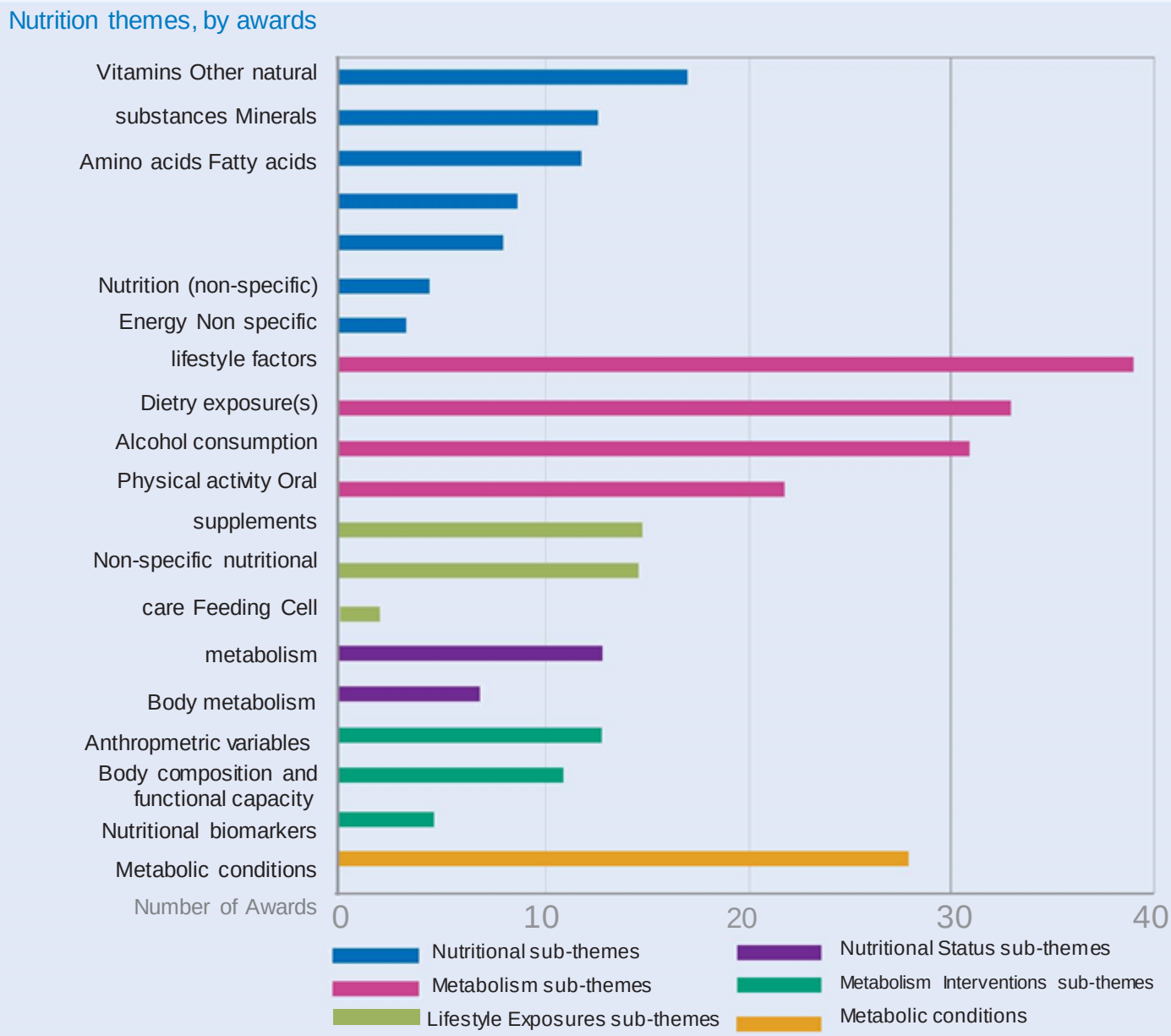


Figure 14: Breakdown of nutrition themes into sub-themes by number of included awards between 2009 and 2013, total n=158

*Awards may investigate more than one nutrition theme.

4.4.3 Nutrition theme by study type

Once included, awards were coded for study type (human interventional, human observational, animal and/or in vitro study). Figure 15 gives an overview of nutrition themes by study type. Awards sometimes include more than one study type and use different study types for different nutrition themes; we were not able to distinguish this in the mapping. A significant proportion (127 out of 158, 80%) of awards were human studies; of these half were interventional (n=77) and half were observational (n=75). Only a few awards were made to animal (n=15) and in vitro (n=33) studies. The stringent exclusion criteria applied during the mapping may have excluded some animal and in vitro studies because the nutritional relevance of such studies is likely to be less direct than human studies.

Amongst human studies, nutrition and lifestyle exposures were the two most popular nutrition themes (35% and 54%), followed by metabolic conditions and nutritional status (22% and 20%). There was a large spread of different study types within 'nutrition' studies. Most of the human observational research was on understanding the link between lifestyle exposures and cancers (69%). In vitro studies were predominantly used to study metabolism (45%) with very few human studies in this area.

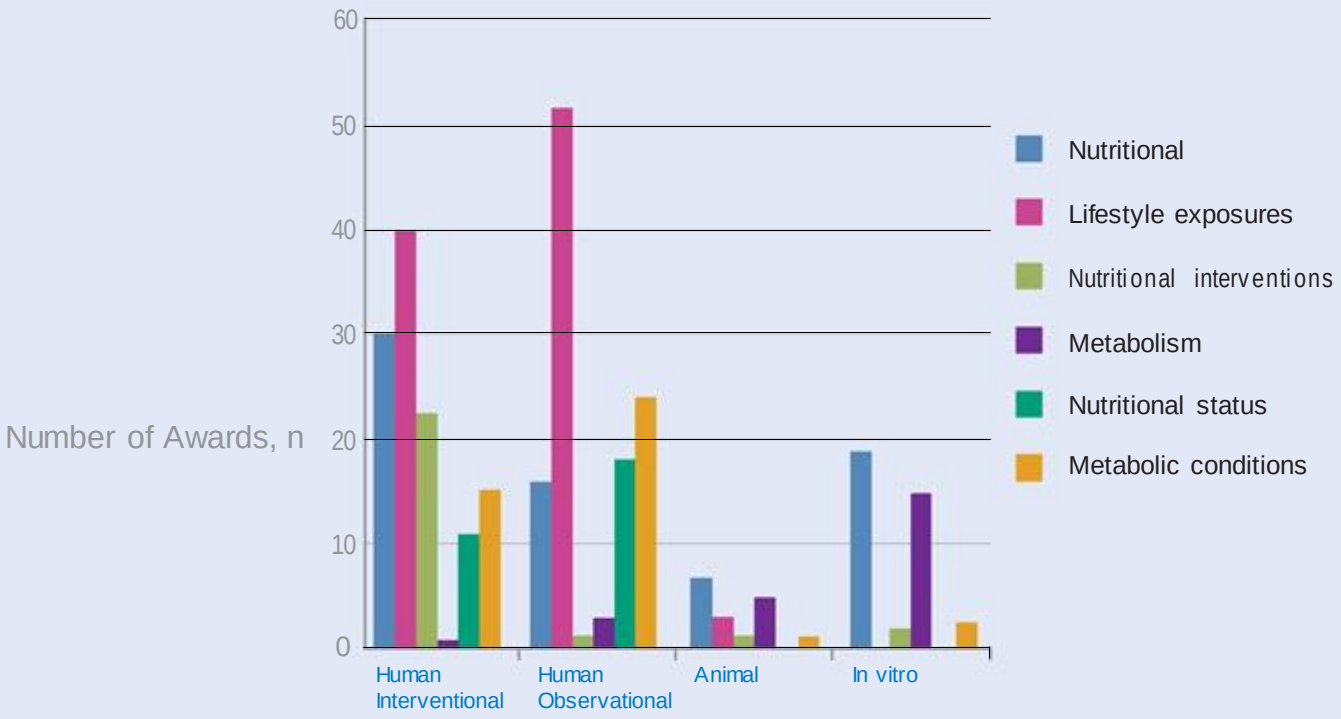


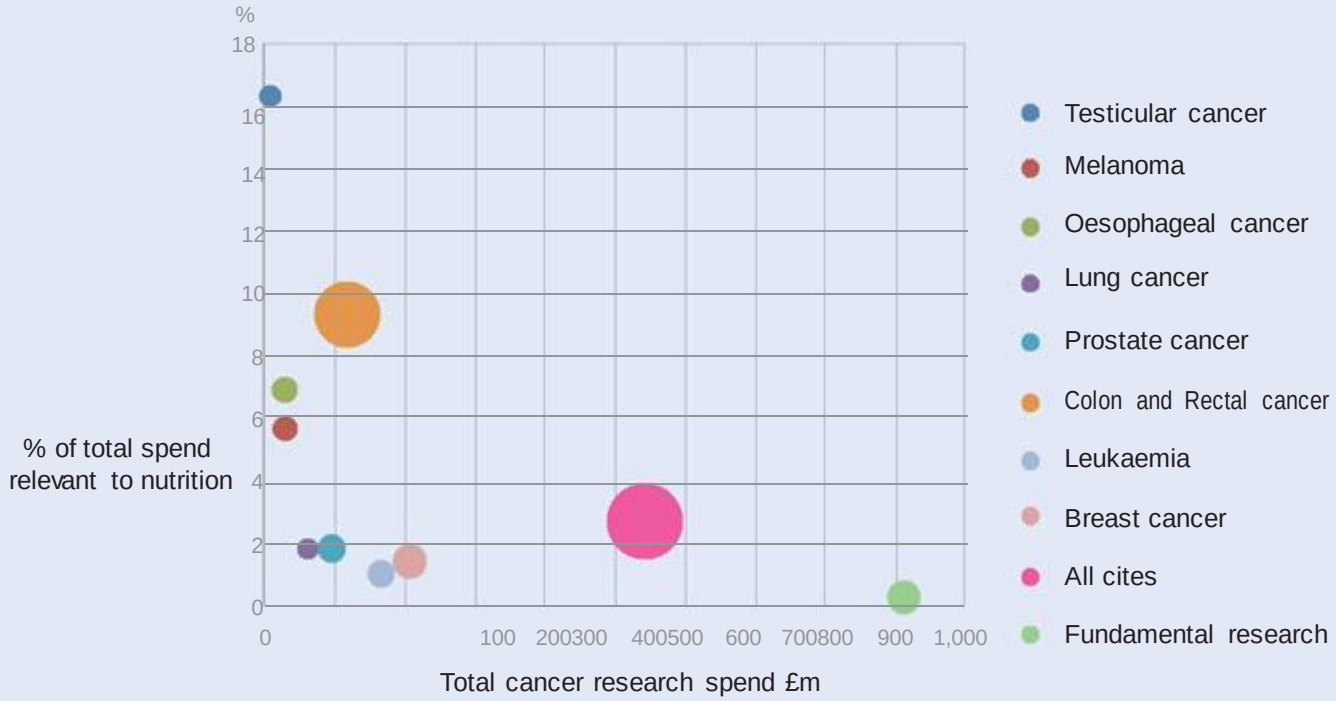
Figure 15: Nutrition theme by number of included awards across different study types, 2009-2013 (total n=158)

4.4.4 Overview of cancer sites

Cancer sites were coded by the NCRI (Appendix 10). Thirty eight per cent of cancer and nutrition research did not specify a cancer site. Of those that did, the most common site-specific cancers were colon and rectal cancer (23%), lung cancer (11%), breast cancer (10%), oesophageal cancer (10%) and oral cavity and lip cancer (9%). An overview of the cancer sites by spend and the number of included awards is available in Appendix 14.

Investment in cancer and nutrition research is calculated based on the total spend for included awards for each cancer site. Care must be taken when interpreting these figures as it was not possible to estimate the proportion of spend which could be attributed to nutrition-related research activity within each cancer site. Nutrition and cancer research related to non-site-specific cancers (coded as all sites) was the most funded research. For 10 cancer sites with the highest cancer and nutrition spend, an analysis of cancer and nutrition spend as a proportion of the total cancer research spend in the NCRI database was performed (see Figure 16). The greatest nutrition-related cancer research spend was on non-site-specific cancers (£14.3m, 2.6% of total research spend on non-site-specific cancers), and colon and rectal cancer (£10.8m, 9.3% of total research spend on colon and rectal cancer). There was just over £900m spent on fundamental research during the five years, of which 0.3% was relevant to nutrition. A fraction of the spend on breast, leukaemia, prostate and lung cancer research was related to nutritional considerations (1-2%). The total spent on research for melanoma and oesophageal cancer was small and although a greater proportion of the research was nutrition-related (6%-7%), the overall amount spent on cancer and nutrition was still relatively little. The proportion spent on nutrition in relation to testicular cancer was greater (16%). However, as we were unable to estimate the proportion of spend attributable to nutrition in individual awards and there were only three awards for testicular cancer research, it is possible that this observation is skewed by the large size of these awards.

Figure 16: Cancer and nutrition spend of the top 10 cancer sites as % of total cancer research spend in the NCRI database in 2009-2013.



The size of the circles represents the sum (£) of cancer and nutrition spend, i.e. the amount of cancer spend on research with nutritional relevance. The top 10 cancer sites were selected according to the total cancer and nutrition spend recorded in the database between 2009 and 2013.

The size of the circles represents the sum (£) of cancer and nutrition spend, i.e. the amount of cancer spend on research with nutritional relevance. The top 10 cancer sites were selected according to the total cancer and nutrition spend recorded in the database between 2009 and 2013.

Breast, lung, prostate, and colon and rectal cancers are the four most prevalent cancers in the UK and the evidence that they can be prevented through diet, nutrition and lifestyle is strong[12 13]. Figure 17 shows the sum of included awards on each of these cancer sites. Despite being relatively more common than other cancers and potentially preventable, the nutritional aspect of these cancers was poorly funded over the five years. Apart from colon and rectal cancer, the spend on nutrition-related research of these cancers (particularly breast cancer) declined between 2009 and 2013.

National data on cancer incidence and spend on cancer research were compiled and compared against the cancer and nutrition awards. Eight of the cancer sites included in the mapping are among the most common and heavily invested cancers in the UK. Figure 18 summarises these eight cancers by prevalence, by cancer spend, and by cancer and nutrition spend. Overall, the distribution of cancer and nutrition activities is generally in line with the amount of funding in the UK[14 15]. The pattern of investment in nutrition research for prostate, bowel and pancreatic cancers is similar to national cancer prevalence and funding, while great differences were observed for the five other cancer sites.

An analysis of nutritional theme by top cancer sites is shown in Appendix 13.

[12] Cancer Research UK, UK Cancer Incidence (2011) by Country Summary, January 2014.

[13] The World Cancer Research Fund, Cancer Preventability Statistics http://www.wcrf-uk.org/uk/preventing-cancer/cancer-preventability-statistics, last accessed March 2015.

[14] The National Cancer Research Institute (NCRI) Cancer research in the UK 2002-2011: An overview of the research funded by NCRI Partners. 2013.

[15] Cancer Research UK, UK Cancer Incidence (2011) by Country Summary, January 2014, last accessed March 2015.

Figure 17: Patterns of spend on nutrition research in the NCRI database for the four most common cancers in the UK between 2009 and 2013

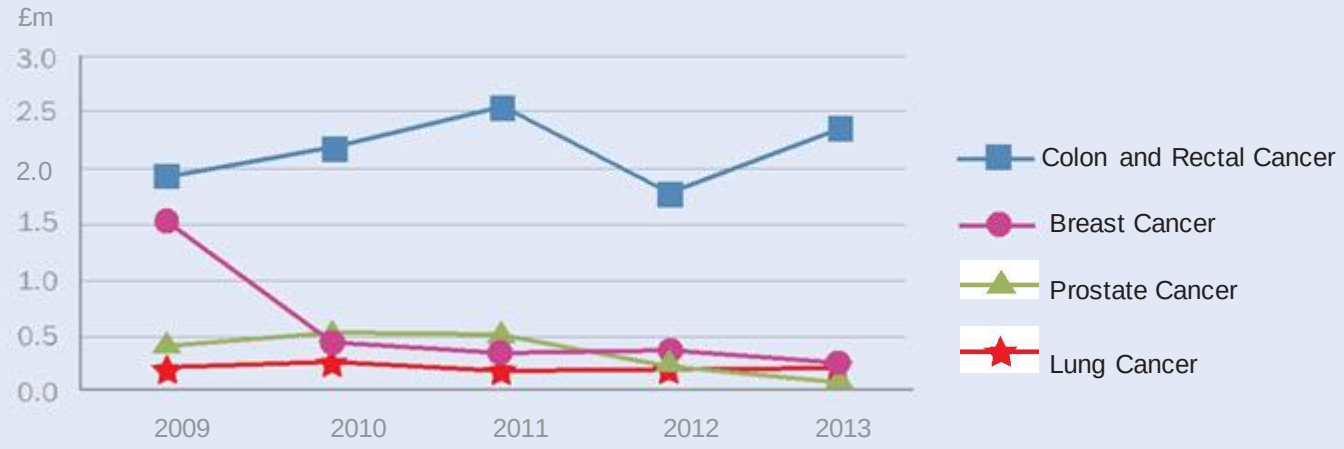
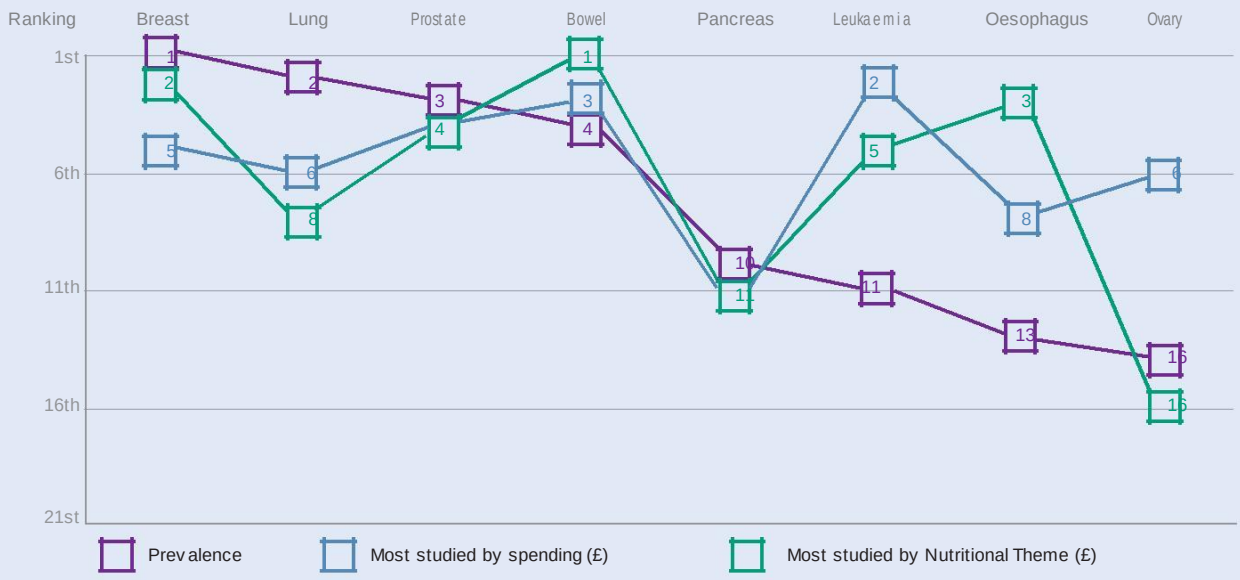


Figure 18: Comparison of 8 common cancers in the UK by ranking of prevalence, research spend and nutrition research spend in the UK in 2009-2013.



4.4.5. Overview of cancer research category

Cancer research category was coded by NCRI using the Common Scientific Outline (CSO) system (Appendix 9). Overall, cancer control, survivorship and outcomes research (CSO6) was the most frequent research area by included awards in the mapping (61%) (Figure 19). There was a relatively large proportion of awards on aetiology (CSO2, 36%) and prevention (CSO3, 33%), but a smaller proportion on the role of nutrition in cancer biology (CSO1, 15%), early detection, diagnosis and prognosis (CSO4, 10%), and treatment (CSO5, 16%).

Figure 20 shows the trends of spend on the six cancer research categories with direct relevance to nutrition between 2009-2013. In general, there was more money spent on aetiology (CSO2) and prevention (CSO3) than other categories. Investment in early detection, diagnosis and prognosis (CSO4) and cancer control, survivorship and outcomes (CSO6) research was reduced during the five-year period, whereas biology (CSO1) and treatment (CSO5) research increased.

Figure 21 presents CSO sub-codes by number of included awards against total spend between 2009 and 2013. There was a notable difference between the number of awards and amount of research spend for cancer control, survivorship and outcomes research (CSO6).

The most funded sub-category was nutritional science in cancer prevention (CSO3.2) (£7.4m, 2009-2013), which reflects the larger number of awards in this category (n=26). Resources and infrastructure related to aetiology (CSO2.4) was included in 12 awards for human observational studies; this area received £7.4m over the five years (grants made to provide infrastructure support or resources, for example awards made to support follow-up data collection within a large cohort are generally larger in size than awards for specific studies).

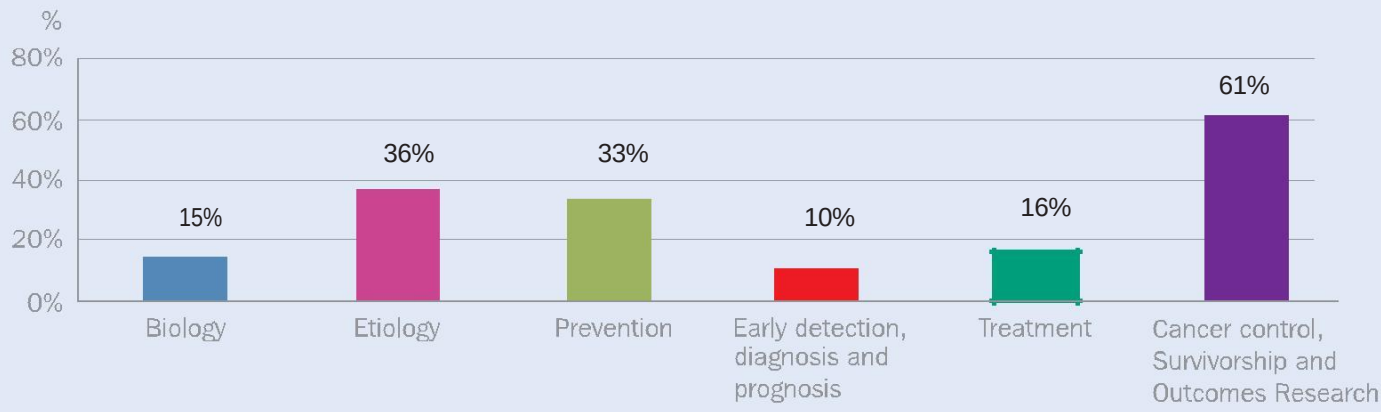


Figure 19: Overview of cancer research category, % of total included awards (n=158)

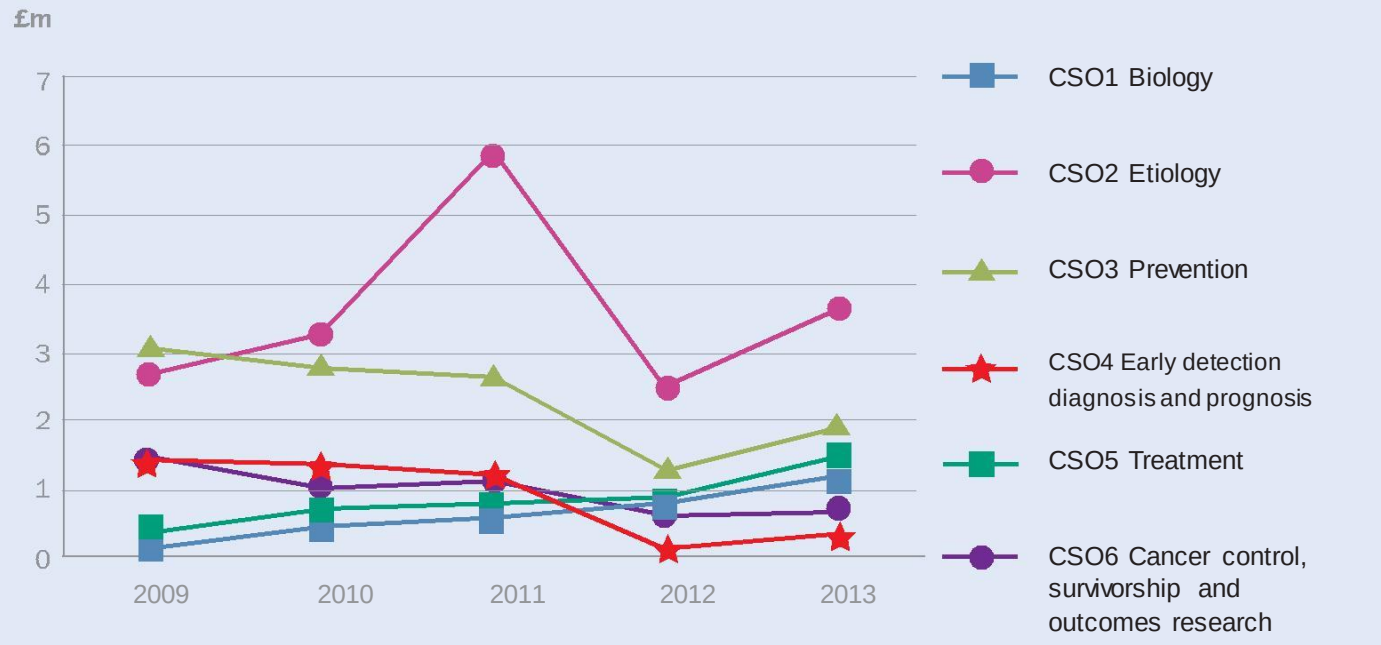


Figure 20: Patterns of total spend on the six cancer research categories with relevance to nutrition between 2009 and 2013

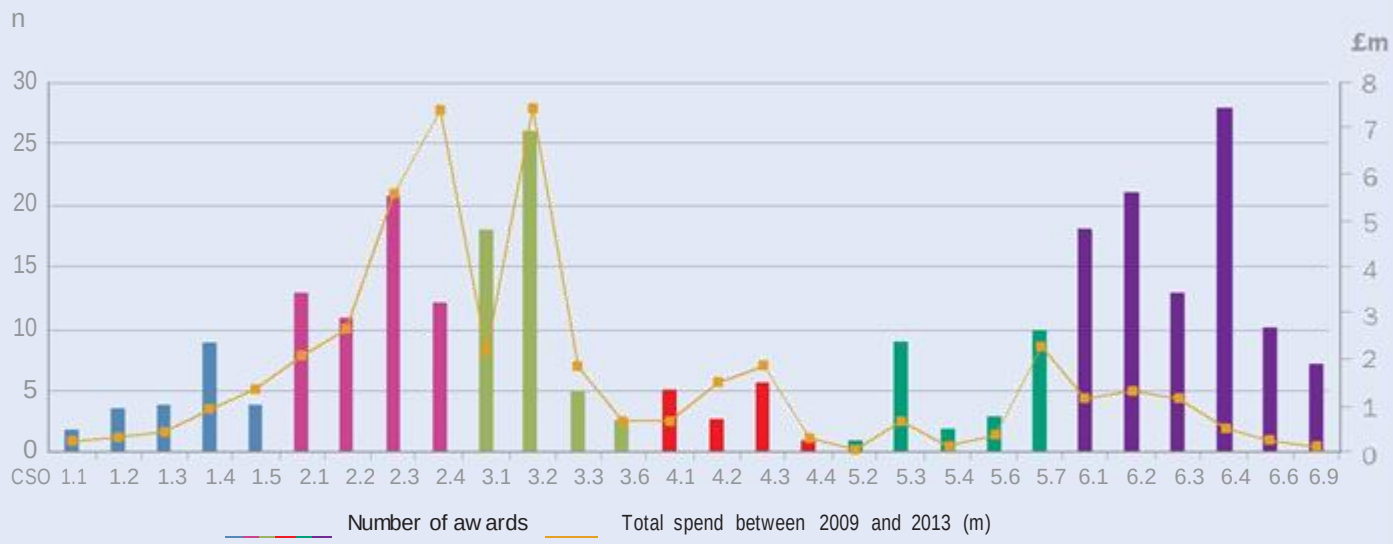


Figure 21: Comparison of CSO sub-codes by number of included awards and by total spend between 2009 and 2013

4.5 Strengths and limitations of the mapping methodology

We used the NCRI database as the sole data source for the mapping. The NCRI database provides grant information collected from the UK's biggest research funders (according to annual spend) and its wide coverage means it captures a large part of cancer research activities in the UK, all of which could be captured in the mapping. Information in the NCRI database (cancer sites, areas of cancer research and relevant proportioned costs) is independently coded by two coders, which increases the quality of the data. Using the NCRI database removes the risk of missing unpublished work as well as the problem of publication bias, because it includes work in progress regardless of whether the work is subsequently published. However, research funded by non-NCRI partners, informal research or small scale, local work may not be included in the database and will not be captured by the mapping. The Task and Finish Group sought to minimise this through discussion with relevant networks and stakeholders to identify where other work might be happening in the UK.

We included a quality assurance process as part of the mapping: one coder from the Task and Finish Group screened all the search results to decide if it should be included, and coded the relevant nutrition information. Using only one person to screen the results ensured coding decisions were consistent. When nutritional relevance was not obvious, the Task and Finish Group discussed the award to reach consensus on the final coding.

A number of limitations of the mapping methodology should be recognised. Firstly, awards made by small cancer research funders with annual cancer research spend less than £1million were not captured in the NCRI database, for example awards made by WCRF UK. Secondly, an individual award's relevance to cancer was subjectively judged by the funders and then NCRI, which means there may be awards with relevance to cancer which have been excluded from the NCRI database. Thirdly, during the mapping process, the coder relied on the information provided in the award's abstract to code nutrition elements. Some nutrition-related research may provide insufficient detail of the nutritional element in the abstract, which would result in it being excluded from the mapping or coded inaccurately. Given the number of awards to screen within the time available, we were limited to looking at abstracts. A more detailed mapping exercise, looking at full study protocols where necessary could be undertaken at a later stage, resources permitting. It was not possible to estimate the proportion of an award attributable to nutrition. Therefore some studies where nutrition was only a minor part of the work might have been included.

4.6 Key findings

1 A small proportion of cancer research awards included an explicit nutrition component (11%).

2 A large proportion (80%) of included awards were human studies, more than a third of which looked at the relationships between non-site specific cancers and lifestyle exposures without specifically characterising a nutrition theme. These human study awards were predominately for:

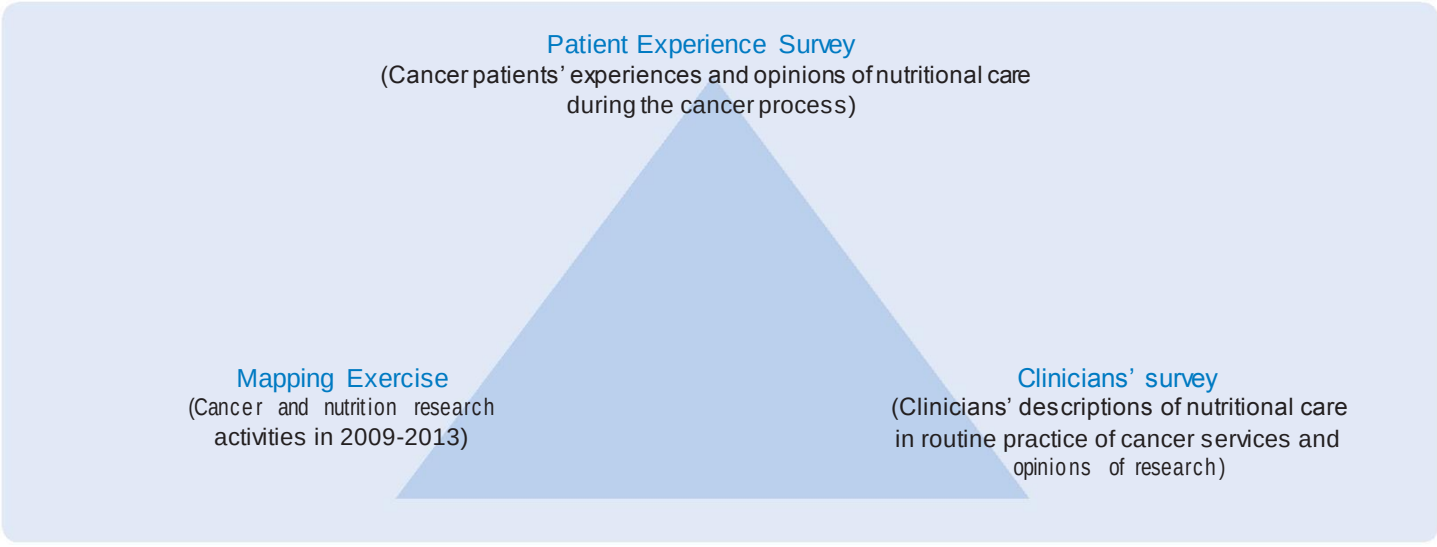
- Supporting large cohort studies to collect dietary data and specimens, or conduct statistical data analysis
- Understanding the effects of nutrients or nutritional status on cancer risk by using observational or interventional data
- Surveillance of, or intervention on, cancer risk factors such as dietary patterns, body weight and physical activity

3 There were only a small number of relevant animal and in vitro study awards, which may be due to the stringent exclusion criteria applied. However, animal studies explicitly exploring at the link between cancer and nutrition were included, e.g. a mouse prostate cancer model to test oral supplements

4 The most frequent specific cancer sites studied in relation to nutrition were colon and rectal cancer, breast cancer, lung and oesophageal cancer. These cancer sites have most potential preventability through diet and physical activity.

5 Summary of results and recommendations

5.1 Triangulation of results



Triangulating the findings from the mapping exercise, patient experience and clinicians' surveys, the Task and Finish Group made the following observations:

1 A relatively small proportion of cancer research funding was spent on nutrition. This may reflect difficulties in securing funding for nutrition research (as suggested by the clinicians' survey).

2 Few animal studies exploring the mechanisms linking nutrition to cancer risk or progression have been conducted during the last five years.

3 Patients who participated in the Dragons' Den session at the NCRI 2014 conference and those who completed the patient experience survey reported that the quantity and quality of nutritional care currently provided is unsatisfactory. In particular, patients felt there was a lack of support and advice given to overcome the side effects of chemotherapy.

4 Clinicians observed that there is no agreed approach to nutritional assessment of cancer patients, and it is therefore not carried out in a systematic way. Clinicians also felt that there is insufficient support and formal guidance on how assessment should be conducted.

5 The mapping exercise highlighted the relatively small number of nutritional intervention studies taking place in the UK. The clinicians' survey supports this finding as clinicians reported difficulties in accessing funding and in receiving ethical approval for large-scale clinical trials as well as a lack of infrastructural support to conduct research. They highlighted the need for good quality evidence which could be translated into improving clinical practice. Similar comments were given by attendees at the NCRI workshop who explicitly stated the need for more large scale intervention studies in the UK.

6 Nutrition is recognised as an important factor in cancer risk and progression but it is under-investigated for a variety of reasons. Consequently clinicians do not have robust evidence to support nutritional care. A common approach to measuring nutritional status is lacking.

5.2 Recommendations: Research and clinical practice

A primary objective of the collaboration is to facilitate the generation of evidence to improve cancer prevention and the nutritional care of people with cancer. To help achieve this, the following recommendations have been identified by the Task and Finish group:

1 There is a large evidence base on the associations between diet and behaviours and cancer incidence, but less on effective preventive interventions. Evidence for interventions on diet and behaviours to improve cancer outcomes is also limited and does not provide a firm base for the nutritional management of cancer in general, or specific cancers.

We recommend: There should be focused research on the efficacy and effectiveness of nutritional interventions on cancer prevention and in the management of diagnosed cancer. This could utilise existing studies e.g. through 'piggy backing' a nutritional component on to existing therapeutic trials.

2 Published research on cancer incidence in relation to food, nutrition and physical activity is systematically collected, analysed and synthesised by the Continuous Update Project of the World Cancer Research Fund. However, such evidence in relation to cancer treatment, recurrence and survivorship is not collected systematically, and therefore the nutritional management of patients already diagnosed with cancer is not well informed.

We recommend: A system to collate and synthesise this evidence should be established to enable and encourage systematic analysis of the effects of nutritional interventions on cancer outcomes. It would also help identify areas where future trials are most needed and also most likely to generate significant benefit.

3 Most laboratory experimental studies are directed at understanding tumour biology as a basis for identifying targets for pharmacological or immunological therapeutic interventions. Little attention is paid to the transition from normal to cancer cell, which would help inform preventive approaches, or specifically address nutritional aspects of cancer management.

We recommend: Studies specifically addressing the nutritional biological mechanisms underpinning cancer development, progression and management, and variations between people and patients.

4 In contrast to randomised controlled trials (RCTs), observational data do not allow robust conclusions on efficacy or effectiveness. However, RCTs are resource intensive and can test only one or few hypotheses. Therefore careful analysis of good quality observational data is needed to generate hypotheses that are most likely to yield benefit. Currently there is no agreed or conventional set of measures of nutritional state that are performed routinely on all patients in a standardised and quality assured manner in order to generate such data. Opportunities to interrogate routine clinical data as a basis for developing hypotheses to test are limited.

We recommend: Sets of nutritional assessment measures (appropriate from routine to more complex clinical situations) should be developed and agreed for routine use. These nutritional toolbox(es) should comprise aspects of history (appetite, diet, physical activity), anthropometry (body composition), physiology physical function or fitness and metabolic fitness), and biochemistry (nutrient status).

5 To generate reliable data across multiple settings using these toolboxes, requires a trained workforce operating to defined and quality assured standards.

We recommend: Training programmes for health professionals should be developed to ensure that nutritional measures are collected routinely on all patients appropriate to their clinical needs. Such clinical information should be accessible (in anonymised form) to permit its use in identifying appropriate targets for therapeutic intervention trials.

5.3 Recommendations: Collaboration

Collaboration is fundamental to improving the cancer and nutrition research agenda. A community of practice of patients, researchers and clinicians working in nutrition and cancer should be established to foster better collaborative working in these important areas.

5.3.1 Patients

The purpose of the collaboration is to facilitate the improvement of translational research so that patients will benefit from better nutritional care. Listening to patients is imperative in understanding their needs, in order to develop a patient-centred research agenda. Patients are an integral part of the collaboration and there is a need to explore how best to use their experience and to ensure they are fully involved in all aspects of the research and service improvement agenda. Patients agree that this initiative meets a long-standing need and several have offered their time and active support to our work.

We recommend: Novel approaches to patient engagement should be developed, for example using crowd-sourcing platforms to enable patients to help identify priorities for research.

5.3.2 The research community

There is wide variation between people in the progression of cancer and in its response to treatment. The possibility that nutritional factors might underpin this has not been extensively studied. Many existing research proposals could benefit from a robust nutritional component.

We recommend: Researchers testing therapeutic interventions in cancer should work with specialist nutrition professionals to include a nutritional component in the research proposal. A platform which links researchers with complementary skills and expertise would facilitate the development of stronger research proposals.

Groups with a particular interest in specific cancer sites and/or dietary, nutrition and physical activity should engage in structured discussions with the Research Councils to harmonise research where appropriate.

5.3.3 Professional groups

The absence of a robust evidence base means that health professionals are not always able to provide relevant, constructive and consistent advice to patients. Health professional groups are responsible for ensuring the use of standardised approaches to nutritional assessment and producing a trained workforce.

We recommend: The relevant core professional groups including the Medical Royal Colleges, the British Dietetic Association and the Association for Nutrition should agree on core clinical nutritional information to be collected routinely (nutritional toolboxes) and supply the training needed to support its collection

5.3.4 Industry

In this context, industry is a broad term and encompasses a range of organisations and individuals. Industry has the responsibility to conduct its economic activity with the health of the population in mind, and should be involved at all stages along the cancer journey. As such, they may have an important role in the future of this work.

Table 6 provides some examples of organisations considered to be part of 'industry'. The examples are separated according to each stage of the cancer journey; it is by no means an exhaustive list and may be populated further as ideas for engagement become clearer.

Prevention (Individuals and organisations involved in economic activity which affects factors that may cause or reduce cancer, including environmental, behavioural and social aspects)	Screening and diagnosis (Producers of equipment designed to help in the routine screening and diagnosis of a range of cancers)
Food industry e.g. manufacturers, lobbyists, advertisers, retailers Industrial waste producers Town planners e.g. transport infrastructure, leisure facilities App developers e.g. Google PR agencies that protect any cancer-causing industries	Manufacturers of diagnostic equipment e.g. CT scans, endoscopy, IVU, MRI etc. In vitro diagnostic equipment Manufacturers of measurement tools e.g. for body composition, SECA, DXA Genetic tests and genotyping Information systems e.g. medical software
Treatment and Care (Broadly, the pharmaceutical industry)	Palliative care (Organisations that produce and manage services that help support individuals for end of life care)
Manufacturers of therapies e.g. pharmaceuticals, chemotherapy, radiotherapy, hormone therapy, biological therapy, radiofrequency ablation, cryotherapy Manufacturers of medical devices e.g. surgical equipment (varied and broad), active medical devices (using electrical supply to replace body functions)	Producers of artificial and supplementary feeding End of life institutions & hospices e.g. designers, managers and food providers Insurers

This collaboration has existing relationships with parts of NIHR and the wider NHS infrastructure that may be of interest to industry. Part of NOCRI's role is to support and help facilitate the development of these relationships.

We recommend: Opportunities for industry collaboration and support should be explored. This report has not tried to explore options for engaging with industry but this should become an explicit task for future activities as the research agenda becomes clearer.

5.3.5 The UK's devolved administrations

Although all parts of the UK conduct activities in cancer and nutrition, NOCRI's responsibilities lie solely in England and therefore, to date, the work of the collaboration has been focused primarily in England (with the exception of the mapping which included awards from all areas of the UK). However, the Experimental Cancer Medicine Centre (ECMC) Network is UK-wide so inclusion of additional ECMC members in the collaboration will help ensure the collaboration is more nationally representative.

We recommend: The collaboration should seek to engage counterparts in the devolved administrations so that options identified through the collaboration can be extended to the whole of the UK.

5.4. Recommendations: Communicating results

To disseminate the results of this scoping activity, this report will be posted online on the collaboration's website (www.nihr.ac.uk/cancer-nutrition). It will be shared with the network of stakeholders identified at the outset of the project the collaboration's mailing list (which includes a number of patients and clinicians who have signed up in response to completing the patients or clinicians' surveys).

We recommend: The Collaboration should host an event which 'launches' this report, shares its ambitions with stakeholders (including patients, researchers, funders and clinicians) and provides an opportunity for such stakeholders to offer their support. Members of the Steering Committee should share the report across their networks. Opportunities to collaborate with other research groups should be explored, in particular among the wider ECMC network, to better define the key research gaps and provide guidance to the other parts of the NIHR infrastructure.

In addition to sharing this report, regular opportunities for sharing news in the future should be established. This may include conferences, online consultations, lectures, newsletters and papers for publishing. Discussions of these options by the Steering Committee are planned in the next phase.

An open online discussion forum hosted on the initiative's website has been created. At present, an insufficient number of people have signed up to make this a fruitful platform for discussion. Following the publication of this report, an invitation will be sent out to all stakeholders previously identified during the first phase to join the forum and provide feedback on the report. To ensure that the forum produces a lively and constructive debate, a structured set of discussion topics and questions will be introduced and the discussion monitored regularly to capture feedback and ensure that the forum maintains momentum.

5.5 Immediate priorities

The scoping exercise has clearly identified unmet patient and public need, and a lack of evidence to help professionals meet this need. To improve the current situation, priorities for the next phase are to:

1. Agree a minimum toolbox of nutrition assessments for use in routine practice, and expanded options for more specialist application, which will be made available to clinicians, the NIHR infrastructure and the wider research community.
2. Develop a quality assured framework of training and capacity (clinical and laboratory) within which to conduct these measures. Develop competency-based training for clinical staff to defined standards to ensure consistency of practice and acceptable standards of care.
3. Monitor the use of the toolbox and evaluate user experiences.
4. Identify the key research opportunities and priorities across the NIHR infrastructure, and explore opportunities for prosecuting an appropriate research agenda for the short, medium and long term.
5. Develop (and maintain) a community of practice to facilitate and promote better practice.

5.6 Lessons learned

During the next phase, the collaboration should be responsible for a number of items and tasks, to:

1. Help facilitate on-going collaborative working in an effort to improve translational research.
2. Maintain awareness of existing and new work in nutrition and cancer in the UK.
3. Maintain a relationship with the NCRI in order to share knowledge and learning with the wider cancer community through the network of NCRI partners.
4. Continue a dialogue between stakeholders, for example through our online discussion forum, mailing list and website.
5. Sustain momentum to ensure that efforts to date are not wasted.

5.7 Next steps

1 The work for the next phase has been broken down into the following five work streams (WS):

WS1. Information provision and communication with cancer patients and the public.

WS2. Creating a skilled community of practice.

WS3. Identifying major research priorities.

WS4. Characterising nutritional status in cancer

WS5. Opportunities for engagement with the commercial sector.

Detailed plans for each work stream will be developed and stakeholders will be invited to take responsibility for certain aspects.

2 The collaboration should seek to invite the wider NIHR research community and other stakeholders to use their research systems and funding to contribute to the WS.

3 Funding from NIHR Southampton BRC to support staff dedicated to working full time on this initiative has been instrumental in its success.

We recommend: To continue to build on this work, the collaboration should seek to secure funding to support dedicated personnel in future work plans. NOCRI support this decision (see letter of intent from the Managing Director of NOCRI in Appendix 16).

5.8 Conclusions

NIHR Cancer and Nutrition infrastructure collaboration has a challenging ambition to share knowledge and expertise across the fields of nutrition and cancer. However, the key goal of this collaboration is to improve the nutritional management of cancer patients, and the prevention of cancer through nutrition. The identification of research gaps and the development and prosecution of a focused research agenda will generate new evidence of direct and lasting importance, to the benefit of patients and the professions alike. The next phase of this collaboration should be to start the generation of robust evidence through good quality observational studies (on specially constructed cohorts as well as routine patient data), through systematic reviews of existing evidence and through the identification of appropriate interventions to test in clinical trials. This work will offer important opportunities for strengthened links with academics, patients and industry and encourage the development of novel approaches to translational research.

6. Appendices

Appendix 1: Minutes of Initial Steering Group Scoping Meeting

Meeting title: Cancer & Nutrition NIHR Infrastructure Collaboration: Initial Steering Group Scoping Meeting

Date: 19th March 2014
Time: 12 noon - 5pm
Location: Presidents Room, Central Hall, Westminster

Present:

Professor Alan Jackson, (NIHR Southampton BRC), Dr Kate Allen (WCRF UK), Dr Jervoise Andreyev (NIHR Royal Marsden BRC), Carrie Bolt (NIHR Southampton BRC), Professor Karen Brown (ECMC network), Lauren Chapman (NOCRI), Dr Karla Duarte (NOCRI), Dr Claire Foster (University Southampton), Dr Anne Helme (CRUK), Professor Peter Johnson (Southampton CRUK Centre), Dr Emma King (CRUK, Southampton), Professor Richard Martin (NIHR Bristol BRU), Dr Rowena Sharpe (NIHR Royal Marsden BRC), Professor Martin Wiseman (WCRF UK), Dr Steve Wootton (NIHR Southampton BRC).

Also invited:

Professor Elio Riboli, Imperial BRC

Welcome

AAJ welcomed everyone to the meeting, expressing delight at the broad spectrum of attendees. He highlighted that it was a planning meeting ahead of a wider national meeting. There is a challenge in bringing together all the threads that make up the activities within 'nutrition and cancer', but it was important to better manage the overlap in order to improve basic research, clinical care, and prevention in public health.

KD acknowledged that sharing of knowledge and expertise across nutrition and cancer could be improved and that collaboration of relevant players is key to taking an agenda forward. This collaboration has support from NOCRI, and NIHR and Department of Health more broadly. NOCRI was set up by DH to have two main streams of activity: collaboration; and industry engagement.

Introduction

AAJ drew attention to the pre-circulated briefing note that summarised the main concerns relating to nutrition and cancer: cancer will be the main cause of death by 2050, and as smoking declines, nutrition and diet are becoming more important; the support that is given to patients is based on general principles without a focused evidence base; known relationship between diet and aetiology of cancer - need for greater clarity on the relationship in particular the mechanisms responsible; need to refine consideration of how nutrition plays a role in biology of cancer and relate this to clinical needs in patient care; NBRC is an opportunity to bridge the space in understanding from molecular and cellular to patient and population level. This meeting was a first step to explore how best to prosecute this ambition.

MW and KA gave a presentation on behalf of World Cancer Research Fund International 'Host factors in cancer development and progression'. WCRF UK is a non-profit organisation that heads a network of national charities, uniquely focused on the links between food, nutrition, physical activity and cancer. It manages a grant programme addressing nutrition and cancer research, of the order of around £2m annually. WCRF UK would consider putting forward funds to support a discrete research programme addressing issues around individual susceptibility or resilience to cancer, within the contexts of policy, population health and clinical care. It is keen to establish interdisciplinary research that incorporates basic science with both epidemiological and clinical studies.

AAJ emphasised the importance of characterising nutritional status in a systematic way, addressing not just diet, but also body composition and functional markers. Although prospective cohorts existed, nutritional state was often poorly characterised. The group discussed whether there is a need for further large prospective cohorts. There are data related to host factors, nutrition, diet and physical activity but there is also a need for research integrating cancer biology with diagnosis, prognosis and management, as well as epidemiology and public health. Although height and weight were captured for the Cancer Intelligence Network, this is not currently readily available for sharing.

Agree Terms Of Reference

Attendees approved the role of the group set out in the tabled TOR. It was proposed that consideration be given to having a PPI representative, and how best to engage representation from the nutrition industry. It was agreed that, subject to a minor amendment below, the TOR should be adopted, to be reviewed in 12 months.

ACTION: J. Andeyev and NOCRI to consider how best to ensure industry engagement and report back to Chair.

ACTION: NOCRI to amend TOR - remove proposed length of time of meetings (2hrs).

Structured discussions on existing activities: key priorities and gaps in portfolio

The group discussed epidemiology, basis biology/mechanisms and clinical care. It was noted that in general research proposals involving nutrition were of poor quality, and did not capitalise on the opportunities of interdisciplinary teams. From the public health perspective, current paradigms in changing behaviour have not been successful and policy level changes would be expected to be more successful. Epidemiology studies needed to move from description to intervention. With regard to clinical care, there were some simple questions that could be addressed relatively easily ("low hanging fruit") such whether loss of appetite in cancer patients (or illness more generally) was an evolutionarily developed protective mechanism. It was suggested that height and weight data in routine care needed to be recorded and made available nationally, but such measure would need to be standardised. Systematic review of poor literature cannot be relied upon; much of the data are not published and it is unclear to what extent negative findings are reported. The better the mechanistic understanding, the more likely to get a better answer to questions of relevance both in clinical and preventive settings, but it would be important to develop working models for complex systems. NIHR support research in humans; important role of this group is to improve quality of research to be better able to address questions and secure funding. There were challenges even in characterising exposures, as well as the timing of exposure (pre, around, after diagnosis or during treatment)

AAJ concluded that this discussion exposed the need for

- a coherent research framework to address these questions; and
- identification of best practice in routine care, and in conducting and reporting research relating to nutrition and cancer

Synthesis of nutritional aspects

Informatics and knowledge management - there is a large body of information that needs to be interrogated effectively. The different data sets, platforms and geographical locations meant that this is challenging. The Farr Institute of Health Informatics Research is a body whose role is to link electronic health data with other forms of research and routinely collected data, as well as build capacity in health informatics research. It was suggested that the Farr should be asked about nutritional data. Attendees suggested linking with Cancer Registration Forum, in particular how to link to specific cohorts: with the CONCORD programme of global surveillance of cancer survival (Michel Coleman) at the London School of Hygiene & Tropical Medicine.

Tumour biology/mechanisms - there was a suggestion that a Crick PhD student could take forward this activity, though it was unclear how nutrition fitted into their strategy.

Clinical care - there is a NCRI network of trial data. ICR in collaboration with ICL had a register of trials relating to studies on the microbiome

Observational cohorts - Nutrition state in head and

neck cancer patients is unknown and data are currently being collected. It is important to characterise nutritional state at baseline in order to be able to measure the effect of nutritional intervention. Inception cohorts with well characterised nutrition state with defined cancer interventions and end points are a valuable way of beginning to address this.

Nutritional interventions - Patient response to interventions was variable and the contribution of nutrition to this variability is unknown. It was suggested that NIHR require all investigators at least to routinely collect data on height and weight of participants. Bolt-ons to existing studies offered potential.

Infrastructure building: Toolboxes for characterising nutritional status, analytics

It is not possible to adequately characterise nutritional status with a single type of measurement. It is important that measurements are taken well (there are known difficulties with measurements of height and weight). There is a need for a toolbox of measurements using standard operating procedures (SOPs) and training with accreditation of competency, not only in taking but also correctly interpreting such measures. It is important that methodologies are appropriate to the question and task (e.g. 7 day food diary not suited to large studies). There is a role in measuring functional markers - measuring metabolic processes rather than nutrient concentrations per se. It was agreed that it would be useful to define minimal nutritional datasets for use in routine clinical care, and in various types of research studies.

Capacity Building

There is a need for relevant nutrition training for all in research. The NIHR training agenda offered some opportunities for 3-6 month interns within NIHR infrastructure. ACLs and ACFs in nutrition are dependent on other specialties as nutrition is not recognised as a speciality. There is a need for infrastructure to be in place before individuals can be trained. There is funding in place for training but a need to identify individuals who want to work in this area. About 50% NIHR training is aimed at non-medical individuals and there is a need to consider nurses who routinely collect research data. NIHR have training opportunities for research nurses and AHPs (e.g. Clinical Research Network Programme; developing academic nurses/AHPs). It was agreed that it would be useful to define a minimum toolbox encompassing both SOPs and training both in carrying out and interpreting nutritional measures.

Reconciliation of Priorities and Next Steps

1. Create network for collaboration - requires a Steering Group to drive forward agenda; need for inventory/mapping of current collaborations in nutrition and cancer, including existing bio-repositories that might be relevant. Steering Group to be convened by NOCRI and review in 6 months (remotely).
1. dentify best practice for conducting and reporting nutrition and cancer research, from basic through clinical to epidemiological.
3. Develop a minimal dataset for nutritional measures collected in routine clinical cancer care and in different types of cancer research. Also minimal training needs in conduction and interpreting nutritional measures; and ensuring people are demonstrably competent - training and accreditation.
4. Inventory of nutritional assessment capacity in NIHR “family” (and more widely)
5. Consider developing a short course to meet need for this research capacity, and to build capacity nationally within NIHR family
6. Need for a large meeting in due course, with the mapping in advance, to address: where are the capabilities; key questions to be addressed; resource.

Appendix 2: Delegate List: Scoping Meeting Wednesday 19th March 2014

Name	*Role & Organisation*
Professor Alan Jackson	Director, NIHR Southampton BRCProfessor of Human Nutrition, University of Southampton
Martin Wiseman	Medical and Scientific Adviser, World Cancer Research Fund International
Carrie Bolt	Centre Manager, NIHR Southampton BRC
Lauren Chapman	Business Intelligence Manager, NOCRI
Dr Karla Duarte	Infrastructure Team Leader, NOCRI
Dr Kate Allen	Executive Director, Science and Public Affairs, WCRF International
Dr Emma King	Senior Lecturer in Head and Neck Surgery, CRUK
Professor Elio Riboli	Director of the School of Public Health at Imperial College London, NIHR Imperial BRC
Dr Jervoise Andreyev	Consultant Gastroenterologist in Pelvic Radiation Disease, NIHR Royal Marsden BRC
Dr Rowena Sharpe	Assistant Director, NIHR Royal Marsden BRC
Professor Karen Brown	Professor of Translational Cancer Research, University of Leicester ECMC Network Representative
Dr Claire Foster	Reader in Health Psychology and Head of Macmillan Survivorship Research Group, University of Southampton
Professor Richard Martin	Professor of Clinical Epidemiology and Prostate Cancer lead, NIHR Bristol Nutrition BRU
Professor Peter Johnson	Professor of Medical Oncology, University of Southampton Chief Clinician, CRUK

Appendix 3: Terms of Reference for the management of the Cancer and Nutrition infrastructure collaboration

The following document outlines TORs for the two management organisations of the Cancer & Nutrition NIHR infrastructure collaboration: the Steering Committee and secretariat (initially convened as Phase One Task & Finish group).

Remit of the collaboration

Cancer now represents the major cause of mortality in the UK, and nutritional factors play an important role in the prevention, development and treatment of cancer. While the UK has internationally competitive research in both nutrition and cancer, there is only a relatively small amount on the overlap between the two areas.

The NIHR Southampton Biomedical Research Centre (BRC) has recognised the need to engage with interdisciplinary stakeholders to bring coherence to existing activities and provide a coordinated framework as a basis for future research into nutrition and cancer. The BRC is undertaking a mapping exercise to capture the existing work on nutrition and cancer in the UK and this information will be used to develop a strategic approach to further translational research.

These activities come under the Cancer and Nutrition NIHR infrastructure collaboration, as coordinated by NOCRI. A formal review of the collaboration will take place in April 2016.

Steering Committee

Constitution and overall purpose
The agreed roles of the Steering Committee are:

1. To develop a strategy and overall vision for the Cancer & Nutrition NIHR infrastructure collaboration.
2. To work with interested parties across the NIHR clinical research infrastructure and other key stakeholders to define the scope and priorities of the collaboration.
3. To develop and deliver a project plan, including defined work streams and communication plan, which aligns with the overall goals of NIHR, NOCRI, WCRF UK and Cancer Research UK and those of other key stakeholders.
4. To ensure appropriate public and patient involvement and engagement during development and delivery of the strategy.
5. To develop capacity and expertise in key areas in order to deliver the overall vision of the collaboration.
6. To assess and monitor progress of the collaboration against the strategy, reporting to NOCRI, who report information to DH.
7. To ensure effective communication of successes and deliverables of the collaboration through appropriate routes.
8. To use influence and authority to assist the collaboration in achieving its outcomes.
9. Establish work streams and / or Task and Finish Group to deliver work that are defined by the Steering Committee

Organisation, meeting frequency and reporting
The Steering Committee will report to NOCRI, who will keep DH updated. It will meet quarterly.

Responsibilities

The responsibilities of the Chair are as follows:

1. Chair will set the agenda for each meeting.
2. Chair will ensures that agendas and supporting materials are delivered to members in advance of meetings.
3. Chair will make the purpose of each meeting clear to members and explains the agenda at the beginning of each meeting.

4 Chair will keep the meeting moving by putting time limits on each agenda items and keeping all meetings to two hours or less.

5 Chair will encourage broad participation from members in discussion by calling on different people.

6 Chair will clarifiy and summarise key outcomes, decisions and actions resulting from the meeting.

7 Chair will approve meeting minutes promptly for circulation to all members and key stakeholders.

The responsibilities of the members are as follows:

1 Members are expected to represent their infrastructure organisations and to work between meetings to ensure they bring an aligned and cohesive view, which is representative of their peers.

2 Members are expected to disseminate information shared at the meeting with the infrastructure organisations they represent.

3 Members should take a genuine and active interest in the collaboration's outcomes and overall success, including ensuring actions are completed within agreed deadlines.

4 Members should act on opportunities to communicate positively about the collaboration.

Membership

Members are selected from among the NIHR infrastructure and other funders with a focus on cancer and/or nutrition, diet and lifestyle. Others may be invited to attend as necessary.

The SC will be supported/serviced by a secretariat (Phase One Task & Finish as interim)

Alan Jackson (Chair)
Former director, NIHR Southampton BRC

Lucy Allen
NOCRI

Kate Allen
WCRF International and WCRF UK

Karen Brown
ECMC Network

Helen Campbell
DH

Ramsey Cutress
NIHR Southampton BRC

Anne Helme
CRUK

Richard Martin
NIHR Bristol Nutrition BRU

Fehmidah Munir
NIHR Leicester-Loughborough BRU

Elio Riboli
NIHR Imperial BRC

Rowena Sharpe
NIHR Royal Marsden BRC

Lesley Turner
Patient representative

In Attendance

Carrie Bolt
NIHR Southampton BRC

Lauren Chapman
NOCRI

Arabella Hayter
NIHR Southampton BRC

Yi Lu
NIHR Southampton BRC

Steve Wootton
NIHR Southampton BRC

Martin Wiseman
NIHR Southampton BRC & WCRF International

Phase One Task & Finish Group/Secretariat

Constitution and overall purpose

The agreed roles of the Task and Finish Group are to:

1. Be responsible for implementation of the project
2. Carry out work packages defined by the Steering Committee
3. Work collaboratively with NOCRI
4. Facilitate the ambition of the collaboration
5. Act as secretariat to the Steering Committee

Meeting frequency

The Group will meet monthly or as required.

Membership

Membership will comprise of nominees from across Southampton BRC and the wider collaboration.

1. Alan Jackson (Chair)
2. Martin Wiseman (NIHR Southampton BRC, Lead for Nutrition; WCRF International, Medical and Scientific Adviser)
3. Carrie Bolt (NIHR Southampton BRC, Manager)
4. Ramsey Cutress (NIHR Southampton BRC, General Surgeon/Associate Professor)
5. Steve Wootton (NIHR Southampton BRC, Lead for Infrastructure)
6. Arabella Hayter (NIHR Southampton BRC, Project Manager)
7. Yi Lu (NIHR Southampton BRC, Research Assistant)

On completion of Phase One, the Task and Finish group will be dissolved and replaced by a Secretariat. Additional Task and Finish groups may be convened for specific work streams as required. The roles of the Secretariat will be as per the Task and Finish group.

Appendix 4: Report from the NCRI Annual Conference, November 2014

Engaging national stakeholders to align current activities and provide a coordinated framework for future research

Introduction

The Cancer and Nutrition NIHR infrastructure collaboration initiative took part in the 10th Annual NCRI Conference held in Liverpool from 2nd-5th November 2014. The following document summarises our involvement at the conference and includes some background to the initiative and updates on our progress to date.

We took part in two sessions: the NCRI Consumer Liaison Group (CLG) Dragons' Den and hosted a workshop. These two sessions were part of an on-going process to engage with national stakeholders, establish collaborative working and provide directions for future research.

Cancer & Nutrition workshop (Tuesday November 4th)

The aim of the workshop was three-fold: i) to describe the processes and structures established to oversee the project, ii) to provide an update on progress, including an initial mapping exercise and iii) to invite all interested bodies, institutions and individuals to engage with this initiative, with a view to forming communities of practice as a basis for interdisciplinary work.

The workshop was attended by approximately 60 people. Of these, the majority came from the research community, national and regional cancer charities as well as a number of patient representatives. All those attending the workshop were invited to share their details to begin creating a network of people interested in cancer and nutrition research. The response to the initiative at the workshop was overwhelmingly positive, and everyone agreed that the work was both important and timely.

Presentation

A presentation was given by Professor Martin Wiseman (NIHR Southampton Biomedical Research Centre [BRC] and WCRF UK) and Ms Arabella Hayter (NIHR Southampton BRC). Copies of the presentation slides are available on request. Martin Wiseman began by explaining the scientific background to the initiative and the rationale for its conception.

Arabella Hayter provided an overview of the mapping exercise and some initial results. The mapping is the first part of the initiative and seeks to understand the extent of all existing work in cancer and nutrition in the UK. The mapping exercise is underway and we estimate that it will be completed in January 2015. Using over 100 nutritional keywords (based on WCRF International's 2007 report: Food, Nutrition, Physical Activity and the Prevention of Cancer: A Global Perspective), searches have been conducted on the NCRI database using data from the last five years. All types of studies will be included in the results (clinical, epidemiological, animal and in vitro) across all cancer sites and at all stages (e.g. prevention, treatment, survivorship). Results of the mapping will be available in a final report to be published in spring 2015.

A major part of the mapping exercise is to understand the gaps in nutrition and cancer research. Identified gaps will provide options to develop a strategic approach to further translational research within, and contributing to, the Department of Health's research strategy Better Research for Better Health. These gaps will illustrate opportunities for interdisciplinary collaboration as well as infrastructure, training and other needs. We are seeking input from relevant stakeholders to understand better where these gaps lie.

Panel discussion

The presentation was followed by a panel discussion, chaired by Martin Wiseman with Arabella Hayter, Mr Ramsey Cutress and Dr Ellen Copson (both from NIHR Southampton BRC and University of Southampton). The audience were invited to ask questions on three themes, i) major gaps in current research, ii) priorities for future research and iii) feedback of the Cancer & Nutrition initiative and mapping exercise.

We received a range of questions asking for specific clinical advice, for example 'what diet should be followed after a nephrectomy?' and 'what evidence is there of the beneficial effects of white/green tea and their constituent epigallo-catechins?' Unfortunately, we are not able to provide answers to specific clinical questions which fall outside of the remit of this initiative. However, these questions highlight important issues, such as: who is qualified to answer patient questions? where do people currently go for advice? what is the quality and consistency of the information they receive? and is it evidence-based? These questions will be considered throughout the process and recommendations for future research to try to answer these questions will be incorporated into our final report.

The mapping exercise

Will you be including results from other countries in the mapping?

The primary objective of this initiative is to map out all of the research activity in the UK. While it would be interesting to include work from overseas, we must be realistic about what we can achieve within the scope of the project and its funding. Once we have successfully mapped the existing research from the UK, we aim to highlight where the main gaps are within the context of international work.

You are solely using the NCRI database which only includes funding awards, not publications. Will you also include publications in the mapping? We have decided to use the NCRI database as it includes over 90% of the cancer research in the UK (as calculated by NCRI using data from its partners). This strategy will capture ongoing research, regardless of whether it has been published, which should also minimise potential publication bias. In addition, through ongoing consultation with stakeholders, we expect to be able to capture other important research activities that may not be included in the NCRI database. Once we have completed the mapping, we will do a cross-check with a selection of known research to ensure it has been captured by our search strategy.

By only using NCRI data, will you miss studies that don't have an explicit focus on cancer and nutrition?

We must be pragmatic and seek to achieve a balance between coverage and granularity to complete the mapping within a short timeframe. We have developed a comprehensive list of nutritional search terms which contains over 100 nutrition keywords and are confident that these will pick up the most important research. At this stage we are only including studies with nutrition as a predefined objective; it will not be possible to include the large number of studies which look at nutrition as a secondary objective.

There are so many silos of data available. How will you ensure that you are capturing the right data? This project highlights the need for effective data sharing so that researchers and patients can get access to a range of data types and sources. We are creating an Access database to record the results of the mapping; we will be making this publicly available once it is completed. We hope this will be the first step to enable a more collaborative approach to research.

We appreciate the audience's feedback and suggestions which will help to ensure that the mapping exercise is carried out appropriately and effectively. We will amend our search strategy where appropriate.

What are the major gaps in nutrition and cancer research to date?

While many epidemiological and mechanistic studies are undertaken, has the mapping identified a lack of clinical studies? Since there are virtually no randomised controlled trials in cancer, will the mapping acknowledge this gap?

Clinical trials are undoubtedly the hardest part of research to carry out. In particular, it is harder to conduct RCTs in areas where there is a lack of guidance, for example chemotherapy dose-intensity in obese patients. At present, this is calculated according to kilogram bodyweight/per day which does not take into account any consideration of body composition. In addition, there is a lack of

good evidence on the effects of different types of body mass on cancer development as well as treatment. This is a gap for future research that has already been identified through the mapping exercise; as a result, there are plans to develop a nutrition 'toolkit' in Southampton.

The NCRI Consumer Liaison Group's Dragons' Den Run by the NCRI Consumer Liaison Group (CLG), and supported by Cancer Research UK, the session was an informal, open table forum designed to get consumer involvement and feedback for research. Our particular objective for taking part was to involve consumers in developing the strategy for this initiative, to listen to the consumer voice on research needs and to learn about their experience of participating in cancer and nutrition research. We believe that PPI is an important aspect of this work and we will be seeking to engage consumers more formally throughout the initiative.

Ten 'dragons' sat at our table, from a range of backgrounds including NCRI Clinical Studies Groups, charities, patients and carers. We began by asking the dragons about their experiences of nutritional support during the cancer process; reports were of inadequate, patchy, contradictory and impractical advice, often focused on magic bullets or 'quackery'. It was also evident that post-operative nutritional support is lacking in hospitals; meals are often poor quality, inappropriately sized and do not take into account patients' individual needs.

Patients would like better nutritional guidance in a number of areas, including prevention (particularly for those with genetic susceptibility), post-treatment and for physical activity. They would like simple, evidence-based advice which clinicians and patients could refer to. As consumers, the dragons have found it hard to filter advice to know which is bona fide and can be trusted; they would like quality control criteria which could be applied to research so they know which sources can be trusted.

We discussed how to engage industry in the initiative and received some helpful suggestions. Participants also recommended a number of relevant organisations and individuals working in nutrition and cancer research to involve; we will be following up with these people in the coming weeks.

We greatly appreciate the support and involvement of the dragons in the initiative and will be incorporating their suggestions into our work as we go forward.

How can you get involved?

If you were unable to attend the workshop and would like to register your interest in the initiative, or have feedback on any other aspect of our work, please get in touch with Arabella Hayter, Project Manager, on cancer_nutrition@nihr.ac.uk.

New website

We now have a Cancer and Nutrition website. You will find more information on the initiative, an opportunity to sign up to our mailing list and an online discussion forum. We encourage you to sign up and become an active member of the collaboration. You can access the website here: www.nihr.ac.uk/cancer-nutrition

Patient Experience Survey

We will be launching a survey in the coming weeks for patients. We would like to ask patients about their experience of nutritional support, advice and care throughout all stages of the cancer process. We want to understand a range of issues, including: what are the nutritional and dietetic needs for patients as they go through diagnosis, treatment and post-treatment? Are patients being given consistent, evidence-based advice? What other nutritional advice would patients like to receive?

The survey will be available on the website in the coming weeks. Please visit the website later in December and complete the survey online, or alternatively, if you wish to register your interest to take part when the survey is available, please contact us on www.cancerandnutrition.nihr.ac.uk

List of Attendees at the NCRI Cancer & Nutrition workshop

Name			Organisation
Dr	Farzaad	Amirabdollahian	Associate for Nutrition & Liverpool Hope University
Dr	Alyson	Huntley	Bristol University
Miss	Wenji	Guo	Cancer Epidemiology Unit, Oxford
Dr	Ruth	Travis	Cancer Epidemiology Unit, Oxford
Prof	Tim	Key	Cancer Epidemiology Unit, Oxford
Mrs	Pam	Smith	Cancer Forum, Group 23 (Patients)
Dr	Paula	Berstad	Cancer Registry of Norway
Dr	Katherine	White	Christie NHS Trust
Mrs	Jacqui	Gath	CRP
Mr	Tom	Stansfeld	CRUK
Dr	Haoran	Tang	CRUK Manchester Institute
Ms	Clare	McManus	CRUK Manchester Institute
Dr	Helen	Campbell	Department of Health
Ms	Elliann	Fairbairn	Early Phase Trials and Nutrition
Mr	Christopher	Khuoge	Greenwich University (PhD Student)
Miss	Dalia	Ismail	Institute of Cancer Research
Prof	Richard	Mithen	Institute of Food Research
Mr	John	Reeve	Leukaemia & Lymphoma Research and Haematological Oncology CSG
Mr	Nicolas	Lee	MacMillan Cancer Support
Dr	Jeanette	Marketon	MRC
Ms	Lynn	Maslen	MRC-NIHR National Phenome Centre, Imperial College London
Dr	Angela	McCullagh	NCRI board (Lay member)
Mr	Jim	Elliott	NETSCC Public Involvement Ref Group (Co-chair) & CRUK Public Involvement
Mrs	Victoria	Nnatuany	NIHR Consumer Liaison Group (Associate member)
Dr	Sarah	Chilvers	Pancreatic Cancer UK
Miss	Amy	Dyer	Prostate Cancer UK
Dr	Yunyun	Gong	Queen's University Belfast
Miss	Alison	Chilvers	South Tees Hospital NHS Trust
Ms	Andrea	Corkhill	Southampton Clinical Trials Unit
Mrs	Louise	Little	Southampton Clinical Trials Unit
Prof	Jane	Wardle	University College London
Prof	Annie	Anderson	University of Dundee
Dr	Gillian	Smith	University of Dundee
Prof	Karen	Brown	University of Leicester
Dr	Lee	Machado	University of Northampton
Prof	Diana	Eccles	University of Southampton
Mr	Nicholas	Morgan	Word on Nutrition

Appendix 5: NCRI Consumer Liaison Group Dragons' Den at the NRCI Conference

A summary of the Cancer & Nutrition NIHR infrastructure collaboration initiative's involvement 3rd November 2014

The Cancer and Nutrition NIHR infrastructure collaboration participated in the Dragons' Den session at the NCRI Conference. Hosted by the NCRI Consumer Liaison Group, the session was an informal, round table discussion designed to enable researchers to get feedback from consumers on their research. The following document is a non-verbatim transcript and overview of the session; italicised words are quotes from participants.

Ramsey Cutress, Arabella Hayter, Yi Lu facilitated the discussions. The session was attended by 10 participants (9 of which were consumers themselves) and representing a range of backgrounds including CSGs (Colorectal; Haematological Oncology; Supportive and Palliative Care), charities (Lymphoma & Leukaemia Research; Trekstock - for post-cancer patients aged 18-30years; Tenovus), patients (cervical; colon; breast) and carers.

Introductions

RIC and AH introduced the session and thanked people for coming. AH asked for verbal consent to record the discussion which everyone agreed to. AH described the aims and objectives of the session and YL provided an update of the mapping exercise. RIC explained the definition of nutrition used in the initiative and explained that our work would be covering all cancer sites and stages of cancer research (prevention, treatment etc.).

Methodology of the mapping exercise

Are you looking at international data as well as the UK? Once you have the map, how will you fill in the gaps? Will you include Cochrane reviews?

RIC and AH described the need for coverage vs. granularity.

RIC described that the ultimate aim is to provide a map of the UK's research; we will then be guided by what is happening overseas to make recommendations for opportunities for future work in the UK. There was general enthusiasm for the initiative, and a sense that this is a huge piece of work and it is optimistic to try to complete it within the time frame.

Outcome: Everyone agreed that there is a clear need to complete this piece of work.

You could use Public Health masters students to do SLRs and engage young scientists. Recently there was a gap analysis for breast cancer which you could consult to see how it was done.
Outcome: Read breast cancer gap analysis.

Dietary advice and patient experience

What dietary advice is given to people when they've had cancer in the UK? What evidence is it based on? (Tenovus member). Having had a total gastrectomy, I received a lot of formulaic advice. Care from surgeons was exceptional but nutrition and dietitians were not good. Something needs to be done about this. I also find in supermarkets it is hard to buy food for one person, my appetite is tiny now and it is hard to cater for this (Colorectal CSG member/colon cancer patient).

Discussion around the table suggested advice varies greatly depending on where in the country you are and which cancer you have had. RIC suggested that advice needs be based on better evidence and that this is an obvious gap highlighted during the initial mapping and consultation process.

Outcome: There is a clear need for more consistent, evidence-based advice.

It would be useful for you to pull together a number of patients' stories about the advice they have been given so that we can see how consistent it is. People are very vulnerable to believing in magic bullets, which is dangerous.

This prompted a discussion about advice given to patients. One person felt magic bullets were useful as it gave people a sense of control: patients need something they can 'do' during the cancer process. Another patient said she was given no advice about what to eat when recovering from her cancer. Others described the food they were given post-operatively and said it was unsuitable, for example

one patient said the first meal they received in hospital was a complete three course meal and no consideration was given to her having just had a complete gastrectomy.

Outcome: There is a need for dietary advice for post-operative cancer patients.

There is a need to understand what is happening for patients now and what patients think are priorities for the future in terms of nutrition. Don't you need to do some research to find that out?

RIC and AH explained that the Dragons' Den session was the first part of an on-going consultation process to understand better patients' needs at all stages of cancer. RIC asked if this should be done more formally and everyone agreed that is should. The Dragons' suggested trying to engage formally with charities as they would be keen to be involved and would be keen to be involved. Someone also suggested accessing the UK's BioBank unit database, which includes lots of lifestyle data.

Outcome: There is an identified need for consulting patients formally as part of this process.

Young people with cancer are particularly susceptible to 'quack' advice and to detoxing. It is important to tell people that while detoxing may help, it's not the answer to the problem. Young people are sold many different concoctions, seeds and supplements. It is important to make sure people know there is a balance. How do you sift through 'quack' advice, for example superfoods and supplements. People are very vulnerable to that guidance.

Evidence should be funded and on the NCRI database, have been peer reviewed by a major charity, published after peer review, or accepted as an NCRI portfolio study. That should be the quality control.

Patients would find that helpful, to know that the source is bonafide, rather than searching on the internet. We ask our clinicians a lot, 'what should we eat? what should we avoid?' It would be good if there was a leaflet which gave specific guidance to patients post treatment and included specific food groups to eat and foods to avoid. It is very hard as a consumer to sift through the evidence. Could you get the supermarkets involved in this initiative?

Outcome: We could include quality control criteria in the mapping. It would be worth exploring options for this.
What are the NICE guidelines for nutrition and cancer? I think you should write a set of NICE guidelines that patients and clinicians can access.

RIC said there are generic NICE guidelines for nutrition in critical illness, rather than specifically for cancer. This lack may be because currently there isn't enough evidence to produce recommendations. There may be some for specific diseases, for example nutrition post colon cancer surgery.

Outcome: Do a quick review of available NICE guidelines.

If people are predisposed to cancer genetically, how should we give dietary advice to those people to prevent them from getting cancer?

RIC said that this is a huge gap in knowledge. Many cancers are polygenic so it is hard to give a definite answer.

Research gaps

Will you be looking at the effect of vitamin D on melanoma and whether this is better from sunlight or from supplements? Do you count supplements as nutrition? What about smoking? It is interesting that alcohol is included in your definition of nutrition.

RIC stressed that the purpose of this exercise is not to do the research ourselves but to map out existing research. Any research currently taking place on vitamin D would be included in the mapping. RIC explained the comprehensive definition of nutrition that we are using in the mapping exercise. We are still deciding whether smoking should be included.

Outcome: Not everyone's definition of nutrition is the same and this must be made clear at the beginning of the final report, and in reference to any future recommendations.

What exercise produces the best nutritional absorption? Macmillan is doing a lot on exercise.

This is the other side of the equation. We need to consider metabolism and physical activity; not just running but active living, and recommendations that are practical for people. (One participant had

recently finished taking part in a study run by Southampton wearing a wrist bands for 7 days). There is a really good trial about exercise for cancer patients post-treatment which can't get funding anywhere. If you have heart problems or diabetes, you can go along to local hospitals and use the facilities, but it is hard to get a foot in the door for cancer patients. (Colorectal CSG member).

We are piloting a new study on exercise for young adults with the YMCA. At different life stages, cooking for one, young people often don't have the skills to cook and need age appropriate exercise (Trekstock representative).

Outcome: We should try to produce recommendations for where we think research should go, which may help with funding. Where there is sufficient evidence, we should aim to produce recommendations of where research should be done to guide policy.

Patient engagement

You could do focus groups in GP surgeries as they are a captive audience.

One participant is a member of the East of England region clinical senate and citizens senate. We could take this forward on your behalf. We have a number of meetings you could piggyback onto which we could then disseminate through, into PPGs(?).

Surely you need qualitative and quantitative data. You could put a survey on your website to ask patients about their experiences of nutrition and cancer advice.

Outcome: Consider quantitative research tools as part of the consultation process and to inform recommendations. This would be a long term goal after the mapping has been conducted in 2015.

Will the information you find be put onto a website?

We will be developing a website as a platform for sharing information and create a community of practice as a longer term output. In the immediate term, we will be writing a summary report collating the information from consumers, as well as the workshop and circulating it to everyone who has expressed interest in the initiative.

Outcome: Develop website, ensure that information is disseminated widely.

Summary and end

RIC and AH thanked people for taking part. They invited participants to attend the workshop the following day and to send any further questions or feedback in to the project email address. All participants were asked to give their names to continue the engagement process.

Appendix 6: Patient Experience Survey

Note: the formatting of the original online version of the survey is not available in offline format - the following document provides an annotated version of the questions.

About you

Are you a patient or carer?

- ☐ Patient
- ☐ Carer

If you are a carer, please fill in ALL questions on behalf of the patient.

Are you male or female?

- ☐ Male
- ☐ Female

How old are you?

- ☐ <15
- ☐ 15-19
- ☐ 20-24
- ☐ 25-29
- ☐ 30-39
- ☐ 40-49
- ☐ 50-59
- ☐ 60-69
- ☐ 70-79
- ☐ 80+
- ☐ Prefer not to say

What area of the UK do you live in?

- ☐ North East
- ☐ North West
- ☐ Yorkshire and the Humber
- ☐ East Midlands
- ☐ West Midlands
- ☐ East of England
- ☐ London
- ☐ South East Coast
- ☐ South Central
- ☐ South West
- ☐ Scotland
- ☐ Wales
- ☐ Northern Ireland
- ☐ Outside of the UK

4a) What stage is/was your cancer?

- ☐ Early (potentially curable)
- ☐ Advanced

4b) Which of the following best describes your situation?

Please tick which one applies.

- ☐ I have received a diagnosis and am due to start treatment
- ☐ I am under active surveillance/watch and wait but have not started receiving treatment
- ☐ I am currently receiving treatment
- ☐ I have finished treatment and am currently being monitored
- ☐ I am receiving treatment for my symptoms but I am no longer receiving active treatment for my cancer

5) When were you diagnosed with cancer?

Fill in as mm/yyyy.

Please provide the year and month if you can remember.

If you can't remember the month, please write 01/yyyy

_____

6) What type(s) of cancer were you diagnosed with?

Please tick all that apply

- ☐ Anus
- ☐ Bladder
- ☐ Blood, bone marrow & lymph
- ☐ Bone
- ☐ Brain
- ☐ Breast
- ☐ Endometrium
- ☐ Gall bladder / bile duct
- ☐ Kidney
- ☐ Larynx
- ☐ Liver
- ☐ Lung
- ☐ Mouth
- ☐ Muscle
- ☐ Nasopharynx
- ☐ Oesophagus - lower
- ☐ Oesophagus - upper
- ☐ Ovary
- ☐ Pancreas
- ☐ Pharynx
- ☐ Prostate
- ☐ Rectum
- ☐ Salivary gland
- ☐ Skin - melanoma
- ☐ Skin - non melanoma
- ☐ Stomach
- ☐ Colon
- ☐ Testes
- ☐ Thyroid
- ☐ Tonsil
- ☐ Vulva
- ☐ Other:

_____

_____

_____

_____

7) Is this your first cancer diagnosis?

- ☐ Yes
- ☐ No

Nutritional needs in cancer

8) What nutritional problems have you faced as a result of your cancer?

I suffered from this	Yes,	No, I did not suffer from this at any stage
Appetite loss		
Changes in taste/smell		
Nausea/vomiting		
Weight loss		
Weight gain		
Unsure what to eat		
Given conflicting nutritional advice		
Problems with chewing/ eating/swallowing		
Full/part removal of digestive tract (with or without stoma)		
Problems with artificial feeding		
Fistula		
Diarrhoea		
Constipation		
Unable to be physically active		
Other		

8a) If you clicked 'other', please include a brief description of the issue here.

8b) If you would like to add any additional comments about the nutrition problems you experienced, please include them here.

8c) In your opinion what are some of the biggest nutritional or dietetic needs for cancer patients?

Please list as many as you like. Please think about the diagnosis, treatment and after treatment stages.

9) Did you receive any nutrition support in relation to your cancer from your healthcare team?

- ☐ Yes
- ☐ No

For those answering Yes to Q9, they were given the following questions to answer:

Nutrition support from your healthcare team

9a) Which of the following statements best describes the nutrition support you received:

Please tick all that apply

- ☐ I was given some form of written information/advice from my healthcare team
- ☐ I was given some form of face-to-face or telephone assistance from a professional
- ☐ I was put on, or am still on, a special diet
- ☐ I received intravenous feeding (parenteral feeding)
- ☐ I was given a feeding tube (enteral feeding)

Other:

9b) Was this nutrition support offered to you or did you have to ask for it?

- ☐ It was offered to me
- ☐ I had to ask for it

9c) Which of the following professionals did you receive nutrition support from?

Please tick all that apply

- ☐ GP
- ☐ Dietitian
- ☐ Specialised cancer dietitian
- ☐ Nutritionist
- ☐ Specialist (surgeon/oncologist)
- ☐ Nurse
- ☐ Someone, but I don't know what their role was
- ☐ None of the above
- ☐ Other:

10a) Were you provided with any advice about the following at diagnosis?

10b) Were you provided with any advice about the following at treatment?

10c) Were you provided with any advice about the following after treatment?

Note: A separate table (as below) was presented for 10a, b and c

	Yes	No	Don't know
General healthy eating	☐	☐	☐
Specific foods to eat	☐	☐	☐
Foods to avoid	☐	☐	☐
Portion sizes	☐	☐	☐
How to lose weight	☐	☐	☐
How to gain weight	☐	☐	☐
Recipes	☐	☐	☐
Vitamin and mineral supplements	☐	☐	☐
Protein/energy supplements	☐	☐	☐
Other supplements	☐	☐	☐
Physical activity / exercise	☐	☐	☐
Where to find advice online	☐	☐	☐
Nutrition support groups	☐	☐	☐
I received none of the above	☐	☐	☐

10d) If you were told to eat or avoid specific foods, which foods were you told about and why?

10e) If you received any other nutritional advice not mentioned above, please briefly describe what it was about.

10f) What additional nutrition support would you like to have received?

Please mention at what stage of the cancer process this was (e.g. at diagnosis, treatment or after treatment)

Quality and consistency of advice

Note: A separate table (as below) was presented for 11a, b and c

11a) At diagnosis

11b) At treatment

11c) After treatment

	Very poor	Poor	Neither good nor bad	Good	Very good	Not applicable
How well were your nutrition needs met?	☐	☐	☐	☐	☐	☐
How consistent was the advice you received?	☐	☐	☐	☐	☐	☐
How easy was the advice to follow?	☐	☐	☐	☐	☐	☐

12a) Did you receive any advice that you thought was wrong or inappropriate?

☐ Yes

☐ No

12b) If yes, please explain why:

13a) Was the nutrition support you received consistent within your healthcare team?

☐ Yes

☐ No

13b) If not, in what ways was it conflicting?

14a) Was the nutrition support you received consistent between the healthcare team and any advice you found elsewhere?

☐ Yes

☐ No

☐ Not applicable, I did not receive advice from any other sources

14b) If not, in what ways was it conflicting?

For those answering No to Q9, they were given the following questions to answer:

Please fill in this section if you did not receive any nutrition support in relation to your cancer

9) If you did not receive any nutrition support why was this the case?

- ☐ I chose not to receive any
- ☐ I wasn't offered any
- ☐ I didn't know it existed
- ☐ I didn't know how to access it
- ☐ I didn't think nutrition was important
- ☐ Not applicable as I received some
- ☐ form of nutrition support
- ☐ Other:

10) What nutrition support would you like to have received?

Please mention at what stage of the cancer process this was at (e.g. at diagnosis, treatment or after treatment)

The survey will now take you to Q15. (Q11-14 are not applicable if you did not receive any nutrition support)

All respondents were given the following questions to answer:

Other sources of nutrition support

15a) Did you receive face-to-face or telephone advice about nutrition from any of the following?

Please tick all that apply

- ☐ Cancer support group
- ☐ Cancer charity
- ☐ Other patient
- ☐ Family memberFriend
- ☐ I was given no face-to-face or
- ☐ telephone
- ☐ advice Other:

15b) Was this advice helpful?

- ☐ Yes
- ☐ No
- ☐ Not applicable, I did not receive any

15c) Please add any additional comments about this advice you feel may be relevant.

e.g. what was the advice about?

16a) Did you look for written nutritional information online or from another source *(e.g. recipe book)?*

Yes

No

16b) If so, which of the following did you use?

Please tick all that apply

- ☐ Website - cancer charity
- ☐ Website - online medical
- ☐ advice Website - other
- ☐ Leaflet - e.g. from NHS, local health
- ☐ authority
- ☐ Recipe book
- ☐ Book
- ☐ None of the above
- ☐ Other:

16c) Please provide the names of any specific websites or resources that you used.

_____

_____

16d) Please add any additional comments about these resources you feel are relevant.

e.g. were they helpful and why?

_____

_____

17) Were you ever given any of the following additional lifestyle advice in relation to cancer?

Please tick all that apply

- ☐ Increase physical activity/exercise
- ☐ Reduce sun exposure
- ☐ Stop smoking
- ☐ Reduce alcohol consumption
- ☐ I was given no lifestyle advice
- ☐ Other:

18a) What is your opinion of the food you received in hospital?

	Very poor	Poor	Neither good nor bad	Good	Very good	Not applicable
Suitability of food	☐	☐	☐	☐	☐	☐
Nutritional quality	☐	☐	☐	☐	☐	☐
Appropriateness of portion size	☐	☐	☐	☐	☐	☐
Appetising nature of food	☐	☐	☐	☐	☐	☐
Personal preference taken into account	☐	☐	☐	☐	☐	☐

Gaps in nutrition and cancer research

19) In your opinion, what are the major gaps in nutrition research in relation to cancer?

Other comments

20) If you would like to add anything else, please write it in the box below

Thank you for taking part in this survey.

Your answers will be very useful in helping the Cancer and Nutrition NIHR infrastructure collaboration team understand the experiences and needs of patients. If you would like to hear about the results of the survey, or be added to the mailing list for this project, please send an email to cancer_nutrition@nihr.ac.uk and we will keep you up to date with our work. Alternatively, you can sign up to the mailing list online at www.cancerandnutrition.nihr.ac.uk

Appendix 7:
Clinician's Survey

NUTRITION AND CANCER IN THE UK:
A QUICK SURVEY FOR CLINICIANS

This questionnaire is about NUTRITION and CANCER in the UK, and the priorities for research in these areas. Responses are anonymous. It should take approximately 10 minutes to complete - ALL questions are on this one page.

The survey will be available until 27th FEBRUARY 2015. Thank you for your input.

BACKGROUND
The aim is to understand what clinicians think are the biggest gaps in terms of evidence, research and support/care in relation to nutrition and cancer. This will inform work at the NIHR Southampton Biomedical Research Centre, which is leading an initiative to map existing research in nutrition and cancer in the UK.

WHAT DO WE MEAN BY "NUTRITION" AND "NUTRITION SUPPORT" IN THIS CONTEXT?

"Nutrition" refers to all the processes by which the body acquires its energy and nutrients for optimal functioning. This is through dietary supply in all its forms, including food, food replacements and supplements. The amount of energy and nutrients the body requires is influenced by levels of physical activity and is an important part of nutrition. We are also interested in body composition, weight, metabolism, eating and feeding (including artificial feeding).

"Nutrition support" includes any kind of information, advice and care given in relation to nutrition, diet and physical activity that is given to patients at any stage of the cancer process.

ANY QUESTIONS?
If you have problems filling in the form online but would still like to complete the survey, or have any other questions, please email the Nutrition and Cancer Project Manager, on cancer_nutrition@nihr.ac.uk.

What kind of health professional are you?

Please tick one that applies

- ☐ GP
- ☐ Surgeon
- ☐ Oncologist
- ☐ Medical specialist (other)
- ☐ Nurse (cancer)
- ☐ Nurse (general)
- ☐ Dietitian
- ☐ Other:

_____

_____

_____

Is your work clinical or research-based?

- ☐ Purely clinical
- ☐ Purely research
- ☐ Clinical & research

Do you treat patients with cancer as part of your job?

- ☐ Yes
- ☐ No
- ☐ NA (purely research)

Do you actively assess or manage the nutritional status of your patients with cancer?

- ☐ Yes
- ☐ No
- ☐ NA (purely research)

If you answered yes, how do you do it?
Please provide as much detail as possible.

If you do not assess or manage the nutritional status of your patients, why not?

- ☐ No infrastructure to do so
- ☐ Do not feel adequately trained
- ☐ Not of primary importance to my patients
- ☐ Do not feel it is important
- ☐ Other:

Do you regularly provide nutritional support, advice or care to patients with cancer?

- ☐ Yes
- ☐ No
- ☐ NA

If you answered yes, please provide details of the sort of advice you give.
e.g. to who and about what?

In your opinion, what are the top 3 priorities for cancer and nutrition research in the UK?

Number 1:

Number 2:

Number 3:

What barriers, if any, do you think exist in undertaking research in cancer and nutrition?

Please add any other comments about Nutrition and Cancer research in the UK e.g. gaps in knowledge, infrastructure needs, support you need in your current role

END OF SURVEY

Appendix 8: The NCRI database

Data collection

The NCRI is a partnership of 22 UK cancer research funders (who each have a minimum spend of £1,000,000 per year) which promotes collaborative initiatives to address unmet needs in cancer research in the UK. These funders include research councils (e.g. Medical Research Council), government (e.g. Department of Health for England, Chief Scientist Office), charities (e.g. MacMillan, Prostate Cancer UK) and industry (Association of the British Pharmaceutical Industry).

NCRI partners are asked to submit information annually on all of their awards with relevance to cancer (as decided by the partners), including award title, abstract, principal investigator, host institution and financial information. The NCRI Secretariat determines, according to the criteria set out by the coding panel, whether these awards should be included in the NCRI Cancer Research Database. The database excludes awards made to support the purchase of land or buildings for the purposes of research, the building or refurbishment of laboratories, the cost of attending or holding scientific meetings, conferences or training courses, and studies focused on policy or advocacy which do not have a research component. The database also excludes awards made for underpinning costs provided to universities by the four funding councils of the UK, or to hospitals by the NHS.

Data coding

Each award is individually coded using two classification systems: the Common Scientific Outline (CSO) which defines the category of cancer research (e.g. biology or etiology) and the NCRI Cancer Site codes; further information on the CSO and NCRI Cancer Site codes can be found in Appendix 9 and Appendix 10. 'Roll-up' cancer site codes are used for coding awards that are relevant to a particular theme or subsidiary cancer site (e.g. paediatric cancer or smoking-related cancer risk)[16].

NCRI includes a breakdown of spend by cancer site and research category for all awards. Where multiple codes are used, the cost of each award is split proportionally according to amount spent on each area of work. Awards that have only a partial relevance to cancer are still included in the database; for these awards, the funding value is calculated based on the proportion of the study which focuses on cancer. Proportions are decided by trained coders (and then double coded by another NCRI member) based on the award title and abstract. Where an award is jointly funded, costs are apportioned across all funders; any support from non-NCRI partners is excluded from the database.

Quality of NCRI data

When consulted about the data, the NCRI cautioned our interpretation of financial figures, for example where the breakdown of costing (for example according to cancer sites) results in many sites being apportioned a low percentage of the total spend. Although a systematic approach was applied during the coding process and a high degree of coding consistency was reported[17], many inaccuracies in the financial figures were noticed during the mapping exercise due to data entry errors, calculation mistakes and out of date figures.

[16] More information on NCRI coding methods can be found in NCRI's Cancer Research Spent in the UK 2002-2011 report.

[17] The inter-rater reliability co-efficient, known as Cohen's Kappa, showed that agreement between coders for major CSO codes across the ICRP database was 'very good' (0.817) and agreement by CSO sub-code was 'good' (0.649). NCRI, Cancer Research Spend in the UK 2002-2011.

Appendix 9: NCRI Common Scientific Outline coding system

Source link:
https://www.icrpartnership.org/cso.cfm, last accessed March 2015

Awards on the International Cancer Research Partnership (ICRP) database are coded using a common language - the Common Scientific Outline or 'CSO', a classification system organised into seven broad areas of scientific interest in cancer research. The CSO is complemented by a standard cancer site coding scheme. Together, these tools lay a framework to improve coordination among research organisations, making it possible to compare and contrast the research portfolios of public, non-profit, and governmental research agencies.

The Common Scientific Outline, or CSO, is a classification system organised around seven broad areas of scientific interest in cancer research:

- Biology
- Etiology (causes of cancer)
- Prevention
- Early Detection, Diagnosis, and Prognosis
- Treatment
- Cancer Control, Survivorship, and Outcomes Research
- Scientific Model Systems

Biology

Research included in this category looks at the biology of how cancer starts and progresses as well as normal biology relevant to these processes

1.1 Normal Functioning

Examples of science that would fit:

- Developmental biology (from conception to adulthood) and the biology of aging
- Normal functioning of genes, including their identification and expression, and the normal function of gene products, such as hormones and growth factors
- Normal formation of the extracellular matrix
- Normal cell-to-cell interactions
- Normal functioning of apoptopic pathways

1.2 Cancer Initiation: Alterations in Chromosomes

Examples of science that would fit:

- Abnormal chromosome number
- Aberration in chromosomes and genes (e.g., in chronic myelogenous leukaemia)
- Damage to chromosomes and mutation in genes
- Failures in DNA repair
- Aberrant gene expression
- Epigenetics
- Genes and proteins involved in aberrant cell cycles

1.3 Cancer Initiation: Oncogenes and Tumour Suppressor Genes

Examples of science that would fit:

- Genes and signals involved in growth stimulation or repression, including oncogenes (Ras, etc.), and tumour suppressor genes (p53, etc.)
- Effects of hormones and growth factors and their receptors such as oestrogens, androgens, TGF-beta, GM-CSF, etc.

1.4 Cancer Progression and Metastasis

Examples of science that would fit:

- Latency, promotion, and regression
- Expansion of malignant cells
- Interaction of malignant cells with the immune system or extracellular matrix
- Cell mobility, including detachment, motility, and migration in the circulation
- Invasion
- Malignant cells in the circulation, including penetration of the vascular system and extrasavation
- Systemic and cellular effects of malignancy
- Tumour angiogenesis and growth of metastases
- Role of hormone or growth factor dependence/independence in cancer progression

1.5 Resources and Infrastructure

Examples of science that would fit:

- Informatics and informatics networks
- Specimen resources
- Epidemiological resources pertaining to biology
- Reagents, chemical standards
- Education and training of investigators at all levels (including clinicians), such as participation in training workshops, advanced research technique courses, and Master's course attendance. This does not include longer-term research-based training, such as Ph.D. or post-doctoral fellowships

Etiology

Research included in this category aims to identify the causes or origins of cancer -genetic, environmental, and lifestyle, and the interactions between these factors

2.1 Exogenous Factors in the Origin and Cause of Cancer

Examples of science that would fit:

- Lifestyle factors such as smoking, chewing tobacco, alcohol consumption, parity, diet, sunbathing, and exercise
- Environmental and occupational exposures such as radiation, second-hand smoke, radon, asbestos, organic vapours, pesticides, and other chemical or physical agents
- Infectious agents associated with cancer etiology, including viruses (Human Papilloma Virus-HPV, etc.) and bacteria (helicobacter pylori, etc.)
- Viral oncogenes and viral regulatory genes associated with cancer causation

2.2 Endogenous Factors in the Origin and Cause of Cancer

Examples of science that would fit:

- Free radicals such as superoxide and hydroxide radicals
- Genes known to be involved or suspected of being mechanistically involved in familial cancer syndromes; for example, BRCA1, Ataxia Telangiectasia, and APC
- Genes suspected or known to be involved in "sporadic" cancer events; for example, polymorphisms and/or mutations that may affect carcinogen metabolism (e.g., CYP, NAT, glutathione transferase, etc.)

2.3 Interactions of Genes and/or Genetic Polymorphisms with Exogenous and/or Endogenous Factors

Examples of science that would fit:

- Gene-environment interactions
- Interactions of genes with lifestyle factors, environmental, and/or occupational exposures such as variations in carcinogen metabolism associated with genetic polymorphisms
- Interactions of genes and endogenous factors such as DNA repair deficiencies and endogenous DNA damaging agents such as oxygen radicals or exogenous radiation exposure

2.4 Resources and Infrastructure Related to Etiology

Examples of science that would fit:

- Informatics and informatics networks; for example, patient databanks
- Specimen resources (serum, tissue, etc.)
- Reagents and chemical standards
- Epidemiological resources pertaining to etiology
- Statistical methodology or biostatistical methods
- Centres, consortia, and/or networks
- Education and training of investigators at all levels (including clinicians), such as participation in training workshops, advanced research technique courses, and Master's course attendance. This does not include longer term research based training, such as Ph.D. or post-doctoral fellowships

Prevention

Research included in this category looks at identifying interventions which reduce cancer risk by reducing exposure to cancer risks and increasing protective factors. Interventions may target lifestyle or may involve drugs or vaccines

3.1 Interventions to Prevent Cancer: Personal Behaviors That Affect Cancer Risk

Examples of science that would fit:

- Research on determinants of personal behaviors, such as diet, physical activity, sun exposure, and tobacco use, that affect cancer risk
- Interventions to change personal behaviors that affect cancer risk

3.2 Nutritional Science in Cancer Prevention

Examples of science that would fit:

- Quantification of nutrients and micronutrients
- Studies on the effect(s) of nutrients or nutritional status on cancer incidence
- Dietary assessment efforts, including dietary questionnaires and surveys
- Development, characterization, and validation of dietary/nutritional assessment instruments

3.3 Chemoprevention

Examples of science that would fit:

- Chemopreventive agents and their discovery, mechanism of action, development, testing in model systems, and clinical testing

3.4 Vaccines

Examples of science that would fit:

- Vaccines for prevention, their discovery, mechanism of action, development, testing in model systems, and clinical testing

3.5 Complementary and Alternative Prevention Approaches

Examples of science that would fit:

- Discovery, development, and testing of complementary/alternative prevention approaches such as diet, herbs, supplements, or other interventions that are not widely used in conventional medicine or are being applied in different ways as compared to conventional medical uses
- Hypnotherapy, relaxation, transcendental meditation, imagery, spiritual healing, massage, biofeedback, etc., used as a preventive measure

3.6 Resources and Infrastructure Related to Prevention

Examples of science that would fit:

- Informatics and informatics networks; for example, patient databanks
- Specimen resources (serum, tissue, etc.)
- Epidemiological resources pertaining to prevention
- Clinical trials infrastructure
- Statistical methodology or biostatistical methods
- Centres, consortia, and/or networks
- Education and training of investigators at all levels (including clinicians), such as participation in training workshops, advanced research technique courses, and Master's course attendance. This does not include longer term research based training, such as Ph.D. or post-doctoral fellowships.

Early Detection, Diagnosis, and Prognosis

Research included in this category focuses on identifying and testing cancer markers and imaging methods that are helpful in detecting and/or diagnosing cancer as well as predicting the outcome or chance of recurrence

4.1 Technology Development and/or Marker Discovery

Examples of science that would fit:

- Discovery of markers (e.g., proteins, genes), and/or technologies (such as fluorescence, nanotechnology, etc.) that are potential candidates for use in cancer detection, staging, diagnosis, and/or prognosis
- Use of proteomics, genomics, expression assays, or other technologies in the discovery of markers

4.2 Technology and/or Marker Evaluation With Respect to Fundamental Parameters of Method

Examples of science that would fit:

- Development, refinement, and preliminary evaluation (e.g., animal trials and Phase I human trials)
- Preliminary evaluation with respect to laboratory sensitivity, laboratory specificity, reproducibility, and accuracy
- Research into mechanisms assessing tumour response to therapy at a molecular or cellular level

4.3 Technology and/or Marker Testing in a Clinical Setting

Examples of science that would fit:

- Evaluation of clinical sensitivity, clinical specificity, and predictive value (Phase II or III clinical trials)
- Quality assurance and quality control
- Inter- and intra-laboratory reproducibility
- Testing of the method with respect to effects on morbidity and/or mortality
- Study of screening methods, including compliance, acceptability to potential screenees, and receiver-operator characteristics
- Research into improvements in techniques to assess clinical response to therapy

4.4 Resources and Infrastructure Related to Detection, Diagnosis, or Prognosis

Examples of science that would fit:

- Informatics and informatics networks; for example, patient databanks
- Specimen resources (serum, tissue, images, etc.)
- Clinical trials infrastructure
- Epidemiological resources pertaining to risk assessment, detection, diagnosis, or prognosis
- Statistical methodology or biostatistical methods
- Centres, consortia, and/or networks
- Education and training of investigators at all levels (including clinicians), such as participation in training workshops, advanced research technique courses, and Master's course attendance. This does not include longer term research based training, such as Ph.D. or post-doctoral fellowships

Treatment

Research included in this category focuses on identifying and testing treatments administered locally (such as radiotherapy and surgery) and systemically (treatments like chemotherapy which are administered throughout the body) as well as non-traditional (complementary/alternative) treatments (such as supplements, herbs). Research into the prevention of recurrence is also included here

5.1 Localized Therapies - Discovery and Development

Examples of science that would fit:

- Discovery and development of treatments administered locally that target the organ and/or neighbouring tissue directly, including but not limited to surgical interventions and radiotherapy
- Therapies with a component administered systemically but that act locally (e.g., photodynamic therapy, radioimmunotherapy and radiosensitizers)
- Development of methods of drug delivery
- Research into the development of localized therapies to prevent recurrence

5.2 Localized Therapies - Clinical Applications

Examples of science that would fit:

- Clinical testing and application of treatments administered locally that target the organ and/or neighbouring tissue directly, including but not limited to surgical interventions and radiotherapy
- Clinical testing and application of therapies with a component administered systemically but that act locally (e.g., photodynamic therapy and radiosensitizers)
- Phase I, II, or III clinical trials of promising therapies that are administered locally
- Side effects, toxicity, and pharmacodynamics
- Clinical testing of localized therapies to prevent recurrence

5.3 Systemic Therapies - Discovery and Development

Examples of science that would fit:

- Discovery and development of treatments administered systemically such as cytotoxic or hormonal agents, novel systemic therapies such as immunologically directed therapies (vaccines,

antibodies), gene therapy, angiogenesis inhibitors, apoptosis inhibitors, and differentiating agents
- Defining molecular signatures of cancer cells
- Identifying molecular targets for drug discovery. Includes mechanistic studies of cellular metabolism, combinatorial chemical synthesis, drug screening, development of high-throughput assays, and testing in model systems
- Investigating the molecular mechanisms of drug resistance and pre-clinical evaluation of therapies to circumvent resistance
- Development of methods of drug delivery
- Research into the development of systemic therapies to prevent recurrence

5.4 Systemic Therapies - Clinical Applications

Examples of science that would fit:

- Clinical testing and application of treatments administered systemically such as cytotoxic or hormonal agents, novel systemic therapies such as immunologically directed therapies (vaccines, antibodies), gene therapy, angiogenesis inhibitors, apoptosis inhibitors, and differentiating agents
- Phase I, II, or III clinical trials of promising therapies administered systemically
- Side effects, toxicity, and pharmacodynamics
- Clinical testing of systemic therapies to prevent recurrence

5.5 Combinations of Localized and Systemic Therapies

Examples of science that would fit:

- Development and testing of combined approaches to treatment
- Clinical application of combined approaches to treatment such as systemic cytotoxic therapy and radiation therapy
- Development and clinical application of combined localized and systemic therapies to prevent recurrence

5.6 Complementary and Alternative Treatment Approaches

Examples of science that would fit:

- Discovery, development, and clinical application of complementary/alternative treatment approaches such as diet, herbs, supplements, natural substances, or other interventions that are not widely used in conventional medicine or are being applied in different ways as compared to conventional medical uses
- Complementary/alternative approaches to the prevention of recurrence (please note that primary prevention using complementary or alternative approaches should be coded under 3.5)

5.7 Resources and Infrastructure Related to Treatment and the prevention of recurrence

Examples of science that would fit:

- Informatics and informatics networks; for example, clinical trials networks and databanks
- Mathematical and computer simulations
- Specimen resources (serum, tissue, etc.)
- Clinical trial groups
- Epidemiological resources pertaining to treatment
- Statistical methodology or biostatistical methods
- Drugs and reagents for distribution and drug screening infrastructures
- Centres, consortia, and/or networks
- Education and training of investigators at all levels (including clinicians), such as participation in training workshops, advanced research technique courses, and Master's course attendance. This does not include longer-term research-based training, such as Ph.D. or post-doctoral fellowships

Cancer Control, Survivorship, and Outcomes Research

Research included in this category includes a broad range of areas: patient care and pain management; tracking cancer cases in the population; beliefs and attitudes that affect behaviour regarding cancer control; ethics, education and communication approaches for patients and health care professionals; supportive and end-of-life care; and health care delivery in terms of quality and cost effectiveness

6.1 Patient Care and Survivorship Issues

Examples of science that would fit:

- Quality of life
- Pain management
- Psychological impacts of cancer survivorship

- Rehabilitation
- Reproductive issues
- Long-term morbidity
- Symptom management, including nausea, vomiting, lymphedema, neuropathies, etc.
- Prevention of treatment-related toxicities and sequelae, including symptom management, prevention of mucosities, prevention of cardiotoxicities, etc.

6.2 Surveillance

Examples of science that would fit:

- Epidemiology and end results reporting (e.g., SEER)
- Surveillance of cancer risk factors such as diet, body weight, physical activity, sun exposure, and tobacco use
- Analysis of variations in risk factor exposure by demographic or other factors
- Registries that track incidence, morbidity, and/or mortality related to cancer
- Trends in use of interventional strategies
- Method development for risk factor surveillance

6.3 Behaviour

Examples of science that would fit:

- Behavioural medicine research and interventions
- nfluence of social factors such as community, policy, education, and legislation, on behaviours related to cancer control
- Attitudes and belief systems and their influence on psychological health and on behaviours related to cancer control. For example, how beliefs can alter attempts to seek screening, detection, and treatment
- Interventions to change attitudes and beliefs that affect behaviour related to cancer control and cancer outcomes
- Influences of attitudes and beliefs on compliance with treatment and prevention protocols
- Psychological or educational interventions to promote behaviours that lessen treatment-related morbidity and promote psychological adjustment to the diagnosis of cancer and to treatment effects
- Burdens of cancer on family members/caregivers and psychological/behaviour issues

6.4 Cost Analyses and Health Care Delivery

Examples of science that would fit:

- Analyses of the cost effectiveness of methods used in cancer prevention, detection, diagnosis, prognosis, treatment, and survivor care/support
- Development and testing of health service delivery methods
- Interventions to increase the quality of health care delivery
- Impact of organisational, social, and cultural factors on access and quality of care
- Studies of providers such as geographical or care-setting variations in outcomes
- Effect of reimbursement and/or insurance on cancer control, outcomes, and survivorship support
- Access to care issues
- Health services research, including health policy and practice
- Analysis of health service provision, including the interaction of primary and secondary care; cost-effectiveness of treatments

6.5 Education and Communication

Examples of science that would fit:

- Development of communication tools and methods
- Education of patients, health care providers, at-risk populations, and the general population about cancer
- Communication to patients regarding therapeutic options
- Educational interventions to promote self-care and symptom management
- Communicating cancer risk to underserved populations, at-risk populations, and the general public
- Alternative teaching methods to communicate therapeutic options and risk-reduction behavior to patients and the general public
- Communication of lifestyle models that reduce cancer risk, such as communication of nutritional interventions
- Communicating smoking and tobacco cessation interventions
- Special approaches and considerations for underserved and at-risk populations
- Education, information, and prevention/screening/assessment systems for

the general public, primary care professionals, or policy makers
- Training, predictive cancer models, pain management, and surveillance systems for primary care professionals, telehealth/telemedicine applications
- Communication regarding cancer genetics, managed oncology care, and communicating with survivors
- Barriers to successful health communication

6.6 End-of-Life Care

Examples of science that would fit:

- End-of-life care issues, including palliative care, psychological interventions with families at end of life, hospice care, and pain management for
- Ethics and Confidentiality in Cancer Research
- Examples of science that would fit:
- Informed consent modelling and development
- Quality of Institutional Review Boards (IRBs)
- Protecting patient confidentiality and privacy
- Research ethics

6.8 Complementary and Alternative Approaches for Supportive Care of Patients and Survivors

Examples of science that would fit:

- Hypnotherapy, relaxation, transcendental meditation, imagery, spiritual healing, massage, biofeedback, etc., as used for the supportive care of patients and survivors
- Discovery, development, and testing of complementary/alternative approaches such as diet, herbs, supplements, or other interventions that are not widely used in conventional medicine or are being applied in different ways as compared to conventional medical uses

6.9 Resources and Infrastructure Related to Cancer Control, Survivorship, and Outcomes Research

Examples of science that would fit:

- Informatics and informatics networks
- Clinical trial groups related to cancer control, survivorship, and outcomes research
- Epidemiological resources pertaining to cancer control, survivorship, and outcomes research
- Statistical methodology or biostatistical methods
- Surveillance infrastructures
- Centres, consortia, and/or networks
- Psychosocial, economic, political and health services research frameworks and models
- Education and training of investigators at all levels (including clinicians), such as participation in training workshops, advanced research technique courses, and Master's course attendance. This does not include longer-term research-based training, such as Ph.D. or post-doctoral fellowships

Scientific Model Systems

Research included in this category looks at the development of new animal models, cell cultures and computer simulations and their application to other studies across the spectrum of cancer research

7.1 Development and Characterization of Model Systems

Examples of science that would fit: Development and characterization of model systems, including but not limited to:

- Computer-simulation model systems and computer software development
- In vitro models systems
- Cell culture model systems
- Organ and tissue model systems
- Animal model systems such as drosophila and c. elegans, zebra fish, mouse, etc.

7.2 Application of Model Systems

Examples of science that would fit:

- Research into new ways of applying model systems, including but not limited to:
- Computer simulation model systems and computer software development
- In vitro models systems
- Cell culture model systems
- Organ and tissue model systems
- Animal model systems such as drosophila and c. elegans, zebra fish, mouse, etc.

7.3 Resources and Infrastructure Related to Scientific Model Systems

Examples of science that would fit:

- Models made available for distribution to the scientific community
- Centres, consortia, and/or networks
- Education and training of investigators at all levels (including clinicians), such as participation in training workshops, advanced research technique courses, and Master's course attendance. This does not include longer-term research-based training, such as Ph.D. or post-doctoral fellowships.

Appendix 10: NCRI Cancer Site coding system

Source: The National Cancer Research Institute (NCRI) Cancer research in the UK 2002-2011: An overview of the research funded by NCRI Partners (NCRI, 2013).

Site-specific

- Adrenocortical
- Anal
- Bladder
- Bone (including Osteosarcoma, Malignant Fibrous Histiocytoma and Ewing's Sarcoma)
- Brain Tumour (including Chordoma)
- Breast
- Cervical
- Colon and Rectal
- Ear
- Endometrial
- Eye (not including Retinoblastoma)
- Gallbladder (including Extra-hepatic Biliary Tract)
- Heart
- Hodgkin's Disease Kaposi's Sarcoma
- Kidney (not including Wilm's Tumour)
- Laryngeal
- Leukaemia (including Acute Lymphocytic Leukaemia, Acute Myeloid Leukaemia, Chronic Lymphocytic Leukaemia, Hairy Cell Leukaemia, Myelodysplastic Syndrome and Myeloproliferative disorders)
- Liver (including Bile Duct) Lung (including Mesothelioma) Melanoma
- Myeloma (including Multiple Myeloma) Nasal Cavity and Paranasal Sinus Nervous System
- Neuroblastoma
- Non-Hodgkin's Lymphoma Oesophageal
- Oral Cavity and Lip Ovarian
- Pancreatic Parathyroid Pharyngeal Pituitary Tumour
- Primary Central Nervous System Lymphoma Primary of Unknown Origin26
- Prostate Retinoblastoma Salivary Gland
- Sarcoma (including Chondrosarcoma, Ewing's Sarcoma, Fibrosarcoma, Osteosarcoma, Rhabdomyosarcoma, Soft Tissue Sarcoma and Uterine Sarcoma)
- Skin
- Small Intestine Stomach Testicular
- Thymoma, Malignant Thyroid
- Vaginal
- Vascular System Vulva
- Wilm's Tumour

In some cases 'roll-up codes' are used where the cancer site focus of an award is not highlighted and to ensure a consistent and fair attribution of funds to specific NCRI Cancer Site codes in these cases. The roll-up codes currently in use are:

Alcohol consumption-related cancers

Oesophageal (22%); Laryngeal (21%); Pharyngeal (16%); Oral Cavity and Lip (16%); Breast (15%); Liver (10%)

BRCA1/2 mutation-related cancers

Breast (70%); Ovarian (30%)

CEA-positive tumours

Colon and Rectal (60%); Lung (10%); Breast (10%); Pancreatic (10%); Ovarian (10%)

Childhood cancers

Leukaemia (35%); Brain Tumour (12%); Nervous system (12%); Sarcoma (10%); Neuroblastoma (9%); Wilm's Tumour (9%)

Dietary-related cancers

Colon and Rectal (50%); Stomach (12.5%); Oral Cavity and Lip (12.5%); Oesophageal (12.5%); Breast (12.5%)

Epstein-Barr virus associated cancers

Pharyngeal (34%); Non-Hodgkin's Lymphoma (33%); Hodgkin's Disease (33%)

Familial cancers

Breast (50%); Ovarian (20%); Colon and Rectal (10%); Melanoma (10%); All Sites (10%)

Gastrointestinal cancers
Colon and Rectal (65%); Stomach (20%); Oesophageal (15%)

Gynaecological cancers
Cervical (20%); Ovarian (41%); Endometrial (32%); Vaginal (1%); Vulva (6%)

Germ cell tumours
Ovarian (50%); Testicular (50%)

Germline p53 mutation-related cancers
All Sites (30%); Breast (10%); Bone (10%); Adrenocortical (10%); Brain Tumour (10%); Lung (5%); Stomach (5%); Colon and Rectal (5%); Pancreatic (5%); Hodgkin's Disease (5%); Kidney (5%)

Haematological cancers
Non-Hodgkin's Lymphoma (40%); Leukaemia (30%); Myeloma (20%); Hodgkin's Disease (10%)

Head and neck cancers
Pharyngeal (34%); Laryngeal (32%); Oral Cavity and Lip (27%); Salivary Gland (7%)

HIV associated cancer
Kaposi's Sarcoma (40%); Non-Hodgkin's Lymphoma (40%); Cervical (10%); Anal (10%)
HPV associated tumours Cervical (60%); Anal (10%); Vulva (10%); Penile (10%)

Multiple endocrine neoplasia
Adrenocortical (25%); Pancreatic (25%); Parathyroid (25%); Pituitary Tumour (25%)

Neuro-endocrine cancers
Pancreatic (40%); Stomach (40%); Parathyroid Tumour (10%); Nervous System (10%)
Neurofibromatosis Nervous System (50%); Brain Tumour (50%)

Photodynamic therapy research
Cavity and Lip (12.5%); Lung (12.5%); Oesophageal (12.5%); Stomach (12.5%)

Smoking-related cancers
Lung (68%); Oesophageal (4%); Laryngeal (3%); Pharyngeal (3%); Oral Cavity and Lip (3%); All Sites (19%)

Smokeless tobacco-related cancers
Oral Cavity and Lip (34%); Oesophageal (33%); Pancreatic (33%)

Second-hand smoke-related cancers
Lung (100%)

Parental smoking-related cancers in offspring
Liver (100%)

Cancers of teenagers and young adults
All Sites (22%); Hodgkin's Disease (18%); Leukaemia (11%); Brain Tumour (9%); Melanoma (8%); Non-Hodgkin's Lymphoma (7%); Ovarian (7%); Testicular (7%); Bone (6%); Sarcoma (5%)

Appendix 11: Nutritional Keywords

Nutritional keywords are based on headings from the World Cancer Research Fund's 2007 report. Whole word search was used when general text search retrieved a large number of irrelevant results, for example, sport identified awards that contain words such as transport and transportation. The keywords that were searched using whole word search function are in bold.

Diet

Foods
Keywords: diet, food, foods, fruits, vegetable, vegetables, cereals, legumes, roots, tubers, nuts, seeds, soy, soya, fish, meat, poultry, dairy, fats, oils, sweeteners, salt, whole grains, refined grains

Beverages
Keywords: beverages, drinks, alcohol, wine, beer, spirits, liquor, tea, coffee

Types of diet
Keywords: vegetarian, vegan, omnivorous, pescetarian

Behaviours

Keywords: exercise, sedentary, sport, sports, recreational, physical activity, sun, sunlight, lifestyle

Nutrition

Macronutrients
Keywords: nutrition, nutrient, nutrients, macronutrient, macronutrients energy, fat, calories, calorie, joule, joules, megajoule, megajoules, carbohydrates, lactose, fructose, glucose, sugar, fibre, amino acid, amino acids, fatty acid, fatty acids

Micronutrients
Keywords: micronutrients, micronutrient, mineral, minerals, vitamin, vitamins, folate, thiamine, riboflavin, niacin, biotin, choline, tocopherol, tocotrienol, retinol, carotene, carotenoids, ascorbate, cholocalciferol, ergocalciferol, ascorbic, trace element, folic acid, potassium, chlorine, chloride, sodium, calcium, phosphorus, magnesium, fluoride, zinc, iron, manganese, copper, iodine, iodide, selenium, molybdenum

Supplements
Keywords: supplements, prebiotics, probiotics

Nutritional support

Keywords: feeding

Natural compounds

Search awards include one of the following exact words: substances, compound, compounds, component, components, chemical, chemicals, carcinogen, carcinogens or carcinogenic
and
Include any of the following words: natural, plant, food, diet, dietary, bioactive

Other keywords: flavonoid, flavonoids, phytoestrogen, phytoestrogens, cannabinoids, cannabinoid, isothiocynates, phytochemical, phytochemicals, lycopene, glutathione, glutamine

Body composition and nutritional status Keywords: nutritional, underweight, undernutrition, fatness, skinfold, adiposity, overweight, obese, obesity, anthropometry, anthropometric, weight, height, BMI, body mass index, waist, WHR, waist-to-hip, MUAC, body composition, muscle mass, lean mass, lean body mass, mid upper arm circumference

Mycotoxins

Keywords: mycotoxin, mycotoxins, aflatoxin, aflatoxins, ochratoxin, citrinin, alkaloids, patulin, fusarium

Metabolism/mechanisms

Keywords: warburg effect, anaerobic glycolysis, aerobic glycolysis, metabolic syndrome, diabetes, hypertension, hyperlipidaemia, hyperlipidemia, hyperglycaemia, hyperglycemia, insulin resistance, glycaemic load, glycemic load, metabolism, metabolomic, metabolomics, metabonomic, metabonomics

Note: Protein was not included because it retrieved a vast number of in vitro awards that were not nutrition-related. The Task and Finish Group had confidence that the combination of other dietary keywords (e.g. diet, food, fish, meat and metabolism) should be able to identify the nutrition-related awards relating to protein.

Appendix 12: Nutrition themes and sub-themes used in the mapping

1 Nutrition

1.1 Nutrition (non-specific)
Awards relating to the investigation of 'nutrition' without providing further details.

1.2 Energy
Awards relating to the investigation of energy intake, consumption and balance.

1.3 Amino acids
Awards relating to the investigation of protein or amino acids which are within the predefined working definition of nutrition (see section 1.4), including dietary protein supplementation and protein deprivation.

1.4 Fatty acids
Awards relating to the investigation of the consumption, metabolism, body concentrations or health benefits of saturated or unsaturated fatty acids.

1.5 Vitamins
Awards relating to the investigation of vitamins, including human studies looking at dietary vitamin supplementation or blood vitamin concentrations, animal studies using diets with different levels of vitamin contents, and in vitro studies using vitamin concentrations.

1.6 Minerals
Awards relating to the investigation of minerals, including dietary mineral intakes, supplementation and mineral status.

1.7 Other natural substances
Awards relating to the investigation of other natural substances that cannot be coded under the categories 1.3-1.6. Examples are phytochemicals and fibre.

NB: Carbohydrates were not listed here because no awards were coded under this category.

2 Lifestyle exposures

2.1 Dietary exposures (non-specific)
Awards relating to the investigation of general dietary patterns, e.g. processed red meat consumption. Awards investigating dietary exposures which cannot be coded under category 1 (Nutrition) due to insufficient information are also included in this sub-category, for example, cohort studies that collect dietary information, without providing further details on the information collected and how it would be analysed.

2.2 Physical activity
Awards relating to the investigation of physical activity levels, including human observational studies on physical activity levels and interventional studies on increasing physical activity levels.

2.3 Alcohol consumption
Awards relating to the investigation of alcohol consumption level or alcohol metabolism.

2.4 Non-specific lifestyle factors
Any other lifestyle factors that fit in the predefined working definition of nutrition and cannot be coded under the categories 2.1-2.3, e.g. positive lifestyle changes relating to obesity prevention.

3 Nutritional Interventions

3.1 Supplements (oral)
Awards relating to the investigation of oral dietary supplements.

3.2 Feeding
Awards relating to the investigation of parenteral or enteral feeding.

3.3 Non-specific nutritional care
Awards relating to the investigation of nutrition care other than the categories 3.1 and 3.2, for example, diet interventions and healthy eating advice.

4 Metabolism

4.1 Body metabolism
Awards relating to the investigation of whole body level metabolism, which fits in the predefined broad definition of nutrition.

4.2 Cell metabolism:
Awards relating to the investigation of cell level metabolism which fits in the predefined broad definition of nutrition. Examples are tumour energy metabolism, tumour lipid metabolism and comparison of the metabolism between normal and tumour cells with regard to nutrients and energy.

5 Nutritional status

5.1 Anthropometric variables
Awards using anthropometric variables that reflect nutritional status. Examples are Body Mass Index and weight.

5.2 Body composition & functional capacity
Awards using body composition (e.g. body fat) and functional capacity measurements (e.g. muscle strength) that reflect nutritional status.

5.3 Nutritional biomarkers
Awards using vitamin and mineral biomarkers.

6 Metabolic Conditions

Awards relating to the investigation of metabolic conditions that are commonly associated with nutrition, including obesity, type 2 diabetes and hypercholesterolemia.

Appendix 13: Nutrition theme by top cancer sites

Table 8: Nutrition theme by top 10 cancer sites

Cancer site	N	Nutrition	Lifestyle exposures	Nutritional interventions	Metabolism	Nutritional status	Metabolic conditions
All sites	60	8	48	5	1	7	18
Colon and Rectal Cancer	36	23	9	5	5	2	1
Lung Cancer	17	9	6	8	1	8	6
Breast Cancer	16	8	8	1	0	4	1
Oseophageal Cancer	15	8	5	2	2	3	1
Leukaemia	12	2	6	0	2	5	5
Prostate Cancer	12	7	4	3	0	1	1
Fundamental Research	10	2	0	0	8	0	0
Melanorma	5	2	3	1	0	0	1

Appendix 14: Overview of cancer sites by the number of included awards and spend

Table 9: Overview of cancer sites by the number of included awards, percentage of total awards, and total cancer and nutrition research spend (£) between 2009 and 2013, total included awards n=158. Cancer sites are sorted descending by the number of included awards.

Cancer Site	Awards n=158 (n)	Spend (% of total awards)	(2009-2013)
All Sites[18]	60	38%	£14,342,433
Colon and Rectal Cancer	36	23%	£10,810,008
Lung Cancer	17	11%	£1,097,131
Breast Cancer	16	10%	£2,878,468
Oesophageal Cancer	15	10%	£2,045,640
Oral Cavity and Lip Cancer	14	9%	£608,746
Prostate Cancer	12	8%	£1,724,548
Leukaemia	12	8%	£1,696,173
Fundamental Research[19]	10	6%	£2,313,665
Stomach Cancer	10	6%	£423,511
Brain Tumour	7	4%	£313,551
Laryngeal Cancer	7	4%	£203,031
Pharyngeal Cancer	7	4%	£196,604
Sarcoma	6	4%	£263,440
Ovarian Cancer	6	4%	£258,739
Melanoma	5	3%	£1,589,391
Salivary Gland Cancer	5	3%	£110,068
Testicular Cancer	3	2%	£1,310,448
Bladder Cancer	3	2%	£949,097
Non-Hodgkin's Lymphoma	3	2%	£391,873
Skin Cancer	3	2%	£158,925
Pancreatic Cancer	2	1%	£556,697
Cervical Cancer	2	1%	£247,087
Liver Cancer	2	1%	£105,671
Hodgkin's Disease	2	1%	£62,864
Nasal Cavity and Paranasal Sinus Cancer	1	1%	£154,470
Small intestine cancer	1	1%	£79,866
Nervous system	1	1%	£24,523
Neuroblastoma	1	1%	£24,523
Endometrial Cancer	1	1%	£16,287
Myeloma	1	1%	£5,092

[18] Cancer sites are as originally coded by the NCRI. All Sites mean all non-site-specific cancers studies.

[19] Cancer sites are as originally coded by the NCRI. Fundamental Research includes fluids, secretions, milk, lymph, blood components, cells, cell fractions, tissues, strains, and experimental tumours.

Appendix 15: Breakdown of CSO into sub-codes by number of awards included, total n=158

Table 10: Overview of cancer research category by included awards, total n=158

CSO Code	Areas of cancer research	N	% of subtotal	% of total
CSO1	Biology	23	100%	14.6%
CSO1.4	Cancer Progression and Metastasis	9	39%	5.7%
CSO1.2	Cancer Initiation: Alteration in Chromosomes	4	17%	2.5%
CSO1.3	Cancer Initiation: Oncogenes and Tumour Suppressor Genes	4	17%	2.5%
CSO1.5	Resources and Infrastructure	4	17%	2.5%
CSO1.1	Normal Functioning	2	9%	1.3%
CSO2	Etiology	57	100%	36.1%
CSO2.3	Interactions of Genes and/or Genetic Polymorphisms with Exogenous and/or Endogenous Factors	21	37%	13.3%
CSO2.1	Exogenous Factors in the Origin and Cause of Cancer	13	23%	8.2%
CSO2.4	Resources and Infrastructure Related to Aetiology	12	21%	7.6%
CSO2.2	Endogenous Factors in the Origin and Cause of Cancer	11	19%	7.0%
CSO3	Prevention	52	100%	32.9%
CSO3.2	Nutritional Science in Cancer Prevention	26	50%	16.5%
CSO3.1	Interventions to Prevent Cancer: Personal Behaviours That Affect Cancer Risk	18	35%	11.4%
CSO3.3	Chemoprevention	5	10%	3.2%
CSO3.6	Resources and Infrastructure Related to Prevention	3	6%	1.9%
CSO4	Early Detection, Diagnosis and Prognosis	15	100%	9.5%
CSO4.3	Technology and/or Marker Testing in a Clinical Setting	6	40%	3.8%
CSO4.1	Technology Development and/or Marker Discovery	5	33%	3.2%
CSO4.2	Technology and/or Marker Evaluation With Respect to Fundamental Parameters of Method	3	20%	1.9%
CSO4.4	Resources and Infrastructure Related to Detection, Diagnosis or Prognosis	1	7%	0.6%
CSO5	Treatment	25	100%	15.8%
CSO5.7	Resources and Infrastructure Related to Treatment and the Prevention of Recurrence	10	40%	6.3%
CSO5.3	Systemic Therapies - Discovery and Development	9	36%	5.7%
CSO5.6	Complementary and Alternative Treatment Approaches	3	12%	1.9%
CSO5.4	Systemic Therapies - Clinical Applications	2	8%	1.3%
CSO5.2	Localized Therapies - Clinical Applications	1	4%	0.6%
CSO6	Cancer Control, Survivorship and Outcomes Research	97	100%	61.4%
CSO6.4	Cost Analyses and Health Care Delivery	28	29%	17.7%
CSO6.2	Surveillance	21	22%	13.3%
CSO6.1	Patient Care and Survivorship Issues	18	19%	11.4%
CSO6.3	Behaviour	13	13%	8.2%
CSO6.6	End-of-life Care	10	10%	6.3%
CS06.9	Resources and Infrastructure Related to Cancer Control, Survivorship, and Outcomes Research	7	7%	4.4%

*Awards may investigate more than one research area. CSO sub-codes are sorted from largest to smallest by the numbers of included awards.

Appendix 16: Letter from the Managing Director of NOCRI

NHS
National Institute for Health Research

NIHR Office for Clinical Research Infrastructure (NOCRI)
140B, Skipton House
80 London Road
London SE1 6LH

nocri@nihr.ac.uk

Dear Colleagues,

This letter has been prepared by the NIHR Office for Clinical Research Infrastructure (NOCRI) to outline our intentions to continue our support for the Cancer and Nutrition NIHR infrastructure collaboration, which is being led by the NIHR Southampton Biomedical Research Centre.

NOCRI works across the NIHR clinical research infrastructure to promote, facilitate and develop collaborative working that deliver benefits for patients and the NHS, maximising the impact of the Department of Health's investment in research infrastructure of over £0.5 billion per year. A key area of focus for our infrastructure work is supporting the establishment of national collaborations within the NIHR infrastructure, where coordinated working can add value and overcome disease and technical challenges.

A key example of this is the Cancer and Nutrition NIHR infrastructure collaboration which is looking to address an area of unmet need, by engaging with interdisciplinary stakeholders to help bring coherence to existing activities and provide a coordinated framework as a basis for future research into nutrition and cancer. Since its inception last year, the collaboration has made great progress, including proactive work to bring together key stakeholders from across Department of Health, World Cancer Research Fund, Cancer Research UK and the NIHR, running two workshops at the national NCRI conference in November and carrying out a large, resource intensive exercise to map out the cancer and nutrition portfolio across the UK to identify gaps in this area.

Having the dedicated resource of a project manager and research assistant funded through NIHR Southampton BRC, and close contact with NOCRI has been vital in driving this work forward, and ongoing support and resource will be key to ensuring they continue to deliver.

Best Wishes

Mark Samuels

Mark Samuels.

Managing Director, NOCRI

Partner organisations of the Cancer and Nutrition NIHR infrastructure collaboration

- Cancer Research UK
- Experimental Cancer Medicine Centres
- NIHR Bristol Nutrition Biomedical Research Unit
- NIHR Imperial Biomedical Research Centre
- NIHR Leicester-Loughborough Diet, Lifestyle and Physical Activity Biomedical Research Unit
- NIHR Office for Clinical Research Infrastructure
- NIHR Royal Marsden Biomedical Research Centre
- NIHR Southampton Biomedical Research Centre
- World Cancer Research Fund UK

NHS
National Institute for
Health Research