

NIHR Cancer and Nutrition Collaboration Secretariat meeting – minutes and actions

Monday 16th December 2019, 11am-12.30pm

Attendees: Sam Ahmedzai (SA) – *by phone*, David Baghurst (DB) – *by phone*, Fiona Davey (FD), Martin Wiseman (MJW) - Chair, Steve Wootton (SAW)

Apologies: Alan Jackson, Rachel Marklew, Josune Olza Meneses

Agenda item	Notes	Person responsible	Required by
1. Welcome and apologies	The Chair welcomed everyone to the meeting and noted apologies.		
2. Minutes of last meeting	<p>The minutes of the last meeting were approved. Action: Upload to website</p> <p>Code of conduct The code of conduct for membership sign-up is almost finalised, with the exception of a statement about intellectual property. Action: any further comments by the end of the week.</p> <p>NCRI engagement At the previous meeting, SA proposed creating a principles document for work streams to engage with NCRI Study Groups. Galina Velikova, co-chair of the LWBC group, is in the process of producing a document for the group which will be relevant to all engaging with the group. Action: SA will edit it to be specifically relevant to the Collaboration.</p> <p>Letter for ICONIC SAW has written the letter to invite ICONIC to be a member of the Collaboration. This needs to be sent to SA for approval, and then to be sent to RM.</p>	<p>FD</p> <p>All</p> <p>SA</p>	<p>20/12/2019</p> <p>20/12/19</p> <p>21/1/20</p>
3. Matters arising	<p>Training FD requested input from the work stream leads about training needs among the work streams, but aside from the Experimental group which had already submitted its proposals, only the CTYA group have responded. Action: Press other work streams to consider potential training needs. Add as explicit item to their next agendas.</p> <p>Membership In preparing for the membership launch, FD was advised to check with CCF comms regarding the situation with Purdah. FD was advised to wait until after Purdah to launch the membership, but was also advised to get</p>	<p>FD</p>	<p>20/12/19</p>

	<p>approval from DHSC to fundraise in this way. A letter has been sent from SA to Louise Knowles and Helen Campbell from DHSC on behalf of the Collaboration to request permission and explain our intentions with the membership programme.</p> <p>Action: Call DHSC to ask when they would be able to respond</p> <p>Patient enquiries FD received a patient enquiry recently which prompted discussion on making it clearer on our website what the Collaboration can and cannot do. The Collaboration is not able to provide personal nutritional advice or to comment on a patient's individual medical situation. Patients can be directed to trustworthy nutritional resources, and can be enlisted to help promote the signposting resource once it is complete. The response to this enquiry was run past LT and she was content with the response, on behalf of the Consumer Panel. SA reported that the British Pain Society, which is a professional organisation, has an informal system of medics/AHPs responding to patient enquiries. Something similar could be utilised if the Collaboration starts to receive many enquiries of this nature.</p> <p>Action: Produce statement for publication to clarify.</p> <p>HSJ award The Collaboration, Macmillan and RCoA were shortlisted for the not-for-profit award of HSJ. A judged presentation will be made in January and then an awards dinner will take place to announce the winner.</p> <p>Action: Contact NIHR comms for promoting the shortlisting.</p>	<p>FD</p> <p>FD/MJW</p> <p>FD</p>	<p>20/12/19</p> <p>14/01/20</p> <p>20/12/19</p>
<p>4. Nutritional guidance resource</p>	<p>There are presently several options to consider in delivering a resource for patients and health care professionals to signpost to trustworthy nutritional advice. FD has drafted an options paper as a basis for a project group to develop.</p> <p>Options currently include: Dutch WCRF website (for both patients and healthcare professionals) Minervation (patient facing) Southampton Hospital Charity funding (for patients) BDA GET application (focused on non-specialist dietitians)</p>		

	<p>NIHR Dissemination Centre (all audiences) These opportunities are not mutually exclusive, some options may be complementary. Action: Members of the project group to be invited and meeting to be set up for 1st week of January.</p> <p>Action: DB to send form to FD</p> <p>The Dutch WCRF website has been having conversations with a children's hospital and has plans to include information for children's cancers. Action: Link this activity into CTYA arm of ICONIC</p>	<p>FD</p> <p>DB</p> <p>FD/RB</p>	<p>18/12/19</p> <p>18/12/19</p> <p>21/01/20</p>
5. Collaboration structure	<p>An amended version of the 'restructuring the executive function' document was presented. Further comments were received which need to be addressed.</p> <p>This will be brought to the January Secretariat for final sign off and will be presented to the February/March Steering Committee</p> <p>Action: Any further comments by end of this week</p> <p>Finalise document by end first week January 2020</p>	<p>All</p> <p>FD</p>	<p>20/12/19</p> <p>10/01/20</p>
6. Guidance for receiving support for research	<p>The principles for receiving support for research document has been edited according to comments received.</p> <p>Action: Any further comments by the end of the week</p> <p>Action: Upload to website and circulate to work streams</p> <p>Action: DB to provide comments from NIHR perspective</p>	<p>All</p> <p>FD</p> <p>DB</p>	<p>20/12/19</p> <p>21/1/19</p> <p>20/12/19</p>
7. Cross-work stream meeting	<p>The Collaboration's cross-work stream meeting took place on the Monday of the NCRI conference.</p> <p>The listed actions in the notes need agreement between the work groups of who takes responsibility for each.</p> <p>Action: Circulate notes and ask work stream leads to explicitly consider overlaps with other work streams. Add as explicit item to their next agendas</p> <p>Action: Inform leads that there will be another cross-work stream meeting next year</p>	<p>FD</p> <p>FD</p>	<p>6/1/20</p> <p>6/1/20</p>
8. NCRI nutrition	<p>SA spoke with Mariano (NCRI) last week. NCRI is eager to work with us on cancer and nutrition</p>		

conference	<p>focused conferences for 2020. NCRI would be happy to bear the costs of this. The work streams need to be steered to work with them.</p> <p>A clearer statement of the purpose of the meeting, what it would look like and what it would lead to is required.</p> <p>Topics of interest for the conference include:</p> <ul style="list-style-type: none"> • Pre-clinical • Laboratory work • Clinical practice • Long term patient experience <p>A clear programme of what the NCRI will give to support researchers in this area</p> <ol style="list-style-type: none"> 1) Conference late spring/early autumn dedicated to cancer and nutrition 2) Sandpit event Spring (3 day sandpit) across whole of NCRI – open for us to pitch nutritional projects to all of NCRI 3) LWBC is organising annual trials meeting 23/24th March. Hoping to get one speaker on nutrition for the 24th. Birmingham or Manchester <p>The sandpit event will provide the opportunity for ideas to be pitched to the NCRI groups to gain traction and support for the topics, but funders will likely be invited.</p> <p>Action: Organise t/c for SAW, MJW, AAJ and SA. SA to send potential dates to FD</p> <p>Helen Campbell is on NCRI board on behalf of NIHR Action: Ensure she is informed about our plans</p>	FD	6/1/20
8. International collaboration	<p>ICONIC is planning a face to face meeting in London on 10th March.</p> <p>ICONIC should be linked up with the NIHR Global Health programme. DB is currently leading this. Action: Get info on NIHR Global Health Programme</p> <p>NIHR Global Health Programme as a sub-item for the next Secretariat meeting</p>	FD	16/01/20
9. Work stream updates	<p>CTYA Wellcome Trust Grant The group has established a vibrant group of collaborators in UK and overseas to look at nutrition and exercise interventions for</p>		

	<p>treatment. It has recently created a theoretical conceptual framework for why children are affected metabolically post-stem cell transplant. The group is looking at why the effects persist and where the opportunities to intervene are. The group is expecting to have the proposal ready to submit to the Wellcome Trust by Q1 of 2020.</p> <p>The Wellcome Trust PDG group will also work alongside the core CTYA group to define the minimum required nutritional measures in ongoing registries/studies.</p> <p>Toolkit Action: A face to face meeting was not possible so FD will arrange a teleconference with BMC in January.</p> <p>Professionals Action: SAW to sign off final authorship/acknowledgements for the manuscript</p>	SAW	20/12/19
10. AOB	FD is pursuing reviewing the GDPR and privacy policy with UHS as they are our host institution, and NIHR Comms advised that our policies must align with the host institution.		

Next meeting 23rd January 2020