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| **Meeting title:** | | Nutrition and Cancer NIHR infrastructure collaboration Steering Committee | | | |
| **Date:** | | 12th May 2015 | **Time:** | 11.30am-1.30pm | |
| **Location:** | | Imperial College, Praed Street, London, W2 1PG | | | |
| **Present:** | | Prof Alan Jackson (AAJ) – Chair  Lucy Allen (LA), Kate Allen (KA), Carrie Bolt (CB), Karen Brown (KB), Lauren Chapman (LC), Arabella Hayter (AKMH), Anne Helme (AH), Richard Martin (RM), Fehmidah Munir (FM), Elio Riboli (ER), Lesley Turner (LT), Martin Wiseman (MJW), Steve Wootton (SAW), Yi Lu (YL). | | | |
| **Apologies:** | | Helen Campbell (HC), Ramsey Cutress (RC). | | | |
|  | **Welcome and apologies**  AAJ opened the meeting and thanked everyone for coming. Apologies were received from Helen Campbell and Ramsey Cutress. Rowena Sharp has left Royal Marsden BRC and will no longer be a member of the SC. A replacement is being sought. Fehmidah Munir has joined the SC from Leicester/Loughborough BRU. | | | | **Action** |
| **1.** | **Previous minutes and matters arising**  The minutes from the last meeting (26th February 2015) were agreed.   * 1. **Timeline and update of progress**   AKMH presented an updated copy of the Gantt chart. The priorities and tasks for the next few months are to be decided based on the outcomes of this meeting.   * 1. **Board membership**   The DH have clarified that the collaboration should be self-managing and NOCRI will keep DH informed through its oversight group.   * 1. **Links with Palliative and Supportive Care CSG**   LT has discussed the collaboration and its activities with the Palliative and Supportive Care CSG, whose chair has invited a member of the collaboration to speak at its next meeting on 22nd September. The application to present at the NCRI 2015 conference was not successful. LT has explored with NCRI the basis for this decision and was informed that it was considered that the proposed session appeared unlikely to have sufficient new data to present. NCRI encouraged a submission for the meeting in 2016.   * 1. **Imperial & Oxford Epidemiology of Chronic Disease event**   ER is organising a one-day Cancer Epidemiology event on 16th September 2015, which will be held at the Royal Society. Further discussion was held later in the meeting and is minuted under item 2c. | | | |  |
| **2.** | **Phase 1 report (attachment – Phase 1 report)**  MJW presented a summary of the final report and highlighted some key findings. AAJ stressed the importance of identifying gaps in the evidence that should be shared with the wider cancer and nutrition community, so they can be addressed. AAJ invited SC members to comment on the report. The feedback is summarised thematically.  **Report layout**  LT suggested changing the order of the chapters, with those on patient and clinician surveys presented before the information from the mapping exercise. This was agreed.  **Evidence base & results of the mapping**  KB asked about reliable resources on nutrition and cancer that could be given to patients on diagnosis. If not, KA suggested developing a booklet of recommendations for patients under the auspices of this group. It was noted that this helpful suggestion should be based on robust evidence, and could be considered at a later time.  RM made three points. Firstly, that the purpose of developing toolkits should be made explicit in the report, along with a definition of nutritional assessment, because toolkits might mean different things to different people. KB said that when reading the report she did not get a clear feel of the effect these toolboxes would have on outcomes. AAJ suggested adding a definition of toolboxes and their purpose to the report.  Secondly, RM described some challenges when trying to engage with other disciplines within Bristol BRU. He said he would appreciate more help with expertise on physical activity (for example understanding how to implement moderate PA interventions) and how to engage the behavioural psychology community.    Thirdly, RM would appreciate help in understanding which nutritional, dietary and behavioural interventions have been proven to work which could be used for cancer patients. He said that having a database of such interventions would be useful.  **Recommendations**  LT reflected the need to consider how the patient movement could be involved more to identify research needs and improve the evidence base. She suggested the need to be proactive in encouraging greater patient collaboration, using the example of the Breast Cancer Campaign. They have used a crowd-sourcing platform to enable patients to inform the research agenda and identify ideas for research. LT added that collaboration with patients should be included within the recommendations. KA also suggested approaching the International Alliance of Patient Organisations for further patient engagement. They cover all disease areas, not just cancer.  AH suggested that any recommendations regarding research funding should be very specific, rather than saying ‘more funding is needed in this area’.  LA proposed two ways of presenting the outputs from the report and considered which would be the most meaningful: either the results are presented as recommendations from the initiative or as a base to inspire the cancer and nutrition community to identify key areas, and put together their own proposals and business plans.  LT recommended breaking down all recommendations into smaller parts to make it easier to deliver on the ideas proposed.  KA and LT proposed some revisions to the recommendations on engaging with industry, removing the tobacco industry and adding in Google and other app developers.  **ACTION:** All of the suggested revisions will be incorporated into the report and revised version shared with the SC for signing off.  **Next steps – developing work streams**  Summarising, AAJ suggested that for the next phase of the collaboration four work streams should be developed. For each one, individuals were invited to write a concept note to guide discussion at the next SC meeting:     1. **Toolboxes (concept note: SAW)**   Standardised approaches are needed for the assessment of nutritional status using validated methods within a quality assured framework. They should be characterised as a series of toolboxes of increasing complexity with clear definitions of their purpose and scope.   1. **Engaging with professional groups (BDA, AfN, Royal Colleges) (concept note: MJW, AKMH, YL, AAJ)**   Dietitians and nutritionists as the responsible professional groups should be encouraged to work together with the wider health professions to provide clear guidance on best practice in the different areas of importance for nutrition in cancer.   1. **Engaging with patients and with CSGs (concept note: LT)**   LT noted the many different patient organisations that might have a useful input, but as a first step considered that it might be most helpful to invite comment from Richard Stephens, head of the patient group which sits on the NCRI CSGs.  The Chairman of the palliative and supportive care CSG has invited a representative of the steering group to give a presentation to one of their meetings. There is a particular interest in weight gain and weight loss. LT suggested there are opportunities for interaction with the psychosocial group, and with breast cancer groups.   1. **Deciding the ‘big picture’ and the long term ambition (concept note: RM, ER, KB, and ER to meet with CRUK)**   AAJ suggested that the main item for the next phase would be to define clearly a preferred research agenda. This might include both the long-term, broad goals and intermediary steps leading to that end. LT stressed the importance of publishing the research priorities that are identified. By raising awareness of the gaps there would be opportunities to add value to other trials and work currently being planned. | | | | **AKMH / YL**  **SAW**  **MJW / AKMH/ YL/AAJ**  **LT** |
| **3.** | **Future engagement**   1. **Communications strategy**     AKMH, with input from NOCRI, has drafted a communications strategy, which includes the strategy for disseminating the report and longer-term communication goals.  Members made suggestions for developing the strategy further:   * Promote initiative via general and technical press * Share news via LinkedIn * Tap into stakeholders’ dissemination channels (post a link to our website on their websites, and send out news in their newsletters) * Ask ‘high profile people’ to promote the initiative * Develop infographics (good for tweeting and sharing) * Produce clips of patients and clinicians talking about the importance of nutrition and cancer, and of the initiative * Set up a Facebook page * Build stakeholder engagement into the strategy * Develop branding for the initiative and make website look more ‘professional’   AH stressed the need for clear and concise messages, appropriate to each target audience and communication channel, and with clarity on the specific actions being sought.  LA indicated that NOCRI may be able to provide technical and financial support in developing the collaboration’s website. An active website will need to be maintained; AKMH said she would be able to do this. KA offered the support of WCRF in the branding and presentation of the final report.  **ACTION:** AKMH will prepare a proposal for the website and send to NOCRI, using the examples of the rare disease translational research collaboration and the dementia collaboration as a guide. KA will set up a meeting with the AKMH and the WCRF communications team to discuss this further.  LA suggested hosting a stakeholder engagement event to launch the collaboration, the report and the website. She asked if this could be associated with the Imperial Cancer & Epidemiology event to be held in September. ER thought this would be a good idea as there is good overlap between the two areas and a large number of stakeholders will already be present, thus broadening the audience.  The Cancer and Epidemiology day will finish at 4.30pm so the event could be held at 5.30pm, with an hour-long workshop followed by a reception. A range of stakeholders, including patients, will be invited to attend and a small number of attendees also invited to speak.  **ACTION:** AKMH to meet with LA and LC to discuss the launch. AKMH to form a group and be responsible for making the launch event happen.   1. **Initial mapping of CSGs**   YL had conducted a preliminary mapping of all of the CSGs, to clarify the range of nutrition-related research taking place across the network.  KB will be giving a talk at ECMC network and offered to talk about the collaboration to begin the dissemination process.  **ACTION:** YL to produce some headline slides and share with KB. | | | | **AKMH /KA**  **AKMH/**  **LA/LC**  **YL/KB** |
| **4.** | **Priorities and next steps**  AAJ stressed the need to be clear about the priorities for the next phase and suggested creating a Gantt chart for the next year.  LA said that NOCRI have developed templates for work streams, designed for use by all their collaborations. She will share these with AKMH for her to develop further. | | | | **LA/**  **AKMH** |
| **5.** | **AOB**  AAJ informed the group that from June 30th 2015 he will be stepping down as Director of the Southampton BRC. The future chairmanship of the Steering Committee would need consideration. | | | |  |
| **6.** | **Date and host of next meeting:**  The next meeting will be held of July 22nd. The venue is to be confirmed but may be Imperial or WCRF. | | | | |