



**NIHR Cancer and Nutrition Collaboration Steering Committee**  
**Tuesday 11<sup>th</sup> December, 11am-1.45pm**  
**Location: WCRF**

**Present:** Sam Ahmedzai (Chair) (SA), Fiona Davey (FD), Rachel Marklew (RM2), Richard Martin (RM), Giota Mitrou (GM), Fehmidah Munir (FM), Jane Murphy (JM), Clare Shaw (CS), Mike Stevens (MS), Lesley Turner (LT), Martin Wiseman (MJW), Steve Wootton (SAW)

**Apologies:** Kate Allen (KA), Lucy Allen (LA), Annie Anderson (AA), David Bowrey (DB), Helen Campbell (HC), Bernard Corfe (BMC), Alan Jackson (AAJ), Anbalakan Paramasivam (AP), James Thorne (JT)

Agenda item	Notes	Person responsible
1. Welcome and apologies	The Chair welcomed everyone to the meeting and noted apologies. We welcomed Rachel Marklew to the meeting, who has recently joined the International Cancer and Nutrition Collaboration (IUNS/WCRF/IAEA/UICC task force) as their project manager.	
2. Minutes of last meeting and matters arising	<p>The minutes of the last meeting were accepted as an accurate record.</p> <p><b>Action:</b> Upload to website</p> <p><b>Matters arising</b></p> <p><b>NCRI JLA PSP</b></p> <p>SA provided an update on the CRN cancer portfolio and shared the NCRI JLA PSP priorities with the group. Relevant research grant applications from the Collaboration should now cite the priorities as justification in applications.</p> <p>The CRN now has an open data platform (ODP) which is semi-automated. SA would like to find funding for a trainee to work on the dataset for a few months to analyse the nutrition components of ongoing research, which can be linked back to the OSCHR review.</p> <p>Within the Supportive and Palliative Care CSG, exercise, nutrition and prehabilitation have been made a specific priority for the group. The remit of this CSG is across the whole spectrum of the cancer and includes adverse effects, and is not just in palliative/end of life treatment. Support of family and carers is also within the remit.</p> <p><b>NCRI conference 2019</b></p> <p>Prof Stephen Hursting (SH) has been confirmed as a plenary speaker for the 2019 conference. The session will focus on cancer prevention (animal and human models); obesity and weight reduction programmes; and nutritional influence on response to treatment. The NCRI conference planning committee has 4 subcommittees. A parallel session was proposed by the 'Cancer control' subcommittee. It is proposed that SH and SA will co-chair this session. The session will cover 3 topics within 90 minutes:</p> <ul style="list-style-type: none"> <li>- Models of obesity</li> </ul>	FD

	<ul style="list-style-type: none"> <li>- Population-based interventions for primary and secondary prevention</li> <li>- Clinical trials of nutritional and activity interventions to support patients before, during and after treatment</li> </ul> <p>Another session has been proposed on the biological basis of cancer symptoms, which includes pain, cachexia and fatigue or depression, and nutrition will also feature within these topics.</p> <p><i>Post-meeting note: Both these proposed sessions were approved, but the committee was asked to merge them. SA is working with the committee and members of the Collaboration to achieve a balanced programme.</i></p> <p><b>Action:</b> Work stream members to be encouraged to submit oral papers and posters for the 2019 NCRI Conference.</p> <p><b>Action:</b> Explore the possibility of having a stand either by ourselves or jointly with NIHR CRN (Cancer Cluster Office).</p> <p><b>Further CSG engagement</b></p> <p>Consideration to be given to further engagement with CSGs. It was proposed to create a 1 page manifesto of the offer of nutritional expertise to proposals within CSGs, which can be tailored to each CSG cancer site.</p> <p><b>Action:</b> Write manifesto and promote to CSGs by March Steering Committee</p> <p><b>BRC Oncology Day, March 11<sup>th</sup></b></p> <p>The Collaboration is running a workshop at the BRC Oncology day. This opportunity will be used to highlight the JLA priorities and to provide clarity to the BRCs about the impact the Collaboration has made.</p> <p><b>NCRI ‘Beyond the Horizon’ conference proposal</b></p> <p>AAJ has agreed to take on the lead of transforming the Beyond the Horizon proposal into a manuscript, and will come to this in the New Year. Adil Mardinoglu from KCL will contribute. SA will contact NCRI to find out the outcome of the Collaboration’s bid for a conference.</p> <p><b>CRUK/Ludwig meeting</b></p> <p>CRUK/Ludwig held a meeting on nutrition and cancer prevention on 3-4<sup>th</sup> December. A number of Collaboration representatives attended. It was structured around themes on future research directions as discussed in the WCRF CUP reports.</p> <p>Each section was useful and introduced new ideas with older ideas. However, it was found that there was not a lot of cross-talk between different sections. The policy section was particularly useful and a recommendation was received to engage this group with the Collaboration.</p> <p>The organising committee of the meeting will be putting together a summary paper of the meeting.</p>	<p>All</p> <p>FD/SA</p> <p>Secretariat</p> <p>AAJ</p>
3. Phase III plans	<p>The committee was reminded that whilst the three research work streams have their own research strategies, these have not yet been brought together into an overarching coherent strategy for the Collaboration.</p> <p>SAW presented to the group an overview of current progress with restructuring the Steering Committee. The group agreed that the ‘petals’ reflect the requirements of the Committee. The SC should</p>	

	<p>have a function of providing strategic direction, monitoring and nurturing the group.</p> <p>A Steering Committee typically has an odd number plus a Chair (11+1 often used) so the Committee is looking to downsize.</p> <p>It was suggested that AMRC could potentially represent charities on the committee. This could help them influence how money donated to charities is granted.</p> <p>Clarity to be sought on which ‘hats’ are being represented among the committee. Where possible, people should represent more than one constituency for efficiency, and it should be clear what purpose they serve on the committee. A formal process of disseminating information back to the organisation(s) a member is representing needs to be put in place.</p> <p>The decision was taken to evolve the Steering Committee to its new representation in time for the next financial year, beginning in April 2019. It can be in a transitional phase throughout the early part of the next financial year but the direction must be in place. The slate will be ‘wiped clean’ to form a new committee.</p> <p>A separate work stream executive was proposed. The collaboration will try to initiate face to face meetings with just the work stream Chairs to promote more cross-working. This will enable differentiation of strategic oversight of the SC from operational activity.</p> <p>The SC should move towards having tighter objectives for its objectives and a sense of how progress can be measured.</p> <p>MS suggested that a larger scale annual partnership meeting representing all constituents could be held.</p> <p><b>Action:</b> take back to Secretariat to discuss and offer an option(s) to SC</p> <p>Feedback was received that the existing mission statement is lengthy and unclear.</p> <p><b>Action:</b> LT to draft a new mission statement, SC and Secretariat to vote on a new mission statement which accurately reflects our purpose.</p> <p><b>Collaboration Membership</b></p> <p>The Collaboration is formalising its membership framework with both individuals and organisations. This is a part of our long-term engagement strategy and will help us to identify our stakeholders and collaborative opportunities. Letters to invite work stream members to formalise their membership were sent out at the beginning of November as a pilot. The sign up form also provided the opportunity to give feedback about what members considered to be the main benefits of working with the Collaboration, which will inform our external engagement.</p> <p>The main question raised from individual members was the concern that we had increased expectations with the new membership or that we expected exclusive working, both of which are not correct. In general our members seemed to be happy to formalise their commitment and see the benefit in this.</p> <p>Charities that attended our second and third workshops have been approached to become organisational members, as well as all NIHR</p>	<p>Secretariat</p> <p>LT</p>
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	<p>BRCs. Three charities have expressed interest in Associate membership to date, with a number more informing us that senior management will be discussing it.</p> <p>Questions raised include:</p> <ul style="list-style-type: none"> <li>- A need to see minimum levels of funding for each membership category</li> <li>- What form of a statement of support is required for Associate Membership?</li> </ul> <p>AMRC were contacted to find out about the thresholds for charity sizes but this methodology appears to be too complex for our requirements. GM suggested finding out the thresholds used by ICRP.</p> <p>The committee agreed that a minimum amount of support of £1000 per year was reasonable, and that the nature of this support could be 'in kind', eg supporting a meeting.</p> <p>A retaining fee for all levels of organisational membership was suggested, which needs to be given further thought. The charities that signed up to Associate membership were previously told that there were no financial commitments with this type of membership.</p> <p><b>Action:</b> SA to write and send welcome letters to charities/other organisations that sign up.</p> <p><b>CRFs</b></p> <p>The Collaboration has made progress with engaging with the CRFs. A survey was conducted over summer, which received 21 responses. 19 CRFs were interested in receiving support to improve their capacity and capability to deliver research in cancer and nutrition. The survey found that they are currently ill-prepared to deliver against the research agenda as they don't have the structure, systems or processes in place to deliver high quality research. The Director of the UKCRF Network attended the Secretariat meeting in October and the view was expressed that the network would like to support our activities.]</p> <p>LA also presented to NIHR CRFs directors' forum on our behalf to look at how we might work with CRF network so the CRFs could have an effective mechanism to deliver experimental medicine in cancer and nutrition.</p> <p>The network conference summer school in 2019 will be used to run a workshop with the CRF directors to show them how our views on measuring nutritional wellbeing might help them become better equipped for research in cancer and nutrition.</p> <p><b>Action:</b> LA to promote manifesto to CRFs</p> <p><b>Publication strategy</b></p> <p>A number of publications are in the pipeline and it would be beneficial to have a strategic overview of what publications the Collaborations aims to publish. A relationship could be forged with a journal to propose a series of editorials on behalf of the Collaboration.</p> <p>NIHR policy states that publications from NIHR-supported groups should be published in open access journals. This is normally at a</p>	<p>SA</p> <p>LA</p>
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	<p>high cost. The Collaboration can apply for reduced or waived charges as a non-profit organisation but this is at the editor's discretion. Grant applications should include a line for open access fees where possible. The Collaboration can also considering applying to charities to fund this cost.</p> <p>The publication strategy should also set out guidelines on authorship for papers, eg 'On behalf of Collaboration', following full editorial principles</p> <p><b>Action:</b> Draft publication strategy</p> <p>Further to the last meeting's minutes, the editorial proposed to the journal 'Nutrients' is on hold as the editorial board resigned.</p>	MJW
4. Finance	<p>SAW presented the Collaboration's finances for the current 6 month period and set out the financial projection for the next financial year (April 2019-March 2020). £54k has been underwritten from various sources in the current financial year to date (2018-19) to enable the Collaboration to be active.</p> <p><b>Action:</b> All SC members to explore funding opportunities from their own institutions in order to support the core Secretariat costs as a matter of urgency (~£100k p.a.)</p> <p>Expected new income:</p> <ul style="list-style-type: none"> <li>• £25k Macmillan</li> <li>• £5k from the Wellcome Trust CTYA activity</li> <li>• £10k from Southampton BRC</li> </ul> <p>A delay was experienced in receiving the Macmillan money because there was no mechanism for a charity to give money to a non-charity. This has now been resolved and is expected to be received before the end of the year, as Macmillan's financial year coincides with the calendar year. The SC formally thanked June Davis for her assistance and support for the Collaboration.</p> <p>The Collaboration thanked WCRF for its ongoing support of MJW in the position of Secretariat Chair, and Southampton BRC for its support for the current financial year and ongoing support for LT as patient representative.</p> <p>The Royal Marsden continues to support CS in her research role for the Collaboration (4 sessions per week).</p> <p><b>Further funding:</b></p> <p>Further conversations to be had with Nottingham, Manchester and Bristol BRCs regarding supporting the Collaboration.</p> <p>From next year, the terms of BRC contracts with NIHR will be that they are required to support Collaborations, not just expected to.</p> <p><b>Charities</b></p> <p>Macmillan was asked whether they could fund the Secretariat, this conversation is continuing.</p> <p><b>Action:</b> SAW to continue conversations with Pelican Trust</p> <p><b>Industry</b></p> <p>SAW and LA are meeting with BSNA and MNI in January to discuss opportunities for funding. However, the position remains that the Collaboration should not be exclusively industry funded or be beholden to them.</p>	<p>All</p> <p>SAW</p> <p>SAW/LA</p>

	<p><b>Crowdfunding</b>  NOCRI has secured a project manager to work with us from January on the crowdfunding project. Crowdfunding campaigns need a tangible product and it is proposed that the authoritative nutritional guidance for the public and the production of videos could be supported through this campaign.</p>	
5. Children, Teenage and Young Adult (CTYA) Oncology	<p>The inaugural meeting of the CTYA group was held on 11<sup>th</sup> October. 25 individuals from the multidisciplinary field of CTYA oncology attended. MS thanked the Secretariat for its support and SAW for facilitating on the day. The SC thanked CCLG/TYAC for its financial support, which covered travel and accommodation costs for those that required it.</p> <p>The workshop covered the areas of:</p> <ol style="list-style-type: none"> <li>1) Nutritional vulnerability</li> <li>2) Nutritional intervention</li> <li>3) Healthy growth and lifestyle/survivorship</li> </ol> <p>There are 3 broad goals:</p> <ol style="list-style-type: none"> <li>1) Identifying the barriers and facilitators</li> <li>2) Using existing data – how complete and usable is it?</li> <li>3) To establish a group to look at key challenges in nutrition and survivorship</li> </ol> <p><b>Action:</b> circulate workshop report and briefing paper to SC</p> <p>The CTYA group was formally approved as a work stream of the NIHR Cancer and Nutrition Collaboration, and MS will represent the work stream as a member on the SC.</p> <p>From 15-17<sup>th</sup> October, the Wellcome Trust held a ‘sandpit’ event. A team including MS and SAW was successful in being awarded £50,000 for a Programme Development Grant over the next year. The group will work with the Wellcome Trust to submit a full application worth £5m over 5 years. The study will be on nutritional and physical activity interventions for children undergoing bone marrow transplants to improve their metabolic risk. The grant will be managed through the University of Southampton.</p> <p><b>Action:</b> SAW/MS to produce summary statement of study for SC.</p>	<p>FD</p> <p>SAW/MS</p>
6. Experimental work stream	<p>The proposal was welcomed and the SC encouraged the reinvigoration of this work stream under JT’s leadership. As JT sent apologies for this meeting, it was decided to discuss this proposal with him separately.</p> <p>The decision was made to keep the work stream as a separate entity for now.</p>	
7. PPI work stream	<p>The group has welcomed two new members (one patient, one public representative) who were recruited through a formal recruitment process.</p> <p>LT raised the opinion that the PPI work stream does not need to be a separate work stream as its members are now integrated throughout the Collaboration.</p> <p>A number of suggestions were made and the decision was taken to redefine the group as a ‘Patient Reference Panel’. The SC commented that there is value in the group being an entity and it</p>	

	<p>facilitates applying for money to supports its activities. The group could work under a model that it charges to access its contributions (via the Secretariat).</p> <p>Further PPI members should be recruited for specific projects, not only to be a member of the group.</p> <p>The PPI group is encouraged to work with the crowdfunding project and to work more on advocacy and communicating with the public engagement aspect of PPI/E.</p> <p>It was clarified that for a study, PPI should be involved throughout the whole process:</p> <ul style="list-style-type: none"> <li>- Involved in bid and research questions</li> <li>- PPI activities in conduct of research</li> <li>- Conclusions and inferences</li> <li>- Dissemination</li> </ul>	
8. Research work streams	<p><b>Pop Health</b></p> <p>The group has been working on a publication on the methodological framework of interventions in primary and secondary cancer prevention with the aim that this will be submitted to the Lancet. No studies from this group are yet in development. The SC would like to see at least one collaborative trial being submitted each year. A key activity for the group is the organisation of a satellite symposium for the European Congress on Obesity on 27<sup>th</sup> April. The SC thanks WCRF for its support of £1500 towards the running of this. Prof Elio Riboli has returned from sabbatical and is re-joining the group as a member.</p> <p><b>LWBC</b></p> <p>Prof David Bowrey has taken up the position of Chair. The group has been divided into themes to work on developing new studies in sub-groups.</p>	
9. Professionals work stream update	<p>JM and FM have been leading on drafting the manuscript on training requirements of the workforce and this will be ready for submission in the New Year.</p>	
10. Report from Toolkit work stream	<p>SAW and BMC will be picking up the manuscript on screening and assessment needs in the new year.</p>	
11. Next steps and priorities	<ul style="list-style-type: none"> <li>- Producing a clear manifesto for use with stakeholders</li> <li>- Setting out a clear budget and securing sustainable funding</li> </ul>	
12. AOB	<p><b>BRC Oncology day</b></p> <p>The BRC Oncology day is taking place on Monday 11<sup>th</sup> March. This is on the same day as the FFACT stakeholder meeting so SA, MJW, SAW and LA will be spread across the two meetings. The Collaboration has a breakout session slot at the BRC Oncology day, which is 75 minutes long. Delegates will be asked to sign up to sessions prior to the day. The session will be used to share research priorities and to challenge thinking around their experimental medicine programmes.</p> <p><b>ESPRC grant</b></p> <p>FM has applied to the ESPRC ‘Transforming community health and care’ funding stream and will also start working a proposal for an app on self-management of cancer treatment side effects and</p>	

	<p>management of lifestyle.</p> <p><b>Future meetings</b></p> <p>Future Steering Committee meetings will be scheduled to last up to 3 hours. Comfort breaks will be timetabled in.</p> <p>Some SC members have requested to dial in for some meetings. The views of the group were consulted and the position remains that only in-person attendance is permitted. Especially with the meetings moving to up to 3 hours, it was felt that it is more difficult to maintain focus throughout this time and to manage discussion that is a mix between in person and by phone. Consequently, it was agreed that each SC member should have a nominated deputy to attend on their behalf if they cannot attend.</p> <p>The SC could also consider a northern location for one meeting per year. The costs need to be considered for this.</p>	
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**Next meeting:** Tuesday 19<sup>th</sup> March, 11-2pm, NOCRI