NHS
National Institute for
Health Research

NOCRI supported Collaboration/Group Work stream Template

Cancer and Nutrition NIHR infrastructure collaboration

Characterising nutritional status in cancer (the Toolkit) work stream

Introduction

The following document outlines the objectives and agreed timelines for delivering a work stream that focuses on the development and/or standardisation of tools for characterisation of nutritional status for cancer patients, at all stages of the cancer patient journey. The Toolkit should be useable by both clinicians; practitioners and researchers to generate research-standard data which will help define and understand the nutritional status of patients. It should not represent a significantly incremental burden on patients at times of distress. The toolkit will consist of a range of tools with standard operating procedures within a quality assured framework. This will include recommended methods for assessing dietary quality, body composition, physical and metabolic fitness and relevant nutritional biomarkers at basic, intermediate and advanced levels. Methods must be fit for purpose, robust and validated, delivered to defined standards of competence, and interpreted in accordance with an agreed purpose and understanding.

Background

Nutritional factors are key determinants of common cancers in the UK, and are important prognostic indicators in people with diagnosed cancer. However, there is often limited assessment of nutritional status beyond height and weight unless patients have been referred to a dietetic service. Application of nutritional screening leads to routine assessment in a subgroup of cancer patients, most likely those appearing undernourished, even though it is recommended by NICE. There are a range of tools being used by clinicians delivering nutritional care to cancer patients and they take one of two forms; screening of nutritional risk e.g. Malnutrition Universal Screening Tool (MUST) and a more comprehensive assessment of nutritional status e.g. Subjective Global Assessment (SGA). .

In order to serve the research agenda of this collaboration, standardised quality-assured procedures for measuring nutritional status in routine care are needed to ensure national consistency in the collation of data. This will provide an opportunity to collate large nutritional data sets from which robust scientific research can be carried out, enabling evidence based nutritional care for cancer patients..

Aims

The NIHR Cancer and Nutrition infrastructure collaboration was set up to foster collaborative translational research in nutrition and cancer for the benefit of patients, clinicians and researchers. The aim of the Toolkit work stream is to develop a quality-assured framework standardised for use by demonstrably competent healthcare professionals in order to characterise nutritional status in cancer patients. The Toolkit may be offered at different levels from the simplest that could be integrated into routine care and within research cohorts through to more advanced specialist nutritional measures that require higher level capabilities and resources.

Project Team and Roles

Work stream member	Role/Responsibilities	Name (interests, networks and affiliations)	Organisation
Work stream lead	Responsible for the delivery of the work stream including communication of outputs and reporting progress to steering group.	**Bernard Corfe** Interests: colorectal adenoma, diet and lifestyle prevention of adenoma recurrence, modelling, nutrition and GI health. Networks: Nutrition Society (Science Committee; Training and Education Committee) ECMC Conference proposer "Nutrition and Cancer Survivorship" RSM-Nut Soc, 2017 Editor: Nutrition and Cancer; European Journal of Nutrition	Representing Nutrition Society; Sheffield ECMC; Sheffield University
Work stream sponsor (if different to work stream lead)	To provide steer and guidance to the work stream lead and team. The sponsor will be a member of the collaboration/group steering committee.	**Steve Wootton**	Southampton BRC, NIHR infrastructure
Team members		**Theresa Wiseman**	Lead for Health Services Research. Royal Marsden
		Margaret MacRae	Dietitian, UCLH
		Rhys White NIHR-funded trainee	Principle Oncology Dietitian at Guy's and Thomas' Hospital. BDA Oncology Specialist Group

		Marie Cantwell	Senior Lecturer in Nutrition and Cancer Epidemiology. Queens Belfast
		Laura Miller	Clinical/team lead oncology dietitian, Nottingham University Hospitals
		Millie Barrett	Project Manager, Cancer and Nutrition NIHR infrastructure collaboration
		Sorrel Burden	Clinical Senior Lecturer in Dietetics, University of Manchester and Salford Royal Hospital
		Fiona Davey	Assistant Project Manager, Cancer and Nutrition NIHR infrastructure collaboration
		Elspeth Banks	Patient and Public Representative NCRI Psychosocial Oncology Survivorship CSG, NIHR Consumer Forum; Trustee of ICPV
		Jacqui Gath	Patient and Public Representative ICPV
		We are in the process of identifying a clinical representative for the work stream	
		Other interested parties who may join later e.g. charity representation	

Work stream Objectives and Project Plan

Objective 1: Collate current nutritional assessment tools in use with cancer patients – a mapping exercise			
Outputs	**Activities**	**Timeframe**	**Responsible person**

1.1 Directory of tools in use across UK incl. devolved nations	Redraft Laura Miller's survey	Months 1-3 2 weeks	
	Apply questionnaire to relevant professional bodies to find out what tools they currently use. Interviews with key personnel?	Months 3-9	
1.2 Identification of the gaps in care and assessment of why gaps exist	Workshop for team members at which findings of mapping exercise are presented and discussed	Date set for 12th October	All
1.3 Identification of best practice in clinical care	A literature review on nutritional measurements and strengths/weaknesses/suitability for patient group A process is needed to identify best practice, and then identify both a wish list for the toolkit as well as realistic deliverables		Sian/BDA Laura Miller (contribute to literature review) Bernard/Marie
Objective 2: Consensus and adoption of recommendations i.e. basic routine data is collected in a standardised and quality assured manner			
Outputs	**Activities**	**Timeframe**	**Responsible person**
2.1 Agree what basic nutritional data is desirable and achievable on a routine and universal basis – the "core" tool or toolkit	Consensus building exercise and standardisation of protocols	October 2016 - February 2017	Laura Miller (contribute to) All
2.2 Identify what is needed to ensure routine capture of this data systematically	A needs assessment Engagement with Farr Institute of Health Informatics Research*, Cancer Registration Forum, and CONCORD programme (and others?)	Months 12-24	
2.3 Design of quality assured framework whereby methods are fit for purpose, robust, validated, delivered to defined standards of competency, with agreed purpose and understanding	Working group set up to design Standard Operating Procedures within Quality Assured Framework		
2.4 Training for relevant staff designed and rolled out	Design and delivery of training programmes for relevant staff, based on SOPs within a QAF		

(or is this part of professionals work stream?)			
Long term Objective 3: Deliver high quality nutritional data on cancer patients for use in future research studies			
Outputs	**Activities**	**Timeframe**	**Responsible person**
Roll out of toolkit phase 1 (minimum measures)	Do we not need a trial first before a role out? to see if achievable in clinical practice? Launch in areas where all relevant personnel are trained and competent		
Roll out of toolkit phase 2 (advanced version)			

*The Farr Institute is a body whose role is to link electronic health data with other forms of research and routinely collected data, as well as build capacity in health informatics research

Progress report (June 2016)

- The questionnaire has been modified from LM's original version.
- It is being piloted with dietitians from Southampton, oncologists, surgeons and nurses.
- The electronic version of the survey has been developed for free using iSurvey. The technical function of the survey has been tested using the 'Preview' function of the website.
- A thematic framework has been developed to enable the analysis of the survey data.
- Contacts have been identified within the BDA (Oncology Specialist Group as well as general BDA), Royal College of Nursing forums, Association of Cancer Physicians and BASO ACS which will facilitate the distribution of the questionnaire.
- It has been arranged to have the survey advertised via the NIHR and NOCRI Twitter accounts, and for a news story to be published on the NIHR website.
- Two teleconferences have been held so far. Dates are being set for further teleconferences up until November 2016 (excluding August). A face-to-face meeting is being arranged for early October, which will also include members of the Professionals work stream.

Progress report (September 2016)

Membership: Following discussions at the previous Steering Committee, Jacqui Gath and Elspeth Banks have joined the work stream to ensure inclusion of the patient voice. Both bring a wide range of expertise and value to the group. Two other members have been unavailable over the summer for personal reasons but are now re-engaging.

Activities: Since the last SC, the WS has completed development of a questionnaire exploring nutrition screening and assessment processes in current clinical settings. The questionnaire was piloted, feedback incorporated and subsequently disseminated via a wide range of organisations such as the BDA Oncology Group and others. We have 411 responses in total, including 145 dietitians, and 182 nurses. Data from respondents has been entered into a spreadsheet. Initial top-level analysis of the dietitians' data will be presented to the SC on 13/09/16. A plan for more detailed analysis and key questions has been developed by the WS.

Ongoing: Our analysis of the survey data is in very early stages, and we aim to report as a paper. Feedback from SC would be appreciated in the value or otherwise of trying to increase numbers of clinicians (currently 42 doctors, 11 surgeons) in the samples.

We are planning a joint face-to-face meeting with members of the Professionals work stream in October.

We are starting consideration of the organisation of a modular toolkit. Initial thoughts were around a Bronze/Silver/Gold standards model. However another suggestion from the WS is a stage-specific toolkit for Diagnosis & Treatment / Survivorship / Palliative. As different research environments and questions might be involved, germane (but relatable) toolkits may be needed. Continuous dialogue with the research WS would therefore be a key part of our planning and development.

Work stream communications & stakeholder engagement

Work stream communications and stakeholder engagement should be developed in line with the collaboration/group communication plan.

Communication should be well thought-out at work stream, objective and output levels. In addition, consideration of whether communication should occur before, during and/or after completion of outputs, objectives and the overall work stream is also important.

Outputs from each objective of the work stream will be used to inform subsequent objectives and may also be communicated externally to key stakeholders. In order to tailor the output appropriately, consideration will therefore be given to:

- Format (e.g. written report, verbal recommendation, data, briefing note, presentation slides, leaflet etc...)
- Audience (e.g. internal stakeholders v.s. external stakeholders)
- Communication route (e.g. NIHR Hub, as part of comms from other NIHR strategic objectives, etc...), and
- Timing (e.g. Q1 20YY/YY, Month YYYY, or during what point in the work stream (before, during and/or after an objective or output)).

The work stream will generate a range of communication needs and opportunities that will be relevant for both internal and external stakeholders. For both the overall work stream, and specific outputs from each objective, key audiences will be identified and assessment will be made of the appropriate content and timing of messages.

Internal Stakeholders (work stream members and steering committee)					
Communication Type (e.g. status report, achievement of output, etc)	**Audience** (e.g. project team, advisory board)	**Format** (e.g. report, slides)	**Frequency/Timing**	**Route** (e.g. meeting, t-con, email)	**Who is responsible for this?**
Regular email contact and meetings	Work stream team	Reports, brief updates	TBC	face to face; Skype or email	BC/SW
Progress reports on objectives	Other work streams, Steering Committee, NIHR/NOCRI	Papers, slides	TBC	Email, meetings, slides, teleconf	BC/SW
External Stakeholders					

(external to work stream and steering committee)					
Communication Type (e.g. status report, achievement of output, etc)	**Audience** (e.g. NIHR Infrastructure, NOCRI)	**Format** (e.g. report, slides)	**Frequency/Timing**	**Route** (e.g. meeting, t-con, email)	**Who is responsible for this?**
Bulletins on progress	Professional bodies and their members; patients and public	Papers; collaboration newsletter?	TBC	Email, presentations at meetings, posted on collaboration website	BC/SW/MB
Promotion of completed outputs	Professional bodies and their members; patients and public	Papers, slides	TBC	Email, presentations at meetings, posted on collaboration website	BC/SW/MB