

NOCRI MRC-T Cancer and Nutrition Workshop Report

Can We Work Together To Improve Nutrition Research for Cancer Patients?

Cancer patients want guidance on nutrition and lifestyle factors that will favourably impact on their cancer development, progression and survivorship. They seek advice from health care professionals about what they can do to improve their clinical outcomes and care experience through making changes to their lifestyle, including diet and physical activity. Unfortunately, the limited availability of reliable evidence means that patients often find inconsistent or inaccurate information from unaccredited sources.

A workshop was held on the 5th September 2016 in London to bring together the UK's leading cancer charities supporting and funding health research to discuss how to join up cancer and nutrition research in the UK for the benefit of cancer patients. The workshop, organised and hosted by the [NIHR Office for Clinical Research Infrastructure](#) (NOCRI), the [Cancer and Nutrition NIHR infrastructure collaboration](#) and [MRC Technology](#) (MRC-T) was attended by over 20 medical research charities that fund cancer research. These charities included Cancer Research UK, World Cancer Research Fund, Macmillan Cancer Support and Marie Curie. A full list of attendees can be found in Appendix 1.

The programme was split into 3 sessions. The first session of the day included a patient and carer panel discussion led by the patient representative from the Cancer and Nutrition NIHR infrastructure collaboration's steering committee, Lesley Turner. This was then followed by an introduction to nutrition and its role in cancer from Professor Martin Wiseman, Medical and Scientific Advisor, World Cancer Research Fund. During the patient and carer panel, the importance of availability and provision of consistent, trustworthy advice to patients was highlighted. The panel stated that being provided with basic, yet consistent, nutritional and lifestyle advice from their healthcare professionals was better than not being given any information at all. The panel reported desperately wanting to feel in control of their cancers and felt that being able to modify their diet and lifestyle through appropriate advice was a route through which they could achieve this. Whilst patients would ideally like a personalised cancer care pathway which included well evidenced diet, nutritional and lifestyle advice across all stages of their cancer and treatment, they stated that they did not necessarily expect this and that simply being given information that was considered "best practice" based on what is currently known, would be sufficient.

Professor Wiseman reminded the audience that the definition of nutrition is wider than simply diet. He also described the [WCRF's Continuous Update Project](#) which is an ongoing programme to analyse global research on how diet, nutrition, physical activity and weight affect cancer risk and survival. It is estimated that if the evidence from this project in terms of healthy eating and lifestyle recommendations were followed, that between a quarter and a third of all cancers could be

prevented. This effect size is comparable to that seen with the introduction of statins to prevent cardiovascular disease, but does not cost anything.

***Definition of nutrition** – nutrition is a 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 the 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. Put most simply, nutrition can be defined as “what we eat, what we are and what we can do”.*

The second session of the day introduced the audience to the Cancer and Nutrition NIHR infrastructure collaboration. This collaboration, which was established in 2014 and brings together researchers, clinicians, health professionals and patients from across the cancer and nutrition research communities aims to:

- Raise awareness of opportunities for improved research to benefit patients and the public at all stages of the cancer process
- Promote and enable research to address knowledge gaps in nutrition at all stages of life in relation to cancer and
- Foster a community of patients, the public, and researchers to share knowledge, understanding and best practice to jointly deliver the highest quality research.

Mike Johnson, Divisional Director, Corporate Partnerships, MRC-T provided a high level overview of some of the charity consortium-type models that the MRC-T have already been involved in setting up which includes the [Dementia Consortium](#) and the Neurodegeneration Medicines Acceleration Programme ([Neuro-MAP](#)). It was clear from the examples presented that in order for a funding consortium to be successful the following three principles must be established and agreed amongst all consortium members:

1. A common purpose
2. A clear evaluation and selection process for research proposals
3. Members “elect to fund” and contribute at a project level, rather than upfront commitment of a set amount of funding over a pre-agreed period.

The third session of the day was an interactive session, led by David Pardoe, Head of Growth Projects, MRC-T, to enable the delegates to talk through the opportunities and challenges presented in the previous sessions, particularly in relation to the formation of a charity consortium to help address the clear need from the cancer patients and carers for consistent nutritional advice. The delegates were asked to consider a number of questions:

- What are the opportunities for joint working?
- What are the barriers?
- How can we make this work?

When discussing the benefits and opportunities for joint working, the following benefits were identified:

- Joint working brings in disease diversity and a variety of perspectives thereby allowing those involved to see the bigger picture
- Provides greater influencing power and impact when working collectively, for example to increase awareness of the importance of providing nutritional advice to patients
- Allows sharing of resources, expertise, knowledge and information thereby enabling charities to achieve more than they could individually, whilst also minimising duplication of effort
- Will help define a common language across patients, healthcare professionals and researchers which will support delivery of consistent messages

Some of the opportunities identified for consortium activities included:

- Development and implementation of common research methodologies with primary endpoints which are patient-driven
- Sharing capacity, capability and knowledge to develop a core nutritional pathway (i.e. across all cancer sites or across clusters of commonality)
- Mapping of the existing evidence to inform research areas and identify gaps
- Develop a centralised database of nutritional guidance
- Develop a shared resource to support the development of high quality nutritional research grant proposals
- Develop a joint capacity and capability to appropriately assess and review grant proposals and applications
- Development of a “real-world-data” platform in order to capture patient experience data of various nutritional guidelines and interventions in order to build up the evidence to support such recommendations
- Standardisation of how patient nutritional data is captured, using a system which allows the data to them be interrogated for research purposes

Some potential barriers to working together were identified, which are listed below, together with the questions that would need to be addressed during the establishment of a consortium:

- Charities having differing research priorities and research strategies which they all need to prioritise
- Charities may have very different starting points in terms of their expertise in the area of nutrition and their prior engagement with their patients around their nutritional needs. For some charities, nutrition may not currently be part of their research strategy and they may not be able to commit resources to a consortium at this time
- Some charities noted that they do not see enough high quality research applications in the area of cancer and nutrition to enable them to provide funding
- May be difficult to get buy-in across all levels of a charity (i.e. trustees)
- There is a need to build trust across all members
- Bureaucracy can lead to delays

The barriers identified raised a number of questions which would need to be addressed prior to or during the establishment of a consortium model to support the cancer and nutrition activity:

- How do we determine the shared research priorities for the consortium?
- Can we develop a model which allows other members to come on board as nutritional research becomes part of their individual research strategies?
- What are the expectations of a member charities in terms of supporting consortium activities (i.e. are there alternative ways to support activities rather than purely requiring a financial commitment)?
- Can the consortium, together with the Cancer & Nutrition NIHR infrastructure collaboration, provide a resource which provides nutritional input into research applications?
- What information would trustees need in order to support engagement of their individual charity with this activity?
- What early successes and quick wins could be used to gain trust and buy-in of charity trustees?
- What is needed to build trust across the various partners?
- What operating model and governance structure can we agree/ develop which reduces delays and maximises impact of the consortium?

At the end of the workshop the delegates were asked if they were interested in being involved in future discussions around establishing a charity consortium to support the Cancer and Nutrition NIHR infrastructure collaboration. Of the 21 charities represented at the workshop, 15 said they would like to be involved in further discussions to help to shape and establish a charity consortium.

Next steps

A follow-up workshop, led by NOCRI and supported by the Cancer & Nutrition NIHR infrastructure collaboration and MRC-T, will be held in late 2016/ early 2017 to discuss the collaborative development of a centralised database of “accredited” or “trustworthy” nutritional information for patients, carers, healthcare professionals and researchers.

If you would like to be involved in this next workshop, please contact the Cancer & Nutrition NIHR infrastructure collaboration: email cancer_nutrition@nihr.ac.uk or phone 023 8120 6317.

Comments from post-event evaluation forms

“Extremely grateful for NIHR and MRC-T for taking leadership on this”

“It has been really valuable to look in-depth at this issue and hear different view points from a range of stakeholders”

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

“Great start. Excellent to hear an almost combined patient voice. Helped concentrate the mind. Lots to be done. Happy to be involved”

“Looking forward to taking this forward”



Appendix 1 - Workshop Attendees

Charities

Association for Medical Research Charities
Brain Tumour Research
Brainstrust
Breast Cancer Haven
Breast Cancer Now
Cancer 52
Cancer Research UK
Macmillan Cancer Support
Marie Curie
NCRI
Neuroblastoma UK

Ovarian Cancer Action
Pancreatic Cancer UK
Prevent Breast Cancer
Prostate Cancer UK
Sue Ryder
Target Ovarian Cancer
The Institute of Cancer Research (ICR)
The Urology Foundation
Wellcome Trust
World Cancer Research Fund
Yorkshire Cancer Research

Professional Societies

Association for Nutrition
British Dietetic Association

The Nutrition Society

Other Stakeholders

Cancer & Nutrition NIHR infrastructure
collaboration
Crowdacure
Innovate UK
MRC

MRC Technology
NIHR Office for Clinical Research Infrastructure
(NOCRI)
Nuffield Health
Patients and carers