



Meeting title:	Cancer and Nutrition NIHR infrastructure collaboration Steering Committee	
Date:	13 th September 2016	Time: 11am-1pm
Location:	Imperial College, Norfolk Place, London	
Present:	Prof Alan Jackson (AAJ) – Chair	
	Kate Allen (KA), Lucy Allen (LA), Millie Barrett (MB), Bernard Corfe (BC), Ramsey	
	Cutress (RIC), Fiona Davey (FD), Lucy Davies (LD)), Martin Wiseman (MJW), Steve
	Wootton (SAW), Lesley Turner (LT), Elio Riboli (ER	t), Karen Brown (KB), Clare Shaw
	(CS), Giulia Mangiameli (GM)	
Apologies:	Helen Campbell (HC), Richard Martin (RM), Fehmio	dah Munir (FM), Mark Hull (MH),
	Mark Samuels (MS), Karen Phekoo (KP), Karla Dua	arte (KD), Amanda Cross (AC)

1.	Welcome and apologies Professor Jackson welcomed everyone to the meeting and thanked them for attending. A list of apologies was given.	Action
2.	Previous minutes These were agreed as an accurate record of the June meeting and will now be posted onto the Collaboration website.	
	Matters arising Work stream 5 'Engaging with Industry' is on hold until other activities have been progressed. SAW and LA are discussing when and how best to take this work stream forward.	
3.	Strategy a) Charity funding event A summary report from the event was tabled at the meeting. LA reported back via Skype on the MRC-T and NOCRI-led event on 5 th September which brought together over twenty medical research charities to discuss the feasibility of forming of a funding consortium. A positive response was given by fifteen of the charities attending, who indicated their interest to have further discussions.	
	NOCRI and MRC-T will meet again next week to plan a second workshop for the interested charities, to discuss possible consortium models in more detail. It is envisaged this will be a competition-based system whereby the charities involved are able to opt in or out of specific projects proposed via the Cancer and Nutrition Collaboration.	
	AAJ thanked LA and others at NOCRI for organising the event, and also thanked LT for putting together a strong patient panel that allowed the charities to hear first-hand about the difficulties facing cancer patients in their quest for consistent evidence-based nutritional advice.	
	Action: Each work stream to consider what opportunities a charity consortium may offer them.	All WS leads
	Action: Each work stream to be represented at the next charity workshop to take place either late 2016 or early 2017.	LA/KD
	It was agreed that it would be beneficial for a charity consortium to be set up in order to demonstrate to new BRC directors what structures the Collaboration has in place	

to involve charity funders in making decisions about research projects.

AAJ commented that this is an important step in moving the research agenda forward, to develop a system that is better fit for purpose than current systems that researchers can at times find too restrictive and difficult to navigate when it comes to cancer and nutrition research. A specific opportunity has been identified to bring about a step change towards working in a more collaborative way, bringing together researchers from different institutions to develop and submit joint funding applications.

b) NIHR infrastructure

MJW introduced the item, explaining the background and purpose to the two documents. The first is a Strategic Plan for 2017-2022 setting out the purpose, aims and vision for the Collaboration. The second is a supporting document specifically aimed at BRC Directors, explaining the potential advantages to them of engaging with the Collaboration.

A meeting of new BRC directors is taking place on the 16th November, if appropriate, with representation from the Collaboration. We will be seeking a meeting with new BRC Directors around the New Year to make progress on securing support for the Collaboration beyond March 2017.

The draft documents were agreed with minor amendments to the Strategic Plan, based on inclusion of some additional wording from Clare Shaw around the impact of cancer on nutritional status.

Action: Additional wording to be added in and document considered signed off.

MB

4. Work stream updates

Joint meeting between Professionals and Toolkit work streams on 12th October FD informed the meeting that arrangements for this joint meeting are going well, and there will be a separate meeting of the project team immediately after this one to discuss the programme and agenda for the day. A venue has been booked in London with approximately twenty five people due to attend.

KA asked if WCRF's Health Information Officer, Sarah Toule, could be invited to this joint meeting, as she is leading on some similar work at WCRF.

Action: Sarah Toule to be invited to the joint meeting as long as numbers allow.

FD

PPI:

There are three new members to this work stream: Jacqui Gath, Paul Charlton and Sophia Turner. ST is a breast cancer patient who accessed nutritional support throughout her treatment via a private clinic and is keen that good practice in the private sector is shared more widely where appropriate.

On 24th November, Hilary Stobart will be presenting to the Breast NCRI CSG and is discussing with Ellen Copson (oncologist at Southampton) the possibility of a joint presentation. There are at least two other CSGs who have also expressed an interest in being kept up to date about the Collaboration – Psychosocial and Palliative Care. It was suggested that the PPI group could start looking into examples of best practice from different service providers, including the private sector, in order to capture the unique patient perspective.

Action: LT to discuss this with the rest of the PPI group at the next TC scheduled for Tuesday 27th September and report back to the Steering Committee.

LT

It was noted that the distinction between registered dietitians and nutritionists is important. The term Registered Dietitian is legally protected while the term Nutritionist is not. The latter therefore offers no guarantee of qualifications, skills or competencies. The UK voluntary register of nutritionists is held by the Association for

Nutrition (AfN), and registrants of the AfN have to demonstrate thay have achived certain standards. However AfN registration is not required to use the title nutritionist. In addition, it was recognised that in the private sector it can be easier to get markers of nutritional status tested, which may not be available in the NHS. Therefore, it should be recognised that the opportunities are different in each setting.

The National Cancer Patient Experience Survey (NCPES) captures some information about diet and lifestyle in the free text answers people are able to give. The Royal Marsden has done some investigation into this. It was suggested that a question specifically about diet and lifestyle advice should be added into the survey in future in order to capture people's experiences more fully.

Action: CS and LT to work together on how we might utilise existing data from the NCPES and improve future data capture.

CS and LT

Professionals:

RIC updated the group about new members to this work stream: Professor Robert Thomas, a consultant oncologist specialising in prostate cancer; Jill Scott, a dietitian and Macmillan Learning and Development Manager; Justin Roe, Clinical Service Lead, Speech and Language Therapy, Imperial and Royal Marsden; and Kelly Gleason, CRUK Senior Nurse, Imperial.

As outlined in the NOCRI template, there are two main pieces of work in this work stream: involvement in the Toolkit survey, and compiling a catalogue of cancer nutrition advice for patients and professionals. For this second task, authoritative national sources of evidence were accessed. The advice is varied in terms of who it is aimed at and who it is written by. It was agreed that the catalogue of advice needs to be distilled first in terms of whether the advice found is consistent with other sources etc. Many charities give advice that is not evidence-based, and this is important as around 50% of advice to patients is coming from charities. It was suggested the catalogue be clustered into advice to professionals and advice to patients. There may be opportunities to disseminate the catalogue of advice via the NIHR dissemination pathway in the future.

Action: Professionals work stream to condense the catalogue into a report that could be made available to cancer charities, at the next meeting to progress the charity funding consortium, for the purposes of cross-checking with advice they give.

Action: Professionals work stream to update their NOCRI template to reflect the changed timelines, due to continuing to focus on the catalogue of advice in order to produce a worthwhile end product.

Action: Once the template has been updated, a new version will be uploaded onto the Collaboration website.

AAJ updated the group on activities of this work stream. A matrix of research proposals has been put together by two members of the work stream and circulated for comment. The Collaboration has indirectly inspired a number of research initiatives focusing on nutrition, physical activity and anthropometry in cancer survival. The intention is to build more evidence in order to strengthen the currently weak evidence base and thereby be able to provide robust advice to patients and improve cancer outcomes for individuals.

Examples include a project led by Diana Eccles around body composition and breast cancer survival in Southampton, and an application to the CRUK Catalyst Programme involving many international partners and using existing population cohorts in Europe: http://www.cancerresearchuk.org/funding-for-researchers/our-funding-schemes/population-research-catalyst-award

The project team will be presenting to the CRUK Special Scientific Panel on 26th November and hope to receive feedback shortly afterwards. The award is for up to £5m for a five year project; only one will be awarded.

RIC, MJW

RIC, MJW

FD

Action: To progress the research work stream, and identify leadership, a conversation will be arranged between AAJ, ER and KB. Toolkit: BC updated the group on activities of this work stream, against the circulated report of preliminary findings from the clinicians' survey. Responses have been received from 145 dietitians and 182 nurses, with far lower numbers from medical respondents. Responses from dietitians are consistent with experiences of the BDA Oncology group according to Toolkit members. Action: The list of organisations and associations approached to distribute the survey will be circulated to the Steering Committee, to identify obvious omissions. It was suggested that the upcoming NCRI Conference may also be an opportunity to increase response numbers. Action: LT to consider how to capitalise on this potential opportunity. LT 5. Communications strategy MB reported that the Secretariat has asked for a small working group to be set up within the Collaboration, to support development of a communications database. The purpose of the database will be to have a small number of lead people and agreed key messages within the framework of the new Strategic and Business Plans. Action: All members of the SC to consider who from their own organisation could join this small working group and contribute to development of a communications database, and pass names to MB. Action: As part of the Communications Strategy, a short quarterly newsletter will be circulated to all Collaboration stakeholders after each SC. 6. Business Plan and budget SAW reminded the group of the Draft Business Plan and budget discussed at the last SC meeting in June. Attention was drawn to item 2.3 in the plan and contributions to this section on benefits and impacts of the Collaboration are welcomed. Action: Contributions to section 2.3 to be sent to MB for addition into current draft. Ongoing support from the Southampton BRC was recognised and welcomed, with special thanks to Karen Phekoo for her role in this. However, there			
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	Directors as it is important to demonstrate our commitment to PPI as a fundamental part of the Collaboration's work. Supporting the Collaboration could also help BRCs meet their obligations in this area. There will be an end of year report from the Collaboration that looks forward to what can be delivered in Phase 3.	
	Action: Secretariat to discuss and schedule writing of end of Phase 2 report.	MJW
8.	Priorities and next steps Finalising Strategic Plan and supporting document, with additional words provided by Clare Shaw. Setting up relevant meetings with BRC Directors to discuss future involvement in the Collaboration.	MB AAJ, MJW, LA, MB
9.	AOB BC reported on a MSc student who has used the Phase One survey with cancer patients in South Yorkshire and has found similar results. Action: BC to send pdf of final project to MB and a reference to this will be put on the Collaboration website.	
10	Date and host of next meeting: The next meetings will be held on Wednesday 14th December at WCRF and on Wed 22nd March at a venue to be confirmed.	nesday