

NHS National Institute for Health Research

| Meeting title: | | Cancer and Nutrition NIHR infrastructure collaboration Steering Committee | | |
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| Date: | | 22 nd March 2017 Time: 11am-1pm | | |
| Location: | | Skipton House, NOCRI, London | | |
| Present: | | Prof Alan Jackson (AAJ) – Chair Kate Allen (KA), Millie Barrett (MB), Bernard Corfe (BC), Fiona Davey (FD), Davies (LD), Steve Wootton (SAW), Lesley Turner (LT), Elio Riboli (ER), Ka Brown (KB), Karen Phekoo (KP), Judit Varkonyi-Sepp (JVS), Clare Shaw (C Mangiameli (GM), | ren S), Giulia | |
| Аро | logies: | Helen Campbell (HC), Richard Martin (RM), Fehmidah Munir (FM), Ramsey (RIC), Martin Wiseman (MJW), Karla Duarte (KD), Amanda Cross (AC) | Cutress | |
| 1. | SAW oper other men Everyone meeting fo | and apologies ned the meeting, as transport difficulties meant delays in arrival for AAJ and nbers travelling from Southampton. introduced themselves and SAW reminded us all that this is the last SC or Phase II, and at there is a need to focus on consolidation of activities ast year and to consider how the Collaboration should move forward into | Action | |
| 2. | posted on Matters a Elspeth Bi developm ESPEN g discuss th cancer - a approach whilst the evidence highlightin guidance funders su | re agreed as an accurate record of the December meeting and will now be to the Collaboration website. | | |
| | The Colla the guidar will consic might be a determine | boration wanted to know if BAPEN were to take a position in response to nce, and we were told they do not usually offer a position on guidance but der the extent to which they will look at other parties' guidance and how it applied to clinical UK practice. The Collaboration also is interested to the position of the BDA. | SAW | |
| | us at the CRUK ind | AW and CS to follow up via the BDA Oncology group and feed back to next Steering Committee in June. licated that they had not yet considered the guidance or research questions this review and how it might influence their approach to funding work in this | and CS | |

| | area. | |
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| | The guidance was previously circulated soon after publication last April, and a response from the Professionals and the Research work streams would be worthwhile. The guidance does not cover all nutritional issues of those with cancer focussing mainly on recommendations for those cancers associated with weight loss and cachexia and there are important areas that remain to be addressed. | |
| | Action: SAW to circulate a one-sided A4 summary of the ESPEN guidance to this group to ensure that all members of the Collaboration are aware of the research recommendations raised by the guidance. | SAW |
| | Commercial strategy background paper: (Slides attached to minutes) | |
| | SAW reminded the SC that the paper that was pre-circulated is a background paper to developing a strategy for consideration in Phase III rather than the final strategy which needs to be agreed by all stakeholders. | |
| | The SC was asked to consider the short term objectives as set out in the document and to consider how to shape the ideas into a Phase III proposal. The expectation is that a core group to develop the work stream be established to consolidate these ideas ahead of a workshop for key stakeholders to secure agreement on strategy and activity. | |
| | [AAJ joined the meeting.] | |
| | Early stage discussions about how to work with industry partners have begun, hosted by the BNF. The Government also wishes to see progress in this arena and is aware of the inherent challenges. It is also necessary to consider which parts of industry have regulatory frameworks, and which do not, operating in unregulated and insecure structures. | |
| | It was agreed that there is a need to create a framework through which structured discussions can be developed. | |
| | Action: AAJ and SAW to secure membership of core group early in Phase III and continue to develop a framework. | AAJ and SAW |
| | At this juncture SAW passed the chair to AAJ and late arrivals introduced themselves (FD, KP, JVS, LT). | |
| 3. | National Office for Nutrition Research update: | |
| | There are three distinct activities ongoing under the umbrella of the National Office for Nutrition Research: the Cancer and Nutrition NIHR infrastructure collaboration; the OSCHR review; and the review into NIHR supported nutrition-related research. The draft report of the OSCHR activity has now gone to panel members, is in the process of being finalised, and is expected to be finalised in a matter of weeks. | |
| | Recommendations within the report are high-level and embrace health-facing activities together with food-facing research as supported by BBSRC (Biotechnology and Biological Sciences Research Council). The Collaboration is expected to share and draw on many of the recommendations that may be presented in the final OSCHR report. | |
| | Review of NIHR-supported nutrition-related research: the findings of this review | |

| | which was completed at the end of last year will be in public domain, with sign-off expected within matter of days. It is not yet clear how it will be made available, and as the methodology was novel, it would be useful to share with others. | |
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| | Arising out of the activities of the National Office for Nutrition Research, two other activities are planned: the first is focusing on the uncertainty around the use of terms in nutrition research and derive a consensus position in three distinct but related areas of research: physical activity and exercise; sarcopenia/wasting/cachexia; and behaviour change. Three workshops are being set up and will take place over next 3-6 months. | |
| | The second activity is around going back to the data we have gathered from the national review into nutrition-related research to better understand the nature of the research being carried out – what, who, where and with what level of resource. This will help establish a secure foundation from which to develop future research activity. This information needs to be positioned against the broader nutrition research activity across the UK. | |
| | It was noted that that Public Health England/Food Standards Agency have announced funding for a further cycle of the National Diet & Nutrition Survey (NDNS). | |
| 4. | Phase II report | |
| | The draft report circulated seeks to capture the work carried out in this Phase of activity and look ahead to what we intend to achieve going forward. AAJ thanked MB and FD for their work carried out in this Phase. The Collaboration has made considerable progress under a period of some uncertainty and secured an excellent platform for entering into Phase III. Further information will be added into the report about PPI activities, with details included about presentations to various NCRI Clinical Study Groups. It should be acknowledged that we have opened up the dialogue, and now will focus on what needs to be done going forward, to bring about a shift of culture in research relating to cancer nutrition. | |
| | It was agreed that a printed version of the Phase II report that maintains the brand and style of the Phase I would greatly aid communication about the collaboration such as with the Directors of the new BRCs. BRC Directors are meeting on 10th April, and again in around six months. During this time NOCRI will visit all new BRCs, and are able to take materials of interest to them | |
| | AAJ asked that all examples of impact of the report are offered to the Secretariat as evidence of output after two reports of Doctoral work secured on the back of the Phase I report. | |
| | Action: KA to ask WCRF Head of Communications if there is any support available from WCRF to produce the report. | KA |
| | Action: JVS to discuss what communications support might be available within Southampton BRC. | JVS |
| | Action: LD to ask CRUK if they would be prepared to support production of Phase II report. | LD |
| | Action: MB to explicitly request work stream leaders to approve their definitive statement of Phase III priorities for the report. Clear timelines to respond will be given. | MB |

5. Phase III Strategic Direction

A draft document was circulated prior to the meeting. SAW presented a couple of slides (attached) to focus discussions – the first being the importance of putting patients and their care at the centre of our ambition and the second offered a potential route map that would help define the strategy and tactics needed to achieve this ambition of better advice, better care and better outcomes for all patients.

The Collaboration so far has been on a journey with three very distinct phases, as set out in the opening remarks from AAJ in the draft Phase II report. We are now entering Phase III and the focus now needs to be about enabling activities. There is a need now to step up to the next level and agree a framework for delivering research. With a framework in place that directly links the activities within the workstreams to defined outcomes – clearly aligning evidence of the needs/priorities for research, synthesising the current evidence (and associated gaps), defining the research opportunities, pulling together the underlying science and technology needed to assess nutritional state, establishing an engagement platform, and defining relationships with charities, industry and funders – and how these will then be used to build the research strategy and action plan. This will lead to a portfolio of studies – propsective, observational, routine clinical data, intervention and mechanistic studies – conducted by the collaboration or stimulated by the activities of the collaboration that will enable a new synthesis of the evidence and guideline development and through this develop both the professional workforce and clinical service.

SAW presented the Year One objectives (slides 13-14), with patients at the forefront. Embedding nutrition research into the NCRI CSGs is essential to realise our ambition. Work is ongoing to achieve this, led by Sam Ahmedzai and Lesley Turner.

Action: At the next meeting in June, LT to feed back about progress with NCRI and CSGs.

LT

SAW presented a slide of Collaboration oversight structure (slide 15) and an operational structure showing all the different stakeholders we may wish to involve on the Steering Committee going forward. It was pointed out this is not set in stone and very much for discussion.

It was agreed that the proposed future direction and strategy, and short term goals offer a most helpful framework for future discussions and that this should be reflected in the Phase II report.

Budgets and Finance

The financial support of the Southampton BRC has been essential in enabling the activities within Phase II. The chair thanked KP on behalf of Southampton BRC for their support and the oversight shown in assisting the Secretariat. SAW confirmed that there had been a formal consolidation of income and expenditure with KP and that all of the funds were now spent.

The Collaboration is now entering Phase III with no funds secured. SAW presented a slide (16) showing an indicative budget for the next six months (£58,631) to maintain current activities. We need to find a mechanism to support the initiative. KP confirmed that Southampton BRC is prepared to meet the minimum budgetary needs (pay costs only) for the next six months. KP and the wider Southampton BRC was thanked for this commitment and it was recognised by the Steering Committee that we are under obligation to consider this a transition period in order to be in a stronger position by the end of the next six months.

The Steering Committee recognised that a funding gap of this nature is potentially a major problem for patient involvement and engagement, because of the costs

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| | associated with travel and taking part in teleconferences. It was suggested that instead of running a separate PPI/E work stream, to save resources for now it may be necessary to focus PPI/E activities through the individuals who are already embedded in other work streams. | |
| | A discussion was held around the extent to which funds might be forthcoming from DH, NIHR and NOCRI to support the collaboration. One specific area of concern was to enable the patients who have supported the PPI work stream to continue to play such an important role in co-designing the work of the collaboration in accordance with the guidance from INVOLVE and NIHR. | |
| | JC stressed that NOCRI does not have funds with which to directly support activities, as their remit is enablement rather than direct support but agreed to take this issue back to NOCRI. JC also made it clear that DH is aware of this difficulty, and it is being discussed at a senior level. The Steering Committee thanked JC for her continued support for the Collaboration. | |
| | An alternative approach to support PPI/E may be by the infrastructure "adopting" PPI/E representatives and thereby meeting some of their own commitments through their PPI budget. The new BRCs will not have finalised their PPI/E strategies yet and it may be opportune to offer this opportunity for participation through supporting the PPI representatives. | |
| | Action: A meeting to be set up to explore how this might work, involving the relevant people from NIHR infrastructure e.g. Philippa Yeeles at NIHR's Central Commissioning Facility and Lesley Turner. | MB/FD |
| | Action: ER and KP will speak to their respective BRCs about adopting PPI representatives. | ER and KP |
| 6. | Charity engagement | |
| | AAJ thanked NOCRI for their role in progressing this activity since first discussions with AMRC last year and getting so many charities involved in the discussion. Two main topics have been the focus of discussions so far: working together to enable access to trusted nutritional guidance for patients and clinicians; funding research to fill evidence gaps. Following the last work shop, charities have been asked to fill in a template giving information about what funding schemes they offer for research in this area. | |
| | Could the core activities of the Collaboration be supported by the charities that have shown interest? LD commented that it might be more helpful if the wording could be more around research 'gaps' rather than 'priorities', because many funders including CRUK and Wellcome do not tend to set priorities or issue targeted calls, instead they look to researchers to come up with what are the most important research questions. | |
| | A discussion was held around evidence 'gaps' and how to fund research to fill them. The SC noted that the deadline for CRUK's 'grand challenge' bid is 17th April and the SC asked the research work stream to offer 'grand challenge' questions to take to CRUK about this gap in the research. | |
| | Action: LD to check dates and terms of the 'grand challenge' and give guidance. | LD |
| | It was agreed that a secondary prevention proposal might be a better option because the study can be smaller in terms of size and cost. This was discussed on the population research sub-group teleconference on 21.03.17 and might be a more | |

| | Action: ER to progress discussions within his research work stream sub-group about the most appropriate proposals to develop. | ER |
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| 7. | Work stream reports: Work stream reports were not considered in detail as they had been circulated previously. There were no specific comments or queries raised. | |
| 8. | Priorities and next steps: Finishing and publishing the Collaboration's Phase II report Finalising the Collaboration's Phase III strategic direction. Asking NOCRI to take our plea around funding to support PPI/E back to DH within recognised constraints. By the next meeting in June, to be held at CRUK, our challenge as outlined within what SAW has presented today, is that we should be well into the transitional Phase IIIa and moving into the more active Phase IIIb. | |
| 9. | Date and host of next meeting: | |
| | The next meetings will be held on <u>Thursday 15th June at CRUK; Wednesday 13th September at</u> Imperial, and Wednesday 13 th December at NOCRI. | |

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