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| **Meeting title:** | | Nutrition and Cancer NIHR infrastructure collaboration Steering Committee | | | |
| **Date:** | | 22nd July 2015 | **Time:** | 1pm – 3pm | |
| **Location:** | | Committee Room, St. Mary’s Campus, Praed Street, London, W2 1PG | | | |
| **Present:** | | Prof Alan Jackson (AAJ) – Chair  Lucy Allen (LA), Karen Brown (KB), Lauren Chapman (LC), Anne Helme (AH), Elio Riboli (ER), Lesley Turner (LT), Martin Wiseman (MJW), Yi Lu (YL). | | | |
| **Apologies:** | | Helen Campbell (HC), Arabella Hayter (AKMH), Ramsey Cutress (RC), Kate Allen (KA), Carrie Bolt (CB), Richard Martin (RM), Fehmidah Munir (FM), Steve Wootton (SAW). | | | |
| **1.** | **Welcome and apologies**  AAJ opened the meeting and thanked everyone for coming. Apologies were received from HC, AKMH, RC, KA, CB, RM, FM and SAW. A replacement for Rowena Sharp has not been provided by Royal Marsden BRC. AKMH/YL to send LA the latest updates on this. NOCRI to help invite and follow up a representative from Royal Marsden. | | | | **Action**  **AKMH/YL/NOCRI** |
| **2.** | **Previous minutes and matters arising**  The minutes from the last meeting (12th May 2015) were agreed.   * 1. **Final report – for information**   A nearly finished draft version of the report was circulated for comment in June 2015. Since the last SC meeting, all the comments received were incorporated into the report.   * 1. **Summary report**   A summary report has been prepared by the Secretariat, which captures the main items in the long full report. It is intended to be reader-friendly and will be handed out at the launch event in October. Both the long and summary reports will be freely available on the Collaboration’s website.  AAJ invited comments on the summary report. LT inquired whether it is possible to reword the sentence ‘The image of a person wasting away to skin and bones, wracked by pain is disturbingly common’ to make it more consumer-friendly. LT also suggested changing “dragon’s den” to “dragons’ den” throughout. A list of participants who attended the workshop session at the NCRI 2014 conference is provided in the report as an appendix, while the list of participants at the dragons’ den session is not provided. LT asked whether it would be better to be consistent and remove the list of NCRI workshop participants.  AAJ encouraged members to send their comments on the summary report to AKMH/YL as soon as possible after the meeting, to enable the design team to continue their work on the report’s layout.  **ACTION**: All members to send comments to AKMH/YL by 28th July  YL to incorporate the suggestions made by SC members. | | | | **ALL**  **28th July**  **YL** |
| **3.** | **Work streams – draft concept notes**  At the last SC meeting, discussions were had about the activities of the next phase, from which 4 work streams emerged. Based on the priorities and interests mentioned, concept notes for each work stream were drafted. For each work stream, individuals will be identified to carry out the relevant activities.  LA suggested sharing the responsibilities of delivering the work streams more widely, suggesting that work streams could be led by members from different organisations. LA also added that it would be helpful to connect the work streams with the gaps identified in phase 1 and demonstrate the potential outputs of the work streams which would be helpful when promoting the collaboration. MJW agreed with LA’s suggestions but also pointed out that it is difficult to identify concrete examples of possible trials until the preliminary and underpinning infrastructure has been developed. Possible trials could however be given as examples of potential future impact. LA responded that an alternative way would be to show how outputs from the work streams could add value to the identified gaps.  **ACTION:** AKMH and YL to revise the proposal document based on the suggestions made.   1. **Nutritional toolbox**   YL presented a summary of the nutritional toolbox work stream and progress to date. The toolbox will include recommended measurements for physical activity level, dietary intakes, body composition, physical and metabolic fitness. Basic, intermediate and advanced levels of complexity will be designed, relevant to whole cancer process from prevention through management to palliation, Their appropriate application in practice will remain at the discretion of clinical professionals. Information on the training, capacity building and quality assurance procedure required to use the toolboxes will also be specified. SAW and YL have started working on physical activity level 1.  LA suggested inviting contributions on its development from other organisations based on their experience, eg Clinical Research Facility. AAJ responded that this is under consideration.  AH added that it would be helpful to collect feedback from toolbox users to evaluate the tools. YL responded that there will be opportunities to monitor the impact through the number of times the toolbox has been downloaded from our website. Researchers will also be asked to share their experiences of using the toolbox. Measuring the use of the toolbox in clinical settings would be difficult, as there are no existing mechanisms for collecting such data.  KB reported that she has submitted a grant application on clinical trials with cancer patients. If successful, she would be able to use nutritional measurements in the study. This would help to demonstrate the value of using validated measurements in cancer clinical trials.  **ACTION:** KB to report the progress at next meeting.   1. **Patient engagement**   MJW reported that this work stream was developed to ensure that the needs of the public and patients remained visibly central to the collaboration. Though patient and public involvement is part of other work streams there is a danger that this might not receive the prominence required without a dedicated work stream of its own. The focus of this work stream is communication and information sharing between the public, cancer patients and practitioners.  LT asked whether it would be better to merge work streams 2 and 3, rather than keeping them separately, since the aim is to encourage the two types of groups to work together. AAJ described that there are advantages of keeping them separate, as the focus of the two work streams are different. The interest and needs of one group may be very different from those of other groups. However, we need to ensure that there is good communication between the two groups.  One issue that has been discussed repeatedly is the availability of reliable sources of nutritional information and advice which is accessible to cancer patients. The relative benefits of having a single portal were discussed. Any portal would need to address the different information needs of different target audiences. Identifying the information provided by different organisations and helping to identify more reliable information might be more feasible. A lead for this work stream is yet to be identified.  **ACTION:** Identifying a lead for this work stream   1. **Engaging with professional groups**   MJW gave a summary of this work stream. A list of professional groups from cancer and nutrition fields were identified, including as a core Association for Nutrition (AfN), British Dietetic Association (BDA), and Academy of Medical Royal Colleges, as well as other relevant professions such as nurses, SALT, pharmacists, physios etc. The primary objective of this work stream is to develop a community of practice, to identify what is known and what needs to be known, to characterise better practice, and to secure quality assured training for professionals (see Work stream 1).  LT and YL added that work streams 2 and 3 are cross-cutting and will be used as the channels to disseminate outputs from other work streams. AH suggested changing the names of the work streams 2 and 3 to be more focused on outputs.  **ACTION:** AH to send YL/AKMH suggestions on the new work stream names   1. **Developing the research agenda**   An outline for this work stream was presented but requires further engagement and development. There is the need to recognise and differentiate the different types of research needed and how the information from different contexts might be brought together. KB offered to develop a diagram to illustrate the range of considerations that should inform the research agenda at different stages of the patient experience. AAJ highlighted there is a need to collect information that has been carried out in clinical care. ER noted that well conducted observational studies would help inform about what appears to work in practice, as the basis for better-structured trials. ER proposed the need to establish a central database within which it would be possible to assemble and compare relevant data to identify better clinical practice. This could be started with setting up a network as a collaborative activity with relatively low cost. Funding support from the pharmaceutical industry could be sought as the network matures and in anticipation of the ability to carry out relatively expensive large-scale RCTs.  MJW stated that using observational data and other evidence to formulate good research questions for trials which have to be highly focused is crucial to ensure good return on investment. AH noted that CRUK is developing a funding scheme for population research. The name and details of this funding scheme will be finalised by November 2015. By then, CRUK will be actively encouraging applications from interested researchers.  LT added that tissue banks might be prepared to collect more nutritional information. Cancer patients are generally open to sharing clinical information.  AAJ, MJW, ER and SAW to discuss potential steps to achieve this ambition.  **ACTION**: AH to share details of the population health funding scheme once available  AAJ, MJW, ER and SAW to have a separate meeting on this work stream. | | | | **AKMH/YL**  **KB**  **ALL**  **AH**  **AH**  **AAJ/MJW/ER/SAW** |
| **4.** | **Communications strategy**   1. **Launch event – 27th October 2015**   AAJ reported that due to diary clashes and the cost of renting the venue at Royal Society, the date for the launch event has been changed to 27th October 2015. This will happen after NIHR BRC/U’s directors meeting.  LA added that the directors’ meeting will finish at 3.30pm. The launch event will start at 4pm and finish at 5.30pm. It will take place at Westminster – Convocation Hall, Church House Conference Centre. The collaboration will be able to use it without additional room hire cost. The venue has a capacity of up to 80 people without seats, or 60 in theatre style. The cost for catering is £8.85 per person for hot drinks and a selection of cakes.  This would make it possible for the Directors to participate in the launch event. There will be approximately 20 attendees from the Department of Health, leaving about 40 more to be invited. We need to be relatively selective with the invites. AH suggested inviting the individuals and organisations that are interested in and would be able to contribute to the work streams. It would also be useful to include a brief introduction of the four work streams planned. Representatives from each work stream can be available at the networking session for attendees to share relevant experience with and ask specific questions.  **ACTION:** AKMH/YL to alter the event programme, including an introduction of the 4 work streams as well as arranging work stream representatives to answer attendees’ questions**.**  All members to send suggestions on the individuals and organisations to be invited to the launch event.   1. **Website**   MJW reported that WCRF design team has kindly offered to design and produce PDF versions of the full and summary reports, and 500 hard copies of the summary version. The team has just started to draft some design concept notes. Vivid Agency, a third party, is contracted by NOCRI to set up the collaboration’s external website.  The Steering Committee thanked NOCRI for underwriting the cost for the design of the reports and website, WCRF for the commitment to design and production of the reports, as well as the SC members who had agreed to contribute to the cost of the report.  **ACTION:** KB to check with Elliann Fairbairn whether ECMC is able to contribute.   1. **Name**   The proposal of a short name has been declined by the DH. However, the proposed tagline has been approved  “Improving cancer prevention and care  For patients. For clinicians. For researchers.”   1. **Design and branding**   Discussed under item 4b. | | | | **AKMH/YL**  **ALL**  **KB** |
| **5.** | **Patient engagement**  **NCRI CSGs event, Sheffield 3rd Jun 2015**  LT provided an update on the first UK Clinical Trials conference that both AKMH and LT have attended. There were about 160 attendees. AKMH led one of the breakout sessions with 35 people to discuss nutritional research. It provided a good opportunity to raise the profile of the collaboration.  LT and AKMH took part in the Dragons’ Den Session which involved pitching for a hypothetical £1 million research grant. LT’s proposal was successful. AKMH’s proposal was about setting up an information portal for patients, using the crowd-funding model. | | | |  |
| **6.** | **Priorities and next steps**  The priorities and next steps are to make the final versions of the reports ready for design and prepare for the launch event. | | | |  |
| **7.** | **AOB**  There were no other items of business raised. | | | |  |
| **8.** | **Date and host of next meeting:**  The next meeting will be held in early October at Imperial. YL to send out doodle polls to arrange a date and time. | | | | |