



<b>Meeting title:</b>	Cancer and Nutrition NIHR infrastructure collaboration Steering Committee	
<b>Date:</b>	14 <sup>th</sup> December 2016	<b>Time:</b> 11am-1pm
<b>Location:</b>	WCRF, Bedford Place, London	
<b>Present:</b>	Prof Alan Jackson (AAJ) – Chair, Millie Barrett (MB), Karen Brown (KB), Jenny Cameron (JC), Bernard Corfe (BC), Ramsey Cutress (RIC), Amanda Cross (AC), Martin Wiseman (MJW), Steve Wootton (SAW), Lesley Turner (LT), Elio Riboli (ER), Giulia Mangiameli (GM), Mark Samuels (MS) for agenda item 5	
<b>Apologies:</b>	Kate Allen (KA), Carrie Bolt (CB), Helen Campbell (HC), Fiona Davey (FD), Lucy Davies (LD), Richard Martin (RM), Fehmidah Munir (FM), Karla Duarte (KD), Clare Shaw (CS)	

1.	<b>Welcome and apologies</b> Professor Jackson welcomed everyone to the meeting and thanked them for attending. A list of apologies was given and new people introduced themselves.	<b>Action</b>
2.	<p><b>Minutes of the last meeting and matters arising</b> These were agreed as an accurate record of the September meeting and will now be posted onto the Collaboration website.</p> <p><b>Communications Strategy:</b> MB will follow this up with individual organisations represented on the Steering Committee. A meeting has been set up with Jane Heath at WCRF in January.</p> <p><b>BRC Directors meeting:</b> AAJ reported that he recently had a helpful meeting with the Department of Health and NOCRI, at which it was suggested there may be the opportunity to present future plans to the meeting of BRC Directors scheduled for the New Year. This would not preclude meeting with the new BRC Directors at a future date.</p> <p><b>a) Updated FY 2016-17 budget</b> SAW reported that this is an updated accurate budget of current support for the Collaboration from Southampton BRC for the current financial year. Future budgets for beyond April 2017 have not been produced yet.</p>	

<p>3.</p>	<p><b><u>NIHR Office for Nutrition Research</u></b></p> <p>AAJ reported on three main ongoing activities related to his role as NIHR Director for Nutrition Research:</p> <ul style="list-style-type: none"> <li>i) A national review of nutrition-related research as requested by the OSCHR committee (Office for Strategic Collaboration in Health Research). A report will be made to OSCHR early in 2017. The panel for the review is organised by MRC and chaired by Professor Chris Day.</li> <li>ii) A review of nutrition-related research supported by NIHR during 2016-2017, which includes activity through the Central Commissioning Facility (CCF) infrastructure and programme sections, Trainees Coordinating Centre (TCC), NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), and the Clinical Research Network (CRN). A report has been presented to DH and NIHR. There is ongoing support for a wide range of nutrition-related research, much of which is in the area of cancer and nutrition. It was noted that much of the nutrition-related research was being conducted outwith the BRCs.</li> <li>iii) The Cancer and Nutrition NIHR infrastructure collaboration provides a worked example of the nature of nutrition-related research. The lessons learnt within the Collaboration have resonance for other areas of clinical research, indicating possible opportunities to better structure activities to enable sharing of experience and greater efficiencies within the process. This suggests opportunities for improved support for patients and patient services in areas of complex disease. There is recognition at senior level within DH and NIHR of what the Collaboration has achieved and encouragement to continue the activities.</li> </ul> <p><b>Action: A formal request to be submitted to The National Office on behalf of the Collaboration, to produce a summary statement of the review into NIHR nutrition-related research at the next Steering Committee meeting in March.</b></p>	<p>Secretariat</p>
<p>4.</p>	<p><b>Phase 2 activities:</b></p> <ul style="list-style-type: none"> <li>a) <b><u>Clinicians' Survey report</u></b></li> </ul> <p>BC presented the Executive Summary (Attachment 8) of the preliminary findings from the Clinicians' survey, a joint effort between the Toolkit and Professionals work streams. In total 490 responses were received, with nurses and dietitians being the highest contributors, with doctors, surgeons and speech and language therapists in smaller numbers. Key findings from the survey were discussed, including data on nutritional screening and assessment of cancer patients (both inpatients and outpatients); collection and storage of nutritional data; most common measurements and tools used; most common nutritional concerns raised by patients; provision of information about diet and nutrition to cancer patients by clinicians; the lack of training in nutritional care for cancer patients; and similarly the lack of awareness of nutritional guidelines for patients amongst clinicians overall.</p> <p>BC commented that the results suggest that many patients may be lost to nutritional assessment if they not identified as being malnourished when screened with the MUST tool. There is scope for improvement the uptake of different screening measures to make sure patients are being picked up and supported. It was commented that the most common nutritional concerns raised by patients are entirely consistent with the results of the smaller Phase One survey. Further qualitative analysis remains to be carried out, in particular to analyse the responses around what nutritional guidelines clinicians are using when discussing</p>	

<p>nutrition with their patients.</p> <p>The ambition is to provide a manuscript for a suitable peer-reviewed journal and other articles for discipline specific journals such as <i>Complete Nutrition</i>, <i>Nursing Times</i>, and <i>Dietetics Today</i>, the official magazine of the BDA.</p> <p>RIC then reported on behalf of the Professionals work stream that they intend to adapt the survey and circulate it to GPs as a modified version, so that the results and write-up can be more complete. It was agreed that in order not to delay writing up of the results so far, primary care and secondary care would be approached as separate surveys with separate write-ups. It was agreed that a patient representative should be on the drafting and writing-up group.</p> <p><b>Action: A patient representative to be identified to join the analysis sub-group as soon as possible, to ensure PPI input at all stages.</b></p> <p>It was agreed that the recommendations we make as a result of the survey findings will be key, and should focus on what needs to be done to rectify the problem we have identified. It may be for others, outside of the Collaboration, to decide what action needs to take place.</p> <p>The Steering Committee thanked and encouraged BC in this endeavour. The importance of this piece of work was formally recognised as an important step in delivering the Collaboration’s ambitions to improve the nutritional care given to cancer patients at all stages of the cancer process.</p> <p><b>Action: The analysis sub-group to move forward with a publication at the earliest opportunity, focusing on secondary care only at this stage.</b></p> <p>b) <b><u>Toolkit work stream</u></b></p> <p>The Joint Meeting in October was very useful and allowed the work stream to start developing a framework for the nutritional toolkit. The toolkit has been divided into seven domains (appetite and symptom management; diet; physical activity; nutrient status; body composition; functional performance and fitness; psychosocial), with different members of the work stream working on each domain. BC reported that he would like to co-opt members of the Professionals work stream to help create the Toolkit, if resources allow.</p> <p>Phase 2 will see development of a top level framework and a road map. Phase 3 will focus on education and implementation.</p> <p>c) <b><u>Professionals work stream</u></b></p> <p>RIC and MJW reported back on updates relating to this work stream. Membership is now complete with primary care representatives included. The Catalogue of Advice is an ongoing activity, and has now been mapped according to different stages of the cancer process. It became clear at the Joint Meeting in October that there are different opinions of what is meant by ‘evidence-based’ information, and therefore a clear framework for judging the evidence included in the catalogue is critical. This piece of work will be part of discussions to be held on 7<sup>th</sup> February with cancer charities attending the second workshop on setting up a charity consortium.</p> <p><b>Action: Professionals work stream to produce a short document about the Catalogue of Advice that can be circulated to charities before the February workshop.</b></p> <p>The NOCRI template has been updated with new timeframes to more accurately reflect planned work stream activities.</p>	<p>BC and LT</p> <p>BC</p> <p>RIC and MJW</p>
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**ESPEN Guidance and a Collaboration response:**

SAW spoke about the recently published [guidance](#) which has been circulated to all work streams and comments sought. The focus of attention in the guidance is on cachectic/wasting cancers, and does not cover nutritional issues relating to non-wasting cancers. This is an omission given the rise of e.g. pre-menopausal breast cancer patients with a high BMI whose weight may remain stable or rise during treatment, possibly leading to poorer outcomes.

AAJ commented that the guidance also contains recommendations for research, so the research (and other) work streams may also wish to consider its contents in relation to planning activities for Phase 3.

**Action: SAW to discuss the ESPEN guidance with BAPEN (British Association for Parenteral and Enteral Nutrition) and incorporate comments into an NIHR response.**

SAW

**d) PPI work stream**

LT reported that all activities set out in the template have been completed, and PPI is embedded across all work streams with two representatives each. Awareness-raising within the NCRI is complete with many presentations made to different CSGs. LT is also helping on the PANACHE bid (Physical Activity and Nutrition during Adjuvant Chemotherapy) being led by Diana Eccles at Southampton. LT presented the PANACHE study to the Dragon's Den at the NCRI Conference in November.

AAJ congratulated LT on setting the pace for activity within her work stream and emphasised the importance of maintaining a strong separate PPI group, in order to allow patients to share their unique experiences and contribute centrally to Collaboration activities in the future. It is critical to the success of what we are trying to achieve, as well as setting the agenda for NIHR activities more widely.

The conversation with NCRI is ongoing, a positive response has been received to the recent proforma filled in, and PPI participation is needed to take this conversation forward into Phase 3.

**e) Research work stream**

This work stream has been split into three sub-groups in order to work more efficiently and facilitate development of grant applications. The group with a focus on epidemiology and public health research held its first TC meeting on 13.12.16 and ER summarised the conversation. A face to face meeting has been proposed for February or March next year, to bring together the relevant people working in this area of cancer research, to include nutrition, diet, physical activity work in the primary or secondary prevention arena.

It was noted that in terms of achievements of the Collaboration, funded research studies are the ideal end point, but earlier stages are also important including collaborative working to discuss ideas, put bids together, and submit applications. It was recognised that the recent CRUK Catalyst and ongoing PANACHE bids were both born out of the Cancer and Nutrition Collaboration, it is important to learn lessons from these experiences and strengthen future applications. It was also agreed that face to face meetings are crucial to the development of strong bids, as well as rehearsals for panel interviews.

**Action: The intention is to hold a half day workshop before the March Steering Committee, to start development of a scientific research programme**

ER

	<p><b>in cancer and nutrition.</b></p> <p><b>f) <u>Engagement with the Commercial Sector</u></b></p> <p>SAW reported that this work stream is live but not fully initiated yet, partly due to restructuring at NOCRI and internal processes taking place there, with Karla Duarte now responsible for this area. Development of this work stream will be a priority for Phase 3 of the Collaboration's activities.</p> <p>AAJ also reported that as part of the OSCHR review process, a meeting may take place involving representatives of the food sector and people from the field of nutrition science to explore ways of working together constructively.</p>	
<p><b>5.</b></p>	<p><b><u>Phase 3 Strategy</u></b> (Mark Samuels joined the meeting by telephone)</p> <p><b>a) Operational planning</b></p> <p>AAJ summarised discussions that have taken place so far for the benefit of MS. A report will be written to capture all the achievements of Phase 2, and start to look forward to identifiable outputs for Phase 3. The biggest challenge for the Collaboration is to find a way to structure itself within the NIHR infrastructure, not restricting itself to BRCs only, and also to take into account people and activities that sit outside the NIHR infrastructure.</p> <p>MS commented that in order to secure future funding for the Collaboration we need to define sharp targets we are aiming for, that are well-defined and measureable. Good communication is key, in terms of what has been achieved so far, and what we set out to achieve in the next phase. Communication to BRC Directors (or others) should be brief, concise and clear.</p> <p><b>Action: Phase 3 plans to be set within a context of defined outputs achieved to date, and deliverable outputs for the future.</b></p> <p><b>b) Funding plans</b></p> <p>Currently the Collaboration is very dependent upon BRC support, but as the activities in cancer and nutrition are wider than the remit of the BRCs there is the need to broaden the base of the Collaboration's support so that it adequately reflects the areas of greatest priority.</p> <p>In future budget planning, protected support for the real costs of PPI activities should be included. This should not be just for travel and phone costs, but also for attending meetings, along the lines of a day rate such as that recommended by the organisation <a href="#">INVOLVE</a>.</p> <p><b>Action: Future budget planning to include more formal recognition of PPI contributions, and this money should be ring-fenced.</b></p>	<p>Secretariat</p> <p>Secretariat</p>
<p><b>6.</b></p>	<p><b>Charity Consortium</b></p> <p>A second workshop is being planned for Tuesday 7<sup>th</sup> February, led by Jenny Cameron at NOCRI. A save the date email has gone out to around 20 charities, most of whom attended the first workshop in September. The second workshop will focus on developing the Catalogue of Advice activity, and also identifying areas</p>	

	<p>where there are gaps in the research and charities could potentially be asked to fund specific research to fill those gaps.</p>	
<p>7.</p>	<p><b>Date and host of next meeting:</b>  The next meetings will be held on Wednesday 22nd March at NOCRI, and Thursday 15<sup>th</sup> June at CRUK.</p>	
<p>8.</p>	<p><b>AOB</b></p> <ul style="list-style-type: none"> <li>● BC reported back on an event he recently attended at BBSRC (Biotechnology and Biological Sciences Research Council) at which higher protein foods for ageing was discussed and could potentially provide a model for funding that the Collaboration could learn from.</li> <li>● It was reported that the Nutrition Society's winter conference in 2017 will be on diet and nutrition in the cancer process.</li> <li>● BC also asked if the Collaboration has a media policy as he had been asked to do an interview for a national TV chat show.</li> <li>● BC raised the point about development of courses in the UK to support health professionals who want to learn more about how best to nutritionally support cancer patients, along the lines of the <a href="#">forthcoming course run by the National Cancer Institute</a> in the US in March next year. It was agreed that this should form part of the Collaboration's Phase 3 activities.</li> </ul>	