



Meeting title:	Cancer and Nutrition NIHR infrastructure collaboration Steering Committee	
Date:	29 th June 2016	Time: 11am-1pm
Location:	The Abbey Centre, Great Smith Street, London	
Present:	Professor Alan Jackson (AAJ) – Chair Kate Allen (KA), Lucy Allen (LA), Millie Barrett (MB), Martin Wiseman (MJW), Steve Wootton (SAW), Richard Martin (RM), Bernard Corfe (BC), Lesley Turner (LT), Elio Riboli (ER), Karla Duarte (KD), Fiona Davey (FD), Mark Hull (MH), Clare Shaw (CS), Mark Samuels (MS), Karen Phekoo (KP)	
Apologies:	Helen Campbell (HC), Ramsey Cutress (RIC), Karen Brown (KB), Fehmidah Munir (FM), Lauren Chapman (LC), Fiona Reddington (FR)	

1.	<p>Welcome and apologies Professor Jackson welcomed everyone to the meeting and thanked them for coming. A special welcome was given to Mark Hull, standing in for Karen Brown from the ECMC Network, and Mark Samuels, Managing Director of NOCRI.</p>	Action/ Target date for completi on
2.	<p>Previous minutes These were agreed as an accurate record of the March meeting.</p> <p>Matters arising All matters arising are included in today's agenda.</p>	
3.	<p>Business Plan and Budget for Collaboration AAJ introduced the Draft Business Plan for 2017-2022, which had been circulated prior to the meeting. It is an evolving activity that aims to set out the overall aims and ambitions of the collaboration, and provide a plan for going forward beyond the current financial year. To date, Southampton BRC has mostly borne the cost of running the collaboration, supporting the Secretariat in the past and present financial year. This funding comes to an end in March 2017 and therefore the resources to support ongoing activity need to be found elsewhere. The collaboration is looking to the wider NIHR infrastructure (BRCs, ECMCs and CRFs) and elsewhere for future support.</p> <p>Due to the ongoing bidding process for BRCs and others, it is not possible to know at this point which Centres will have funding for work in cancer and/or nutrition. Results of this process will be known in September/October.</p> <p>It was agreed that the collaboration needs to be clear about exactly what we want to deliver this year, and what we want to deliver in Phase 3 (beyond March 2017).</p> <p>It was suggested that a mixed model for funding may be the best option, whereby we source core funding for the Secretariat and work stream leads, and look to other sources of funding for other parts of the collaboration's agenda. NOCRI can support the collaboration in this, but it must be led from within the collaboration.</p> <p>It was agreed that the intention is to submit joint proposals to other funding streams within the framework of the collaboration. i.e. bringing people together for maximum support. We will not only be looking to the NIHR infrastructure for support, but also to</p>	

<p>the large charity funders such as Macmillan, CRUK and others. The Chairman identified a 2 step process: first to develop a public facing summary of the Business Plan with clear resource requirements, followed by engagement with BRC directors with a view to convening a meeting in late 2016 with the successful ones to make plans for 2017 onwards.</p> <p>Action: Secretariat to develop a public facing Executive Summary of the Business Plan to help engage BRC Directors and others in the short term, to give them more information about the collaboration during the application process.</p> <p>3a. Engaging with charities LA reported back from a recent meeting with the Association of Medical Research Charities (AMRC) who were supportive of the collaboration. An event for cancer charities is being planned for September, with the intention of encouraging joint working and the establishment of a consortium of charity funders. The consortium is being modelled on a similar initiative, NeuroMap, led by the MRC and focusing on dementia. http://www.medicinesaccelerationprogram.org/ LA is putting together a list of cancer charities to invite to the event and a small working group has been set up involving NOCRI and the collaboration central project team. It was agreed there is a need to reach out to a broad range of cancer charities.</p> <p>Action: LA to circulate list of charities to Steering Committee members and everyone to feed back any additional names to add.</p> <p>AAJ also reported on a parallel conversation with the NCRI (National Cancer Research Institute) about how best the collaboration can engage with them. It was noted that the PPI work stream has good contacts with both the NCRI Consumer Forum and many individual CSGs (Clinical Study Groups).</p> <p>ER informed the group about an infrastructure-facing initiative being led by CRUK - a population health working group that is bringing together many funders who usually work in isolation e.g. British Heart Foundation, Wellcome Trust and others including NIHR.</p> <p>Engaging with industry SAW tabled a draft document for information only, titled 'Cancer and Nutrition NIHR infrastructure collaboration – Industry Engagement Strategy'. This relates to the fifth work stream, not yet activated, the collaboration is still in the early stages of planning the work in this area. It is a complex area, with many different considerations to take into account. SAW highlighted three main points to consider when developing the strategy further:</p> <ul style="list-style-type: none"> i) Industry encompasses a broad spectrum of players, not just the food industry, or pharmaceutical companies, but many different sectors-. A different approach may be required for each. ii) The regulatory framework within which industry operates is complex, operated partly by the Association of the British Pharmaceutical Industry (ABPI) and the Medicines and Healthcare Products Regulatory Agency (MHRA). iii) The experiences of others such as public health researchers working with the food industry, and the need to manage perceptions/concerns 	<p>MJW and LA 08.07.16</p> <p>LA Done</p>
--	---

	<p>around potential conflicts of interest. The recent report from CEDAR in Cambridge is useful and the collaboration should consider how their experiences might influence any action we take.</p> <p>http://www.cedar.iph.cam.ac.uk/news/cedar-bulletin/may-2016/#industry</p> <p>The Steering Committee should now consider how to take this agenda forward and who might lead this work stream. As the area of working with industry is so broad, the work stream members will have to consider how to focus on manageable outcomes.</p> <p>AAJ concluded that as there are many ongoing discussions, including at WHO level, about engaging with industry. It will be important for the collaboration to work out who we should work with and how.</p> <p>It was agreed that NIHR infrastructure needs to be involved, and we need to be clear what the outputs will be.</p> <p>KA commented that WCRF has put a lot of thought into working with different sectors of industry (food, wellbeing etc.) and would be happy to give input.</p> <p>Action: The Secretariat to work with SC members to develop a selective action plan based on the draft strategy document, bearing in mind the complexities involved.</p> <p>Action: Steering Committee members to send suggestions for specific actions based on the draft document to SAW and define what input they could give to developing this work stream by the end of July.</p>	<p>SAW</p> <p>All 31.07.16</p>
<p>4.</p>	<p>Work stream updates</p> <p>WS1 – Patient and public information provision and communication</p> <p>LT reported that the work plan for this work stream was drafted straight after the February workshop and has been on the collaboration website for a couple of months now. The group has been involved in many different awareness-raising activities, including presentations to various CSGs and the NCRI Consumer Forum. A letter of endorsement from the Chair, Richard Stephens, was received and is available on the collaboration website. LT will be attending the next Consumer Forum meeting on 25th July and will update them on the collaboration’s activities. Members of the PPI group have been engaging with Independent Cancer Patients Voice (ICPV), and Trustees of this organisation are keen to support the collaboration. A link to the collaboration has been put on ICPV’s website.</p> <p>Terms of Reference have been agreed for PPI representatives to join other work streams. It was agreed each work stream should have two PPI representatives to secure embedding of PPI in the operational activities of each work stream. It was also suggested a pool of PPI people could be a resource for work stream leaders to go to for involvement in specific pieces of work. KD reported that this approach had worked well in a past initiative she was involved in as it allowed greater flexibility and better use of PPI representatives’ time.</p> <p>Action: MB to send ToR to all work stream leads who will work with LT to secure two PPI reps on each work stream as soon as possible.</p> <p>LT also reported she is working with Justin Webb at Macmillan, a member of her work stream, to see how Macmillan can support the collaboration.</p> <p>Action: LA to include Macmillan on the list for the September AMRC charity consortium event.</p>	<p>MB 08.07.16</p> <p>LA Done</p>

	<p>AAJ commented that the issue of access to patient data for research purposes is a major challenge facing NIHR. It would be helpful if the PPI group might give a perspective on this issue. LT mentioned a group who lead the conversation on this issue on behalf of patients, called Use My Data: http://www.usemydata.org/index.shtml</p> <p>An ongoing review by Dame Fiona Caldicott, National Data Guardian for health and care, on how best to handle the issue of patient data was referred to, and more information about this review can be accessed here: http://www.cqc.org.uk/content/data-security-review</p> <p>In relation to the public dimension of PPI, as opposed to patient, KA suggested the use of WCRF's communication channels as a means of accessing public opinions. KA also suggested LT could write a blog about the collaboration for the WCRF UK website, as an opportunity to talk about wider public engagement. MS also offered the support of NOCRI as they have excellent contacts with the media.</p> <p>Action: MB to consult with KA and LT about opportunities to collaborate with WCRF and build these into the collaboration's overall communications strategy.</p> <p>Action: The collaboration to continue to work with NOCRI on external communications.</p> <p>WS2: Professionals</p> <p>MJW outlined the aims and objectives of this work stream in RIC's absence. The focus is on building a competent work force to deliver quality-assured nutritional assessment and advice to cancer patients at all stages of the process. It is also about working towards a workforce that is competent to assess the evidence in order to give the best advice to patients.</p> <p>The Professional work stream have added a few questions into the Toolkit survey to find out what training clinicians have had on assessing nutritional status and what guidance they are using to advise cancer patients on nutrition/diet. The aim will be to identify the gaps and develop draft competencies with e.g. the Association for Nutrition and others.</p> <p>Membership of the professional work stream is almost complete, the last few members are currently being secured to ensure membership covers all the necessary professional groups such as Speech and Language Therapists who work closely with some cancer patients.</p> <p>Action: Project team to upload Professionals NOCRI template onto collaboration website. Any amendments and updates to be reported to the next Steering Committee meeting in September.</p> <p>WS3: Research</p> <p>Although this work stream has not been active due to personnel changes, important progress has been made for individual activities, e.g. planning collaborative research and meeting with AMRC. RM spoke about the inherent problem underpinning the evidence base in research linking cancer and nutrition – confounding, bias and reverse causation. Bristol BRC, with support from both WCRF and CRUK, is developing a tool that combines genetic data and phenotypic data to try and find a</p>	<p>MB 31.07.16</p> <p>MB Done</p>
--	---	---

	<p>solution to this problem.</p> <p>It was agreed that if the tool being developed works successfully then it is hoped that it will become available to everyone in the cancer-nutrition research community, in order to deliver better quality translational research for the benefit of patients everywhere.</p> <p>ER also mentioned the CRUK Catalyst Programme as an ongoing opportunity for research funding: http://www.cancerresearchuk.org/funding-for-researchers/our-funding-schemes/population-research-catalyst-award</p> <p>This programme supports capacity building and collaboration in population health, enabling groups to deliver impact over and above what they could do alone.</p> <p>Action: A teleconference to be set up for the Research work stream, to agree the key outputs for this group in the current financial year. Following this, a completed NOCRI template will go on the collaboration website.</p> <p>WS4: Nutrition Assessment Toolkit</p> <p>BC reported on progress in this work stream. It currently has eleven members, primarily dietitians, with a good spread across the home nations. Differences in policy and practice have become clear from early discussions. A significant need for a patient voice is recognised, especially as the group will soon start working on developing the Toolkit for use in clinical practice.</p> <p>A survey has been developed and Phase One of dissemination has taken place (BDA Oncology Group, wider BDA, RCN Cancer and Breast Care Forum). The survey has also been advertised on the NIHR and NOCRI websites, Twitter and Linked In. The survey aims to find out what levels of nutritional assessment take place, what advice and guidance is given to patients, and how confident clinicians feel in terms of assessment and advice.</p> <p>CS suggested circulating it to the UK Society of Oncology Nursing as well.</p> <p>The group seeks to capitalise on the networking capacity of all its members, for both survey dissemination and future development of the Toolkit.</p> <p>In parallel with the survey the group is starting to think about development of a modular nutritional assessment toolkit for use in clinical practice. The toolkit will be developed within a quality assured framework, with standard operating procedures allowing for competency-based assessment to ensure consistent application of the tools therein.</p> <p>Teleconferences are taking place, the group is well engaged. A face to face meeting is being planned for October, as a joint meeting with the Professionals Workstream, to consider the results of the survey and agree next steps.</p> <p>Action: BC and LT to discuss patient representation on this work stream.</p> <p>Action: Project team to confirm the date for October joint meeting as soon as possible.</p> <p>Action: Project team to contact UK Society of Oncology Nursing for survey distribution, and consider further linking with WCRF for communication to health professionals.</p>	<p>MB 31.07.16</p> <p>BC/LT MB 08.07.16</p> <p>MB 08.07.16</p>
<p>5.</p>	<p>Communications strategy</p> <p>MB introduced the draft strategy, outlining the three strategic priorities:</p> <ul style="list-style-type: none"> Increasing awareness of the collaboration and the opportunities it provides for researchers, clinicians and patients to work together and share ideas 	

	<ul style="list-style-type: none"> • Develop effective internal communications channels to ensure effective dissemination of information amongst collaboration members • Develop effective external communications channels <p>It was agreed that the collaboration needs to identify a strong network of communications leads from across the key stakeholders, in order to facilitate and enable delivery of the communications strategy.</p> <p>Action: Strategy to be finalised with approval from the Secretariat and updated at the next Steering Committee.</p>	<p>MB 13.09.16</p>
<p>6.</p>	<p>Priorities and next steps</p> <ul style="list-style-type: none"> • Securing two PPI members for each work stream LT and all WS leads • Finalising Business Plan and budget for collaboration AAJ, SAW, MJW and LA • Setting up charity consortium of funders LA • Progress on work stream 5 – engagement with commercial sector SAW • Support WS3 to ensure as wide engagement as possible AAJ, ER, MB, FD, SAW 	
<p>7.</p>	<p>Date and host of next meeting: The next meeting will be held on Tuesday 13th September at Imperial College London</p>	