

NIHR & Charities Consortium for Hospice and Community Research

Paul Charlton

NIHR Patient Research Ambassador

Cancer and Nutrition NIHR infrastructure
collaboration work stream member

London BMA House: 19th April 2018



Aims:

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



Aims:

To promote and enable research to address knowledge gaps in nutrition at all stages of life in relation to cancer.



Aims:

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.



Nutrition and Cancer

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



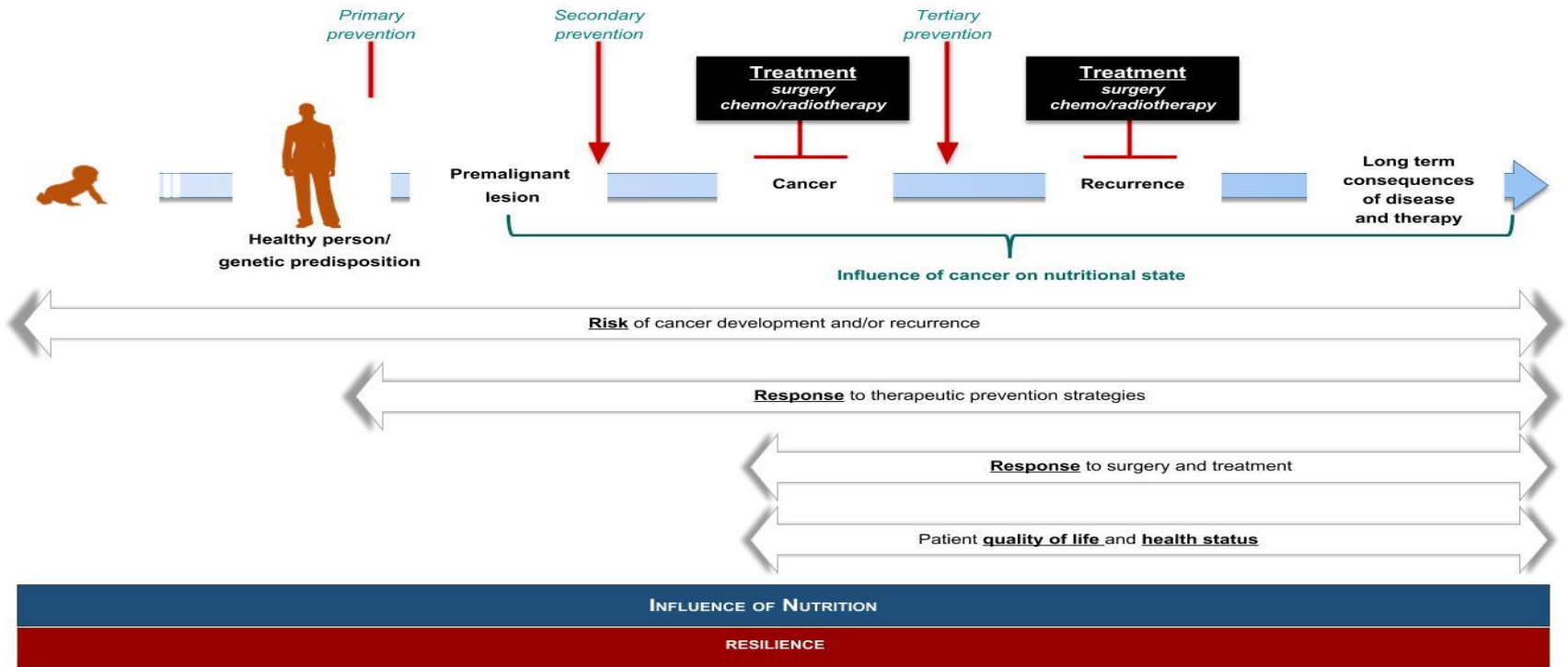
Nutrition and Cancer

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**.




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





Improving research quality and relevance

- Providing a different perspective through personal knowledge and experience
- Making language and content more appropriate and accessible
- Ensuring study methods are acceptable for patients
- Ensuring research outcomes are important to public
- Identifying research topics of importance



”No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.”

Professor Dame Sally Davies, Chief Medical Officer (Foreword in [Staley, 2009](#))

What is important to consumers when working with researchers?

We're just evidence-base junkies...

...looking to score!



<https://kristinastaley.com/2015/08/27/were-just-evidence-base-junkies/#respond>

Patient and public involvement work stream

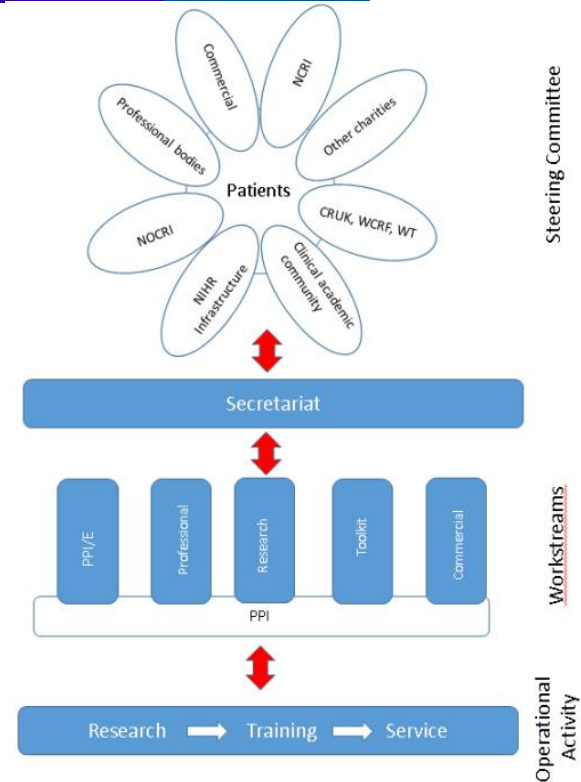
Aim:

- To establish a framework that ensures patients and the public remain at the heart of the collaboration.

How patients and the public drive our activities:

- The patient voice is embedded within all activities of the collaboration – two members on each work stream
- Work stream members have engaged directly in raising awareness within a number of the NCRI CSGs.
- Patient representation on the Steering Committee
- Patients organised and ran a patient panel for the Charity Workshop held in London in September 2016.

Chair: Lesley Turner



Phase One Patient Survey (2015)

To establish if patients are being given consistent, evidence-based advice

To understand what other nutritional support, advice and care would patients like to receive

To determine what the major gaps are in service provision at diagnosis, during and after treatment

Key findings

- N=96, 72% female
- Breast (36%), kidney (20%), blood (10%)
- Many reported unsatisfactory experiences of nutritional care in relation to cancer
- Particular gaps identified by patients: included how to deal with side-effects of chemotherapy, weight changes and specific foods and diets that patients should or should not consume.
- **Identified need for better evidence to allow more reliable and consistent nutritional and dietetic information for cancer patients**

Phase One Clinician Survey (2015)

Aim

To understand clinicians' perceptions of the major gaps in clinical practice and research in nutrition and cancer

Key findings

- n=77
- Getting recognition of the importance of including nutrition in cancer care is challenging
- More large-scale interventional trials are needed, but they are difficult to conduct for practical (funding and infrastructure) reasons
- Better data and scientific evidence needed to produce meaningful advice for patients and recommendations for clinical care
- Nutritional assessment is not carried out in a systematic way
- Insufficient training for dietitians and other clinicians wishing to specialise in nutrition and cancer

Body of authoritative guidance project

- September 2016 - a meeting with cancer charities to discuss how to join up cancer and nutrition research for the benefit of patients
- Identified that patients, carers and health care professionals do not have adequate access to reliable evidence-based advice about nutrition and cancer.
- Two further workshops since then to define the requirements and plan the project



Body of authoritative guidance project

- One overarching project to develop a quality-assured signposting resource of reliable nutritional advice in cancer for patients and carers, and another for health care professionals.
- Funding application submitted to the BDA GET for the health care professional resource, led by Prof Jane Murphy (Bournemouth), Dr Fehmidah Munir (Loughborough) and the BDA Oncology Specialty Group (Lucy Eldridge and Dr Clare Shaw)
- The project team for the patient and carers resource is being led by Katherine Hale, Head of Health Information at WCRF UK, funding application in progress

Research for better advice, better care and better outcomes for cancer patients

PANACHE (Physical Activity and Nutrition During Adjuvant Chemotherapy) – led by Professor Diana Eccles, application submitted to NIHR Programme Grants for Applied Research

- Lesley Turner (lead of the PPI work stream) has been involved from the start and is a co-applicant
- Lesley has been involved in the study design and also co-writing the lay summary and other sections of the application
- The Phase One patient survey helped inform the focus of the study – how to deal with weight changes and the side-effects of chemotherapy

Research for better advice, better care and better outcomes for cancer patients

EAT-CIT (recently funded by Tenovus) – informing the content of a web-resource for self-management of eating difficulties during chemotherapy and immunotherapy.

- Patient representative is a co-applicant, who also influenced the research objectives through providing experience on the eating problems experienced during treatment




Toolkit for characterising nutritional status in cancer

A Toolkit is being developed to recommend which nutritional screening and assessment measurements should be made in routine clinical practice and within cancer and nutrition studies to enable good quality research.

Patients are key to this process as they will feed back on which assessments are feasible and acceptable in routine clinical practice and within studies.

Leads for project: Dr Bernard Corfe (Sheffield) and Dr Steve Wootton (Southampton)



“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

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

www.cancerandnutrition.nihr.ac.uk/
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Ask of you

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Ask of me
And Sam!

Connecting Health Research and The Arts as an expression of patient and carer experience



Reluctant in Departure

Reluctant in departure,
He placed the bonnet upon his head.
Re-tidied the last shift to his raincoat collar.
Moving up to her bed, he bent and stayed still,
Stroked her arm and then her chest.
He caressed her head with a murmuring kiss,
“God bless you Peggy”, loved the words of his parting
address.

WE ARE
MACMILLAN.
CANCER SUPPORT