Cancer and Nutrition
NIHR infrastructure collaboration

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

Report of Phase Two  July 2015 - March 2017
Preface

The purpose of this report is to capture the experience in developing the Cancer and Nutrition NIHR infrastructure collaboration during Phases I and II of its activities and look ahead to Phase III. It sets out what has been achieved to date and the opportunities this provides for further activities that should lead to significant impact for those at risk of cancer, being treated for cancer and living with the experience of cancer.

Since its establishment in 2014 the collaboration has sought to better enable a wide community of interested parties to bring together the high quality research being carried out in cancer together with the high quality research being carried out in nutrition, so that each can add value to the other in the interest of patients and the public.

We have begun to enable the seemingly disparate perspectives of researchers, clinicians and patients to come together and work for common benefit within a community of practice. With the commitment that has been shown and the momentum that has been generated, substantial progress has been achieved and we are close to establishing a self-sustaining network of stakeholders who, by working together, will provide better nutritional support to cancer patients at all stages of the cancer process.

During Phase I we found that patients with cancer want information about nutrition that their health professionals are not well equipped to provide. This is due in part to the paucity of evidence on which to base informed advice and guidance. We therefore sought to bring coherence to existing activities in nutrition and cancer research. A full and summary report of Phase I activities can be accessed via the collaboration website: http://cancerandnutrition.nihr.ac.uk

During Phase II the organised efforts of five work streams have identified and developed an infrastructure to move the agenda forwards in a way that will enable a more coherent strategy and higher quality work focused on specific objectives.

Our aim is to build on this and enable high quality research to provide the knowledge needed to improve care and treatment, bringing tangible benefit to patients. Through this practical experience we aim to develop a self-sustaining community of patients, researchers and clinicians.

This report is an opportunity to share with our stakeholders the progress that has been made so far, to show how by working together even greater opportunities have been created, and ultimately how people’s lives can be improved by the application of nutrition-related translational research to address the problems of cancer and nutrition.

Professor Alan Jackson, July 2017
Chair of the Collaboration
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1 About the collaboration

The Cancer and Nutrition NIHR infrastructure collaboration was set up in 2014 by Professor Alan Jackson and his team at the NIHR Southampton Biomedical Research Centre, together with the World Cancer Research Fund (UK) and CRUK, with support from the NIHR Office for Clinical Research Infrastructure (NOCRi).

The purpose of the collaboration is to establish a coherent and effective infrastructure to enable the best quality translational research that will bring nutritional considerations, including physical activity, into all aspects of cancer prevention and care.

The collaboration comprises two distinct parts, each with its particular roles and responsibilities. The first part is the body of researchers, clinicians and patients who provide direction, identify the research gaps and opportunities, then work together to deliver research. The other part is the Secretariat and other supporting structures. The Secretariat provides coherence to the strategy by managing the process of delivering the research priorities as identified by the stakeholders.

1.1 Meet the team

The Steering Committee is responsible for developing the strategy and overall vision for the collaboration. It meets quarterly and is currently chaired by Professor Alan Jackson.

The Secretariat is responsible for operational delivery of the strategy. Chaired by Professor Martin Wiseman, Medical and Scientific Adviser of the World Cancer Research Fund (WCRF UK), the Secretariat meets monthly.

In addition to the Steering Committee and the Secretariat, the collaboration is made up of five work streams, and together there are around 100 people participating in our activities, including patients, clinicians and researchers from institutions and organisations across the UK (See Appendix A).
1.2 Collaboration vision

To deliver benefits to people and patients through improved translational research in cancer and nutrition where every person and clinician knows and understands how best they can contribute.

The collaboration aims to deliver research that leads to:

better advice, better care and better outcomes for cancer patients

1.3 Responding to patients’ needs

“Patients and lay advocates have been successfully integrated into all aspects of this project. Their views and opinions have been listened and responded to, as a part of the team. For one, I feel that this has been an extraordinarily successful collaboration.”

Jacqui Gath
Member of PPI and Toolkit work streams
1.5 Strategic aims

1. To identify the knowledge gaps around the role of nutrition at all stages of life in relation to cancer.

2. To enable translational research that will address these knowledge gaps.

3. To raise awareness of opportunities for improved research to benefit patients and the public at all stages of the cancer process.

4. To foster a community of clinicians, patients, the public, and researchers to share knowledge, understanding and best practice to jointly deliver the highest quality research.

5. To build capacity and capability in the health workforce; developing the next generation of cancer and nutrition researchers and clinicians.

1.4 Definitions

Through engagement with clinicians, researchers and patients it has become apparent that people may have a different understanding of some of the key words and language in relation to cancer and nutrition.

It is especially important to be clear that nutrition refers to more than just the diet, it also needs to acknowledge what the body can do for itself and physical activity. Therefore, the collaboration uses the following definitions for cancer and nutrition to ensure effective communication:

Cancer
Includes all types, stages, and sites. Stages include prevention, diagnosis, treatment, survivorship, palliative and end of life care.

Nutrition
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 disease states.

“As patients we are critically aware of the importance of nutrition in the fight against cancer. For many years we have been asking for advice and support to help us decide what we can do to help ourselves throughout our treatment and when we are living with and beyond a cancer diagnosis.

We believe that patients should work with researchers to place nutrition at the centre of their activities. We need to ensure that the medical community, and the population at large, are aware of what needs to be done in this area so that patients are given consistent, evidence-based advice to help them make informed choices. A call to action is vital if we are to mobilise to defeat cancer, which will be the major cause of death for the coming generations and a major cost to the delivery of health care.

It is impossible to overstate the importance of delivering a fully integrated, evidence-based approach to nutritional care for cancer patients and we look forward to continue working within the collaboration to achieve this aim.”

Lesley Turner, April 2017
Patient Advocate; Southampton BRC; NCRI Supportive and Palliative Care CSG; NCRI Advanced disease and end of life care sub group; NCRI Breast CSG Symptom Management group; NCRI Consumer Forum; Independent Cancer Patients’ Voice; Breast Cancer Now Tissue Bank Advisory Council Member; Breast Cancer Now Catalyst Grant Committee member.
2 Why nutrition matters

Nutrition is important as part of a healthy lifestyle for all of us and plays a key role in reducing the risk of cancer and other non-communicable diseases. For those living with and beyond cancer, nutrition is an important determinant of wellbeing after diagnosis (resilience), as well as a predictor of response to therapy and survival. For clinicians, nutrition is an essential consideration in the care and management of people with cancer.

People living with cancer can have poor nutrition for a wide variety of reasons. Cancer treatment can contribute to poor nutrition due to side effects and other causes related to treatment. In addition, people with poor nutrition may have a poorer response to treatment and worse outcomes than people with good nutrition.

2.1 The knowledge gap

According to Cancer Research UK, 1 in 2 people born after 1960 in the UK will develop cancer at some point during their lifetime. Approximately 42% of cancer cases in the UK each year are linked to lifestyle factors including poor nutrition, being overweight and a lack of physical activity.

The evidence for what interventions are best for individual patients is lacking and inadequate to support clinical decision making. This is of particular importance because the underlying disease processes as well as the treatment often have a significant impact on nutritional status. There are concerns amongst patients and clinicians that the lack of nutritional understanding and evidence of what are the most appropriate and effective nutritional interventions. This limits our ability to ensure that the nutritional needs of patients are met for all patients in all settings.

Figure 1: Influence of nutrition through the life course

How nutrition, at all stages of the life course and cancer journey, influences the risk of developing cancer, as well as the resilience to cancer and response to treatment.

INFLUENCE OF NUTRITION
RESILIENCE
3 Synopsis of collaboration activities

Figure 2: Three distinct phases of collaboration activity to date

3.1 Phase I (2014 - 2016)
This involved a scoping exercise to identify and characterise the problem. Activities included the mapping of NIHR research activities in cancer and nutrition, as well as a patient and a clinician survey. A report of Phase I activities can be found here: http://cancerandnutrition.nihr.ac.uk

3.2 Phase II (2016 - 2017)
This phase focused on developing and enabling five work streams to address the needs identified in Phase I. Details of work stream members and activities can be found here: http://cancerandnutrition.nihr.ac.uk/work-streams/

3.3 Phase III (2017- 2021)
This phase will see the delivery of defined outputs through established and new work streams. The long-term aim is that the work streams become self-sustaining communities of practice, continuing to deliver improved research and clinical care to cancer patients.
4 Phase II activities

4.1 Work streams

Five work streams have been established to deliver the recommendations identified in Phase I. Each work stream has members from across the research and clinical communities with patient representation at the core. Each work stream aims to help the delivery of better evidence through scientific research, leading to better advice, better care and better outcomes for patients.

To ensure that the activities of the work streams are aligned and have complementarity, joint meetings have been organised to provide the opportunity for face-to-face discussions. In October 2016 two groups (the ‘Professionals’ and the ‘Toolkit’) came together to discuss the clinicians’ survey. This provided the opportunity for both groups to talk about the preliminary findings of the survey from their own perspective, and to discuss the next steps for each group. NOCRI also attended and gave an overview of its role, including how they see the different work stream activities aligning with NOCRI’s ambition to set up a charity consortium of funders.

A research workshop will take place in Autumn 2017 to bring together stakeholders from the three research sub-groups with the aim of developing a research action plan based on priorities as identified by patients, clinicians, and researchers working in the fields of cancer and nutrition. This will set the agenda for the Phase III of the collaboration’s activities.

Work stream 1

Patients and the Public

Lead: Lesley Turner, Patient advocate, Southampton BRC

Aim
To establish a framework that ensures patients and the public remain at the heart of the collaboration and to engage with the public, health professionals and the wider community to improve communication and information sharing.

Principal achievement
The patient voice is now embedded within all activities of the collaboration and work stream members have engaged directly in raising awareness within a number of the National Cancer Research Institute’s Clinical Studies Groups. Organisation of a patient panel for the charity workshop in September 2016 led to increased awareness and engagement between charities and the collaboration.

Work stream 2

Professional Workforce – training and capacity building

Leads: Professor Jane Murphy, Professor of Nutrition, Bournemouth University, Dr Fehmidah Munir, Reader in Health Psychology, Loughborough University

Aim
To establish a framework that brings together doctors, nurses, dietitians and other health professionals across the health system as a community of practice that possesses the necessary generic and specialised understanding, skills and competence to engage in translational research in cancer and nutrition.

Principal achievement
Building on the survey work in Phase I, and working closely with the Toolkit work stream, a more comprehensive clinicians’ survey was carried out as a core part of Phase II activities. Over 500 responses were received from a wide range of clinicians and health professionals involved in the care of people with cancer. The survey sought to gain an insight into clinicians’ awareness and use of existing nutritional guidance for cancer patients, as well as how (or when/whether) nutritional status is assessed in primary and secondary care settings, what measures are made, how these are recorded, and what nutritional advice is given to cancer patients in the UK.

A collaborative project to developing a trusted body of nutritional guidance for cancer patients is ongoing. Work is currently underway to develop a framework to assess the evidence base for commonly used nutritional
guidance. Working together with patients and research charities the work stream plans to develop a publicly available resource that provides trusted nutritional advice for cancer which is tailored to meet both patients’ and clinicians’ needs.

Work stream 3
Research – building an infrastructure and action plan to tackle the evidence gap

Leads: Professor Karen Brown, Professor of Translational Cancer Research, University of Leicester; Experimental Cancer Medicine Centre Network, Professor Elio Riboli, Director of the School of Public Health, Imperial College, Professor Sam Ahmedzai, Emeritus Professor of Palliative Medicine, University of Sheffield

Aim
To establish a framework that brings together investigators from across the research community to better define research priorities and opportunities to engage in collaborative research in cancer and nutrition.

Principal achievement
Three research subgroups have been set up to cover all stages of the research pipeline from basic science to translational research. Experts from across the UK including the devolved nations have been invited to participate to ensure maximum capacity and capability in research design and execution. Each group is actively defining priority areas for research, ensuring the views of patients/public are recognised and acted upon.

As a result of collaborative working a number of grant proposals have been developed and submitted to funders including: a multicentre infrastructure bid to the CRUK Catalyst Programme in Autumn 2016 involving both national and international partners; a collaborative multicentre diet and physical activity intervention for women with breast cancer (PANACHE) submitted to NIHR programme Grants for Applied Research (PGfAR) in early 2017.

Work stream 4
Characterising nutritional status in cancer – the Toolkit

Lead: Dr Bernard Corfe, Senior Lecturer, Molecular Gastroenterology Research Group, University of Sheffield

Aim
To develop a patient-approved “Toolkit” for nutritional assessment that can be applied in routine clinical care as a screening tool to identify those at risk and to enable a more complete nutritional assessment in research settings. To build on current best practice and develop a standardised, quality-assured process for assessing nutritional status in cancer.

Principal achievement
The core capabilities for screening for malnutrition and assessment of nutritional state have been identified and data about their application in current practice has been gained through the Clinicians’ survey. This allowed for the identification of challenges and opportunities in supporting those most at risk and in assessing the impact of nutritional interventions.

Work stream 5
Commercial sector and industry

Lead: Dr Steve Wootton, Associate Professor in Human Nutrition, University of Southampton

Aim
To support collaborative cancer and nutrition research with the commercial sector for the benefit of patients and the public.

Principal achievement
A background paper has been drafted which explores the considerations of engaging in collaborative nutrition research with the commercial sector. Early discussions facilitated by the British Nutrition Foundation have explored the opportunities for working with the many potential partners that make up the nutrition industry (food, functional foods, nutraceuticals, foods for medicinal purpose, medical devices, pharma etc.).
4.2 Clinicians’ survey

In order to extend the findings of the Phase I clinicians’ survey, a larger clinicians’ survey was designed, piloted and carried out in the summer of 2016. The online survey aimed to find out what level of nutritional assessment and support cancer patients are currently receiving from their health care teams. The survey was circulated to dietitians, oncology nurses, doctors, surgeons and speech and language therapists via a number of professional bodies and also by word of mouth. In total, 532 responses were received, with the majority coming from dietitians and nurses.

Key findings from the survey include:

1. Nutritional screening, as distinct from assessment, is undertaken for the majority of inpatients. Fewer outpatients are screened than inpatients. The Malnutrition Universal Screening Tool (MUST) is the most widely used means of screening for risk of malnutrition, but local tools are also used.

2. In total 83% of clinicians provide cancer patients with information about nutrition, with dietitians and nurses being the most likely to do so.

3. In total 44% of clinicians reported being aware of nutritional guidelines for cancer patients. 85% oncology specialist dietitians are aware of guidelines, but only 26% of doctors and 30% of nurses (Figure 3).

4. 92% of doctors and 96% of nurses surveyed discuss nutrition with their cancer patients, but only 15% of the doctors and 22% of the nurses had received training on the nutritional care of people with cancer (Figure 3).

In summary, the survey found that where nutritional assessments were undertaken these were inconsistent between centres and disciplines with neither common standards of practice, nor consistent recording and storage of data. This highlights the need for a standardised approach to assessing nutritional status (the need for a toolbox) within routine

Figure 3: Discussion of nutrition, awareness of guidelines and relevant training by profession
4.3 Charity engagement

Working with cancer charities is an important part of driving forward the collaboration’s agenda. The collaboration recognises that charities are potential funders of research and are uniquely placed to support patients, with many already providing nutrition and lifestyle advice. With patients asking for more and better nutritional advice, charities have an important role to play in helping to build the evidence base that is currently lacking.

With the help of the Association for Medical Research Charities (AMRC) and MRC-Technology, the collaboration has worked with NOCRI to organise two highly successful workshops bringing together charities, funders and professional nutrition organisations (British Dietetic Association, Association for Nutrition, Nutrition Society, and British Nutrition Foundation). The first workshop took place in September 2016 with a follow-up in February 2017 with over 20 medical research charities attending each.

The purpose of the first workshop was to hear from patients directly about their experiences and priorities. Lesley Turner, leader of the collaboration’s PPI work stream, facilitated a patient panel, to set the scene and enable charities to hear directly from patients. A strong message was received:

Patients want better and more consistent advice about nutrition throughout their cancer journey

The second workshop focused more specifically on how the interested charities can work together to fund research and support the development of evidence-based nutrition guidelines for patients and clinicians. During Phase III the collaboration will continue to work with NOCRI to develop a consortium of charity funders in order to fund research that will address some of the evidence gaps identified.

“Really enjoyed the patient panel discussion that introduced the issue.” WCRF

“Great start. Excellent to hear an almost combined patient voice. Helped concentrate the mind. Lots to be done. Happy to be involved.” Prostate Cancer UK
5 Letting people know what the collaboration is doing

At the Cancer and Nutrition NIHR infrastructure collaboration we recognise that success in achieving our ambition will depend largely on excellent communication with our stakeholders in the cancer and nutrition communities.

Throughout Phase II we have continued to build our network of patients, clinicians and researchers who want to be involved in building the evidence base and providing better nutritional care to people living with and beyond cancer.

Key elements of our communications strategy include continuing to develop the collaboration website, use of a quarterly newsletter, production of a Powerpoint presentation to raise awareness at events, and internal systems to ensure timely communication of key messages to work stream members and others involved in collaboration activities.

With over 100 people directly involved in the collaboration via work streams or other channels such as the Steering Committee and Secretariat, robust communication tools and techniques have been established in Phase II.

5.1 Website

The Cancer and Nutrition NIHR infrastructure collaboration has continued to develop its website, adding information about events that have taken place, and providing resources such as the powerpoint presentation used to raise awareness of the collaboration at external meetings.

The website also provides a channel through which people can make contact with the collaboration and tell us about the work they are doing in the field of cancer and nutrition. This allows us to reach out to researchers, patients, and clinicians across the UK, inviting them to join our community of practice and contribute to our shared ambition.

The website allows us to inform our stakeholders about funding opportunities for research into cancer and nutrition. Funders are increasingly looking for collaborative projects with multidisciplinary teams from multiple sites, and we are in a strong position to bring experts together in order to build strong research proposals that have more chance of success in a highly competitive environment.

5.2 Newsletter

A quarterly collaboration newsletter was launched in February 2017, as a way of keeping in touch with both internal and external stakeholders and keeping everyone informed of the collaboration’s activities and plans.

To view the latest newsletter and to sign up to receive future newsletters please contact us at: cancer_nutrition@nihr.ac.uk
6 Moving forward to Phase III
Building and extending the opportunity

The key ambition for the collaboration remains improving the prevention and management of cancer through high quality cancer and nutrition research.

The activities of the collaboration to date have been managed in a coordinated and strategic way. Phase I identified and characterised the problem, then developed a process to address it. Phase II established work streams as separate but integrated components of a coherent activity, with discrete tasks and outputs. Phase III will see this experience transform into a patient centred programme of translational research as shown in Figure 4.

We have gained considerable insight and experience through our activities to date. It has become clear that there is a significant demand from patients and those who care for them for robust, evidence-based advice on nutrition throughout the cancer journey. It is also clear that there is a lack of high quality research to meet that need. The collaboration was set up to meet the patient need and this remains the core purpose of our activities.

Figure 4: Activity pipeline – from work streams to better advice, care and outcomes

The activity of our five work streams will lead to the development of a secure and coherent research strategy and action plan which will promote the delivery of collaborative translational research. This will, in turn, inform practice through guidelines, training and professional development and with commensurate to people living with and beyond cancer.
6.1 Building the research framework

In Phase III the collaboration seeks to draw together those who conduct research in this area within a common framework and shared infrastructure that will help improve coherence and integration across the cancer and nutrition research communities.

We will build on the expertise and capabilities from across the NIHR infrastructure to work to leverage additional funding by working together to address the knowledge gaps in nutritional care of people with cancer.

Different types of evidence will be needed to build the broad evidence base, including basic research, prospective observational cohort studies, and clinical intervention trials, as well as the interrogation of routine clinical data once this is collected in a standardised, quality-assured way.

Underpinning this approach will require engagement of the public, patients, researchers, commercial and clinical practice communities, and the building of capacity among the professional workforce within a service context. The end result of improved coordination and collaboration will be better advice, better care and better outcomes in cancer.

6.2 Moving forward – what does the collaboration offer?

As we progress from the mapping, planning and setting-up phases of our activities into the delivery phase, there are seven distinct but related opportunities the collaboration can offer people and institutions who wish to engage with us:

- Work together with patients and the public in involvement and engagement activities to ensure the research agenda reflects their priorities.
- Identify and help bring together clinicians and researchers to develop shared research priorities and collaborative grant applications to deliver research against these priorities.
- Act as a collective voice to engage with funders (including charities) to inform and influence research opportunities.
- Improve the opportunity for, and quality of, nutritional research through the development, standardisation and implementation of a toolkit for nutritional assessment and sharing access to biobanked specimens where nutritional measures have been included.
- Share training and capacity building for young investigators.
- Work together to identify opportunities for collaborative research with the commercial sector.
- Be part of a growing community of individuals committed to improving the nutritional care of people living with and beyond cancer.
6.3 Moving forward – research opportunities for the future

The collaboration has identified five immediate themes of research in the area of cancer and nutrition. These are based on recommendations and guidance from funders, researchers and clinicians. Patients also have priorities for research and it is important to make sure their voices are heard, through engagement activities with patients, the public and patient groups.

- Lifestyle, diet and physical activity/exercise interventions to improve the resilience and outcomes of patients living with a diagnosis of cancer – both in terms of initial treatment, survivorship and palliative care.

- Interventions to improve the delivery and efficacy of nutritional support to those receiving cancer care – oral, enteral nutrition/percutaneous endoscopic gastrostomy/parenteral nutrition.

- Trials to determine how differences in body composition (sarcopenia/cachexia and excess adiposity), fitness and nutritional state influence the response to treatment in terms of both surgery and chemo/radiotherapy.

- First in man and efficacy studies of novel nutritional therapeutic agents (e.g. turmeric, n3 long chain fatty acids).

- Investigations in humans to better understand the biological processes underpinning the links between nutrition and activity exposures to health and disease outcomes.

6.4 Conclusions

The Cancer and Nutrition NIHR infrastructure collaboration set itself the challenging ambition to share knowledge and expertise across the fields of cancer and nutrition.

The key goal of the collaboration was, and remains, to improve the nutritional management of people with cancer. Significant progress has been made so far, but there remains a great deal left to do.

Over one hundred people from across the UK, including patients, clinicians, and researchers have joined us and are actively working to define and deliver the research agenda that will lead to better outcomes for people living with and beyond cancer.

The next phase of this collaboration will focus on harnessing the energies of everyone involved and coordinate the delivery of novel approaches to translational research.
### Appendices

#### Appendix A

Organisations involved in Phase II

#### Charities

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#### Other organisations (i.e. academic, patient groups)

| Cambridge University Hospitals NHS         | NIHR Cambridge Biomedical Research Centre |
| Foundation Trust                           | NIHR Imperial Biomedical Research Centre |
| Association for Nutrition                  | NIHR Leicester-Loughborough Biomedical Research Centre |
| Bedford Hospital NHS Trust                 | NIHR Office for Clinical Research Infrastructure |
| Bournemouth University                     | NIHR Royal Marsden Biomedical Research Centre |
| Brighton and Sussex University Hospitals   | NIHR Southampton Biomedical Research Centre |
| NHS Trust                                  | Nottingham University Hospitals NHS Trust |
| British Dietetic Association               | Nutrition Society |
| British Nutrition Foundation               | Oxford Brookes University |
| Cardiff and Vale University Health Board   | Queen’s University Belfast |
| Cardiff University                         | Salford Royal NHS Foundation Trust |
| Dundee Centre for Research into Cancer     | The Nutrition Society |
| Prevention and Screening                   | University of Bristol |
| Edinburgh Cancer Research Centre           | University College London |
| Guy’s and St Thomas’ NHS Foundation Trust  | University College London Hospitals NHS Foundation Trust |
| Independent Cancer Patients’ Voice        | University of Dundee |
| Imperial College London                    | University of Leeds |
| Innovate UK                                | University of Leicester |
| Institute of Food Research                 | University of Manchester |
| Loughborough University                    | University of Sheffield |
| MRC-Technology (LifeArc)                   | University of Southhampton |
| NCRI Consumer Forum                        | University of Westminster |
| NHS Lothian                                |                           |
| NHS Research Scotland                      |                           |
| NIHR Bristol Biomedical Research Centre   |                           |