

## **Cancer and Nutrition NIHR Infrastructure Collaboration Charity Workshop Two - Meeting Report**

7 February 2017, London

### **SUMMARY**

Following a successful opening workshop in September 2016, seventeen cancer charities, funders and professional associations (appendix 1) gathered to talk about the importance of nutrition for cancer patients, the guidance and information about nutrition which is currently available for cancer patients, and how it can be improved.

Representatives of the [Cancer and Nutrition NIHR infrastructure collaboration](#) gave an update on their work in this area and the delegates shared their unique experiences and knowledge to start mapping out ways to work together to improve nutritional guidance for patients and support research in this field.

It was agreed at the workshop that the next step following this discussion is to take action. Several actions were identified during the workshop. To help address the current gaps in guidance available to patients, the collaboration agreed to draft a proposal for delivery of a shared body of authoritative guidance that would include roles and opportunities for charities and other interested organisations to participate. They also asked workshop participants to share information about their current review processes for information and guidance. Workshop participants agreed to share the themes of the workshop with their respective organisations to help with raising the profile of nutrition research. To help map opportunities that are currently available, participants are also asked to share information about existing funding and resources for nutrition research. For more details of the actions from this workshop please see the **next steps section** of this report.

### **INTRODUCTION**

The workshop opened with presentations from the Cancer and Nutrition NIHR infrastructure collaboration members, Dr Steve Wootton (University of Southampton), Professor Martin Wiseman (Medical and Scientific Advisor, WCRF) and Dr Fehmidah Munir (Reader in Health Psychology, Loughborough University).



Cancer and Nutrition  
workshop - S Wootton

#### **Introduction and workshop aims**

*Dr Steve Wootton*



Cancer and Nutrition  
workshop - M Wiseman

#### **Nutritional guidance for cancer patients - an overview of evidence**

*Professor Martin Wiseman*



Cancer and Nutrition  
workshop - F Munir.ppt

## Compiling a body of authoritative cancer nutrition advice for patients and professionals

*Dr Fehmidah Munir*

These presentations set the scene for the day by providing information about the Cancer and Nutrition NIHR infrastructure collaboration, outlining what we already know about cancer and nutrition and highlighting current issues around the lack of appropriate nutritional guidance for cancer patients.

The final presentation described a project which the collaboration is working on to create a body of authoritative nutrition advice of cancer patients and professionals. This project aims to identify the current evidence base for good nutritional support for cancer patients and clinicians and to make this information available and accessible to patients and professionals with the hope that it will provide patients with consistent nutritional advice throughout their cancer journey.

### The key messages from the presentations were:

**The Evidence:** We know that there are strong links between nutrition and cancer, and that it plays a role at all disease stages, from prevention and treatment responses, to end of life care. While information about the influence of nutritional choices in the prevention of cancer is both reliable and available ([www.wcrf-uk.org/uk/preventing-cancer](http://www.wcrf-uk.org/uk/preventing-cancer)), there are limited credible resources for specific approaches at diagnosis and beyond. For the purposes of this work, nutrition is about more than just food. It also takes into account the physical and physiological characteristics of each individual and physical activity.

**The Problem:** Feedback from the collaboration's patient and clinicians' surveys show that cancer patients report receiving very little, or confusing, advice on how best to approach nutrition for their cancer and for the different stages of their treatment journey. Also, importantly, this is an area in which they feel there are vital opportunities for them to take positive and active steps towards enhancing their well being. Clinicians reported that they are speaking to patients about nutrition, but often haven't had training or aren't aware of all the resources that are available. Both patients and clinicians felt that personalised nutrition advice would be ideal, however, easy access to agreed best practice would be a great start: **Trusted information = Better care**

**How can we help?:** By working together to ensure that reliable advice is readily available for patients and to expand our current knowledge about nutrition and cancer in areas that will have the greatest impact for patients. The Cancer and Nutrition NIHR infrastructure collaboration have already started work to address this problem but to have the greatest impact this should be a collaborative effort.

## DISCUSSION SESSION ONE

### *Working together to enable access to trusted nutritional guidance for patients and clinicians?*

#### Background

The Cancer and Nutrition NIHR infrastructure collaboration have initiated some preliminary work to identify authoritative guidance on nutrition in cancer care and have completed some initial steps including identifying the most commonly used sources of information. To successfully develop this resource the collaboration needs help to develop the resource, to tailor information to relevant stakeholder groups such as patients, clinicians and researchers and to make this information easily available and accessible to all the relevant parties.

During this first session, participants were asked to discuss the following points:

1. How does your organisation currently provide information about nutrition to patients, carers and professionals and how do you ensure it is quality assured?
2. How can we work together to progress the collaboration's work on the body of authoritative guidance?

#### Summary of discussions

Charities outlined the type of nutritional support they currently provide to their stakeholders and described their process for ensuring its quality.

- There were a variety of approaches identified which ranged from providing information on websites to face to face sessions like cooking demonstrations and meeting with dieticians and nutritionists.
- Most available information focuses on general healthy eating advice rather than specific or targeted information for cancer type or stage.
- Many charities referred to the existing credible sources including WCRF and NICE guidelines and said that they would only use reference material that complied with [Information Standards](#), or other appropriate quality criteria. Some organisations also mentioned that they use internal review processes to ensure the information they share is quality assured.
- Despite the good work that is already being done, participants agreed that there is a lack of targeted information and that availability and messaging is inconsistent. This applied to both recognising reliable advice and knowing what could potentially be harmful.

In the context of the work the Cancer and Nutrition NIHR infrastructure collaboration have undertaken to bring together the body of currently available evidence, the workshop participants discussed the importance of getting this type of information to patients and how this work could be progressed.

To help develop this resource the following points were suggested:

- A number of charities mentioned that they have internal processes to review the information that they share publicly and that there may be an opportunity to learn from and/or use existing processes to help develop the body of guidance.

- It was suggested that charities may have already put some of the information sources identified by the collaboration through a quality assurance process. Therefore, there may be an opportunity to work with charities to identify which sources of information have already been reviewed, hence reducing the workload for the collaboration.
- Where charities have appropriate review processes in place and capacity, there may be opportunities to review some “non quality-assured” guidance through their existing processes.
- Charities discussed the need to have a common agreement of the standards or framework used to create the body of guidance if the information is to be shared and/or used by the group of charities. Therefore, developing the framework/standards in collaboration would be beneficial.

Workshop delegates also discussed how trusted guidance could be made available to patients and professionals:

- Charities agreed that they are well placed to provide wide dissemination and raise awareness of nutritional guidance. It was suggested that information from the “body of authoritative guidance” could be made available to all stakeholders who could then disseminate this information through their existing channels. It was felt that by having a common source of information this would help ensure that cancer patients receive consistent nutrition advice.
- Another option discussed was to create a “central hub” for information which all stakeholders can sign-post to. Most delegates felt this would be extremely beneficial but recognised that this would require considerable resources to develop and sustain which may be challenging.
- In addition to online resources, the importance of complementary sources of information was discussed. The importance and availability of in-person tailored advice (especially for complex cases) was recognised. It was also felt that it was important to have some printed information (or format the content so it can be downloaded) as internet access can’t be assumed for all
- Providing training to relevant professionals would be an effective parallel activity
- ‘Ask the expert’ online help could be a great tool for patients

Some initial thoughts about the criteria for online information were collected from the discussion groups and included:

- **Simple, safe messages underpinned by scientific evidence are key.** Straightforward, general information should be available to all, with specific or targeted resources available through a search function. Where possible, information should also be sorted by cancer stage
- Accessibility and inclusiveness are crucial in design and should take into account different languages; visual impairments; different baseline levels of nutrition knowledge; and different dietary practices eg halal, kosher, vegan and diabetic diets
- Different levels/formats of information should be held for patients versus healthcare professionals
- Ideally, there would be a myth-busting element or scoring/rating system for robustness eg ‘trusted’, ‘worth a try’, and ‘potentially harmful’
- Multiple formats for information would be useful, including cooking guides and videos

**Questions moving forward:**

- **Sustainability:** how would governance work for the body of guidance? Who would be responsible for maintenance and how would this be resourced?
- **Standards:** what screening and thresholds would be applied to content? How could we best capitalise on existing expertise in this area?
- **Coordination:** how would the body of guidance complement other modes of delivery of nutrition information to ensure consistency and best experiences for patients?
- **Mechanisms:** would an MoU be the right approach to establish/manage a central/shared body of authoritative guidance?

## DISCUSSION SESSION TWO

### ***Enabling Research that will improve nutritional guidance for cancer patients***

As well as providing a resource for cancer patients, the Cancer and Nutrition NIHR infrastructure collaboration's body of authoritative guidance provides an opportunity to identify gaps in the evidence base. Along with the experience of charities and professional bodies in working with cancer patients, this presents an opportunity to support research in cancer and nutrition that is targeted to the areas with greatest need and maximum impact for patients.

The feedback from the group discussions showed that there are many potential ways that the participants could work together in this area, some immediately and others in the longer term. Charities interested in the same cancer types discussed pooling existing knowledge and there were wider discussions about setting up a '[Richmond Group](#)' style consortia to foster collaborative development of research initiatives.

### ***Directly Enabling Research:***

Many options for funding research in cancer and nutrition were discussed:

- Tapping into existing networks of expertise that are supported by the charities
- Encouraging researchers to apply to existing funding schemes, focusing on the quality of the research and the importance of nutrition in cancer
- Where there are no appropriate existing funding schemes, supporting researchers to approach one or more funders with well-developed research questions and proposals so that funders have the opportunity to review these and discuss potential approaches to funding
- Making the most of the collaborative approach by developing co-funded schemes with targeted calls that support excellence in the field (and ensuring the review panel is appropriately skilled)
- Using crowd-sourcing models that allow for increased patient and public input
- Collaborating with industry partners
- Providing funding for research posts, including studentships and fellowships, especially supporting people in the earlier stages of their careers to create future workforce capacity

### **Supporting Research:**

In addition to directly funding research there was discussion about other enabling mechanisms:

- Working together to raise the profile of nutrition research to ensure it is competitive, visible and recognised as a priority area. Suggestions included encouraging members of the research community to continue to present pressing research questions to funders, working internally with respective organisations to ensure nutrition features on research agendas, and wider lobbying eg [AMRC](#), Research Councils, other funders and relevant government bodies. It would be most effective to include patients and patient advocacy groups in this work.
- Ensuring the field is sustainable by embedding capacity building in research strategies
- Ensuring cancer and nutrition researchers are tapped into other complementary areas eg chronic diseases
- Issuing letters of support for targeted calls (even in the absence of financial support)

#### **Questions moving forward:**

- **Profile raising:** what are the most effective ways to develop nutrition research as a 'brand'?
- **Existing opportunities:** how can we make the most of existing funding schemes and support mechanisms to further cancer and nutrition research?
- **Mechanisms:** is an MOU, collaboration group or other approach the best way to progress this agenda and ensure appropriate representation of all participants?
- **Priorities:** what would be the best way to manage selection and prioritisation of research questions and projects?

## **NEXT STEPS AND ACTIONS**

**Please complete all actions by 31 March 2017**

### **1. Raising the profile of cancer and nutrition**

Many of the participants said they would be willing to discuss this area further with the appropriate people and teams within their organisations to help us raise the profile of nutrition research in cancer. Raising awareness and highlighting the current issues is an important step to enable change and ensure that cancer and nutrition becomes part of your organisation's agenda.

**ACTION for workshop participants:** Please discuss the themes highlighted in this workshop with relevant people within your organisations.

### **2. Improving the nutritional guidance available for cancer patients**

A number of people indicated on the feedback questionnaire that they were interested in working with the collaboration to develop the body of authoritative guidance. Following the workshop, the key points from the discussion session were fed back to the collaboration members who are working on this project. The collaboration are now working to develop a proposal for how this piece of work can be delivered based on feedback from the workshop. Once a draft has been prepared this will be shared with the charities who indicated that they were interested in working collaboratively with us

on this project in their feedback form. The collaboration are also keen to learn from the workshop participants and have asked that details of internal review processes for information which is made publicly available are shared to help inform the development of the review framework for this activity.

**ACTION for the collaboration:** Prepare a proposal for how the authoritative guidance will be delivered indicating roles for charities and other organisation involvement.

**ACTION for workshop participants:** Provide details of internal review processes relevant to this activity. Please provide details using the *Cancer and Nutrition funding and resources template* provided (email attachment or see appendix 2).

### **3. Enabling research in cancer and nutrition**

During the workshop a number of potential sources of funding/capacity building/other resources were identified and discussed in addition to discussions around potential collaborative funding opportunities. As a next step, we would like to map the existing resources that support cancer and nutrition research. By fully understanding the resources currently available this will help us identify opportunities to progress the work of the collaboration. In addition, this information can also be used to inform the development and areas of focus for a “Richmond Group” style consortia for cancer and nutrition.

**ACTION for workshop participants:** Please provide details of all resources that your organisation provides to fund/support cancer and nutrition research, projects and/or capacity building. Please provide details using the *Cancer and Nutrition funding and resources template* provided (email attachment or see appendix 2).

## Appendix One: Participating Organisations

Name	Organisation	Job Title
Sam Ahmedzai	University of Sheffield; Cancer and Nutrition NIHR infrastructure collaboration	Professor of Palliative Medicine
Karen Brown	University of Leicester; Cancer and Nutrition NIHR infrastructure collaboration	Professor of Translational Cancer Research
Helen Bulbeck	Brainstrust	Director of Services and Policy
Jennifer Cameron	NOCRI	Senior Research Collaboration Manager
Bernard Corfe	University of Sheffield; Cancer and Nutrition NIHR infrastructure collaboration	Senior Lecturer
Ramsey Cutress	University of Southampton; Cancer and Nutrition NIHR infrastructure collaboration	Associate Professor in Breast Surgery
Fiona Davey	Cancer and Nutrition NIHR infrastructure collaboration	Assistant Project Manager
Lucy Davies	Cancer Research UK	Senior Research Funding Manager
June Davis	Macmillan	National Cancer Rehabilitation Lead
Mhairi Donald	BDA Oncology Group	Macmillan Consultant Dietitian
Karla Duarte	NOCRI	Head of Collaboration Development and Delivery
Deborah Gilbert	Bowel & Cancer Research	Chief Executive
Susan Gillespie	NOCRI	Research Collaboration Manager
Kelly Grainger	Maggie's Centre	
Matt Hallsworth	NOCRI	Head of External Relations
Hazel Harper	Innovate UK	Innovation Lead, Health & Life Sciences
Mark Hollingsworth	Nutrition Society	CEO
Caroline Hoffman	Breast Cancer Haven	Clinical and Research Director
Eluned Hughes	Breast Cancer Now	Head of Public Health and Information
Jocelyne James	Prostate Cancer UK	Health Information Manager
Rachel Joliffe	Penny Brohn	Senior Research and Evaluation Officer
Glenys Jones	Association for Nutrition	Communications Manager
Greg Judge	Brain Tumour Research	Public Affairs Officer
Lindsay Keir	Wellcome Trust	Senior Portfolio Developer
Orla Kennedy	Association for Nutrition	Council Member
Jane Loughnane	Target Ovarian Cancer	Nurse Advisor
Giota Mitrou	WCRF	Director of Research Funding & Science External Relations
Oliver Morris	Urology Foundation	Grants & Administration Officer
Fehmidah Munir	Loughborough University; Cancer and Nutrition NIHR infrastructure collaboration	Reader in Health Psychology
Jane Murphy	Bournemouth University; Cancer and Nutrition NIHR infrastructure collaboration	Associate Professor in Nutrition
Elio Riboli	Imperial College London; Cancer and Nutrition NIHR infrastructure collaboration	Director of the School of Public Health

Carolyn Rogers	Breast Cancer Care	Senior Clinical Nurse Specialist
Jill Scott	Macmillan	Learning and Development Manager
Sara Stanner	British Nutrition Foundation	Science Director
Hilary Stobart	NCRI/ICPV; Cancer and Nutrition NIHR infrastructure collaboration	PPI Advocate
Jenna Stockwell	Macmillan	Physical Activity Project Manager
Lisa Trickett	Yorkshire Cancer Research	Community Health Initiatives Manager
Lesley Turner	Cancer and Nutrition NIHR infrastructure collaboration	PPI Work Stream Lead
Justin Webb	Macmillan	Engagement Manager
Sagit Weiss	Crowdacure	CEO
Martin Wiseman	World Cancer Research Fund; Cancer and Nutrition NIHR infrastructure collaboration	Medical and Scientific Adviser
Steve Wootton	University of Southampton; Cancer and Nutrition NIHR infrastructure collaboration	Associate Professor in Nutrition

## **Cancer and Nutrition NIHR infrastructure collaboration Funding and resources template**

### **Purpose**

Thank you for indicating that your organisation is interested in collaborating with us.

During the workshop's discussion sessions, a number of charities mentioned existing funding schemes and internal review mechanisms for information which could help the collaboration to further its work on improving provision and research for nutritional guidance for cancer patients.

To help us move forwards, we would be grateful if each organisation could provide us with information about their funding opportunities to support research and capacity building initiatives (e.g. infrastructure, personal career development, fellowships) that could be relevant to nutrition within cancer research. This will enable us to map existing resources and opportunities and will also help inform any future activity in this area.

To help us develop the body of nutritional guidance for cancer patients, the collaboration is also keen to understand how your organisation ensures that the guidance, advice and information that you provide is quality assured. By identifying and understanding existing mechanisms this may help inform the development of a review framework for the body of authoritative nutritional guidance.

This information can be difficult to find online so we hope that you will complete this form to help us move forward with our agenda as quickly as possible.

We would be grateful if you can return the completed form to [cancer\\_nutrition@nihr.ac.uk](mailto:cancer_nutrition@nihr.ac.uk) by 31 March 2017

**Charity details**

<b>Organisation name</b>	
<b>Form completed by</b>	
<b>Job title</b>	
<b>Date completed</b>	
<b>Email</b>	
<b>Phone number</b>	

**Funding streams (please copy and paste this table if more than one relevant funding stream is available)**

<b>Type of scheme</b>	<input type="checkbox"/> Programme funding <input type="checkbox"/> Project funding <input type="checkbox"/> Infrastructure <input type="checkbox"/> Capacity building e.g. training, PhD or other studentships <input type="checkbox"/> Other* * Please specify:
<b>Scheme name</b>	
<b>How does nutrition fit into the scope of this scheme?</b>  <i>Is nutrition directly within remit of the scheme?</i> <i>Are there restrictions/conditions that would apply?</i>	
<b>Maximum award</b>	
<b>Number of awards given each year</b>	
<b>Application process and timeline</b>	
<b>What can the award be used for? (i.e. research costs, salary costs, travel)</b>	
<b>Website link if online information available</b>	

**Quality Assurance**

**Please tell us about the processes of quality assurance within your organisation for any guidance and information produced/disseminated (for both patients and clinicians)**

***Who is it reviewed by?  
Does it receive the Information Standards mark or other recognised quality standard?***