NHS
National Institute for Health Research

Cancer and Nutrition NIHR infrastructure collaboration

Frequently Asked Questions

Collaboration

- ***What is the Cancer and Nutrition NIHR infrastructure collaboration?***

The Cancer and Nutrition NIHR infrastructure collaboration is an initiative with the ambition to bring benefits to patients through improved translational research in cancer and nutrition. We are bringing together patients, researchers and clinicians to create an infrastructure to achieve this.

- ***What are the collaboration's aims and objectives?***

The Cancer and Nutrition NIHR infrastructure collaboration aims to engage with interdisciplinary stakeholders to bring coherence to existing activities and to provide a coordinated framework as a basis for future research into nutrition and cancer.

- Bring together patients, clinicians and researchers to establish and maintain a national portfolio of clinical trials and other well-designed studies in cancer and nutrition;
- Work together to identify research priorities in cancer and nutrition, build research capability and capacity and develop collaborative grant applications;
- Work together to develop, standardise and implement the capability to identify patients at nutritional risk and assess nutritional status in routine clinical practice and across the research community;
- Curate and offer signposting to knowledge of nutrition-related capabilities, study opportunities, and specimens, and peer-review study proposals ;
- Act as a collective voice to engage with funders (including charitable & commercial partners) to inform and influence research opportunities to support a national portfolio of translational research in cancer and nutrition;
- Offer an expert voice in the development of national initiatives, strategic partnerships and consultations relevant to cancer and nutrition research, and by developing resources of authoritative guidance for the health and research workforce and for patients.

- ***How is it supported?***

From 2014 – March 2017, the Cancer and Nutrition NIHR infrastructure collaboration was supported by Southampton Biomedical Research Centre (BRC). From this time we have been seeking other funders to co-fund the activities. We are looking to other BRCs with an interest in nutrition and cancer, as well as all other parts of the NIHR infrastructure, to invest in our work to enable them to

access and to capabilities. We are also exploring funding through charities and are developing a strategy for engaging with industry. Presently we are not funded through any industry sources.

- ***When was it set up?***

The collaboration was set up in 2014. In discussion with the NIHR Office for Clinical Research Infrastructure (NOCRI), WCRF and CRUK it was agreed that Professor Alan Jackson would lead the initiative as Chair of the Steering Committee. Phase I involved the gathering of data on the scale and scope on research involving nutrition and cancer, and establishing patients' and clinicians' awareness and attitudes. Based on this and the established need, in early 2016 Phase II of the collaboration involved the organisation of the collaboration into five work streams (add what they were). As we move into Phase III, this structure is under review.

- ***Who is involved?***

Presently the collaboration involves over 100 patients, clinicians, scientists and funders. We have engaged with 9 NIHR Biomedical Research Centres and 30 academic institutions. Throughout Phase II we have engaged with over 30 charities in our activities and have also worked with a number of NCRI CSGs to explore how we can integrate nutrition research into their research agendas. We have closely worked with relevant professional bodies and societies such as the British Dietetic Association, Association for Nutrition, Nutrition Society and others, who recognise the importance of our ambitions and support our activities.

- ***How are patients involved?***

Patients are at the heart of our activities. We were established because of the patient-identified need for better nutritional care before, during and after treatment for cancer. We have one work stream in which 12 patient and public representatives convene, and these members are also a part of our other five work streams. We also have a lead patient representative on our Steering Committee.

- ***What are the governance structures?***

The Secretariat is responsible for the operational aspects of the collaboration's activities, and answerable to the Steering Committee. It meets on a monthly basis. Professor Martin Wiseman is current Chair of the Secretariat. The Steering Committee, currently chaired by Professor Diana Eccles, provides oversight and convenes on a quarterly basis. Prof Eccles will be stepping down in June 2018, and a new Chair will be elected by the Steering Committee. The collaboration is supported by the NIHR and overall it reports to the Department of Health.

- ***What has the collaboration achieved?***

Through our efforts, nutrition is now very much on the cancer agenda. Those who care for people affected by cancer mow acknowledge the need for better evidence to inform patients care, more secure guidelines and recommendations, and training.

For nutritionists we have identified the need to bring their skill set to the clinical service to better identify those at risk of poor nutrition and to make a nutritional diagnosis.

For patients, we have demonstrated that we are listening to their calls for better access to secure authoritative advice and care and have fully engaged with them in the research process to identify research that addresses their needs.

We believe we have made the first steps in establishing the foundation on which patients, clinicians and researchers can work together to establish and maintain a national portfolio of clinical trials and other well-designed studies in cancer and nutrition

Since its inception, the collaboration has brought together those in the fields of oncology and nutrition separately to facilitate the sharing of ideas and expertise.
Patients and the public are at the heart of the collaboration. We have a work stream of patient and public representatives, who are also embedded across all of our other work streams. They also ran a patient panel at a charity workshop in September 2016, which led to increased awareness and engagement between cancer charities and the collaboration. Our 'Professionals' work stream is focusing on capacity building within the work force. It led on bringing together over 30 cancer charities in the 2016 workshop and the subsequent meetings since then. This initiated a collaborative project on developing a trusted body of nutritional guidance for cancer patients, which is ongoing.
The Research work streams have been working together to develop new research project proposals. They held their first joint workshop in September 2017 to discuss the potential for collaboration and to gain expert input into their ideas.
In the Toolkit work stream, a survey was undertaken to characterise nutritional screening and assessment practice in the UK. The core capabilities for screening and assessing nutritional state have been identified and this will inform a 'Toolkit' of recommended practice. The survey also identified the challenges and opportunities in supporting those most at risk and in assessing the impact of nutritional interventions.
Two manuscripts are being prepared for publication based on the results of the survey.

- ***How does the collaboration support research?***

We have brought together experts in research, medicine and dietetics across the UK which has enabled individuals to collaborate on studies and generate applications for research funding. By bringing people together expertise and capability can be shared, which strengthens the research that can be conducted.
The collaboration is enabling research to be planned and conducted within a coherent strategy and framework, thus ensuring that the most important research priorities within nutrition and cancer are addressed.

- **What are the collaboration's research priorities?**

The collaboration is currently in the process of developing a comprehensive research strategy, at the level of both the overarching strategy and individual strategies for each research work stream sub-groups' remits.

Throughout our activities in Phase II, we identified five broad themes of research that will be focussed upon:

• 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.

- **What research is ongoing?**

Our research work streams are currently working together to develop grant applications to fund new studies. These applications will be developed across a defined research strategy to ensure that the necessary gaps in evidence are met.

Professor Jane Hopkinson of Cardiff University has been awarded £29,924 by Tenovus for the **EAT-CIT** study to conduct research to inform the content of a web-resource that presents hints and tips for self-managing common eating problems during chemotherapy and/or immunotherapy. It will facilitate problem-solving, partnership working with clinicians and behavioural change for best possible outcomes from cancer treatment. The project fits in with the Welsh Cancer Plan and is supported by the 'nutritional care in people living with and beyond cancer' work stream. The group has provided advice on methodology and dissemination and will continue to support Professor Hopkinson throughout the study.

WesFit, led by Dr Sandy Jack is now open and has recruited its first patients. Pioneering pre-surgery exercise sessions are being piloted at gyms and cancer support centres across the Wessex region in the first project of its kind across the UK. It follows research published in 2014 by Professor Mike Grocott and his team into the effect of tailored exercise programmes on bowel cancer patients after chemotherapy and radiotherapy but before surgery. By training on a bike three times a week, they found patients' fitness returned to pre-treatment levels or improved within six weeks, but remained at post-treatment levels or dropped further for those who didn't.

£2.3m has been awarded in partnership with the Wessex Cancer Alliance, Wessex Cancer Trust and council and community gyms to look at whether or not these exercise programmes along with psychological support, can be taken out of hospital and delivered to patients across the South.

- **What is the Toolkit?**

The 'Characterising nutritional status in cancer' work stream of the Cancer and Nutrition NIHR infrastructure collaboration is working on producing a Toolkit of nutritional screening and

assessment to be used in routine clinical care and within research. It has been established through the patient survey in 2015 and the clinicians' survey is 2016-17 that the nutritional care of people living with and beyond cancer is not standardised across the UK and does not meet the needs of patients. Provision of a Toolkit will help health care professionals be able to recognise when a patient is at risk of poor nutritional state and subsequently be able to treat the problem. This may lead to improved clinical outcomes and patient experience for the patient. This Toolkit will serve as the platform for research. At the simplest level, the screening and basic assessment tools can be incorporated into all studies, even where nutrition is not the primary purpose. The more complete assessment will be incorporated into studies that directly explore the impact of differences in nutritional state on the development or progression of cancer, response to therapy and clinical outcomes as well as those that directly intervene nutritionally to improve nutritional status in primary and secondary prevention.

- **How can I get involved in research? (patient and health care professional answer)**

If as a patient you would like to contribute to influencing research in cancer and nutrition, please get in touch with us by email: cancer_nutrition@nihr.ac.uk If you would like to participate in a clinical trial, you should speak to your healthcare team.
If you are a researcher or clinician and would like to tap into our network of expertise, please email us on cancer_nutrition@nihr.ac.uk. We have research work streams on nutritional care in people living with and beyond cancer, and on public health and epidemiology.

- **What are the collaboration's future plans?**

During Phase III, the collaboration 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 patients.

Cancer and Nutrition

- *What do we mean by nutrition and physical activity?*

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

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.