



Cancer and Nutrition NIHR infrastructure collaboration

Workshop on Tuesday 2nd February 2016, London

Executive Summary

Background

In early 2014, Professor Alan Jackson and his team at the NIHR Southampton BRC, together with the World Cancer Research Fund (WCRF UK), supported by NOCRI, recognised the need to bring coherence to existing activities in the area of cancer and nutrition and provide a coordinated framework for future research into these areas.

The Cancer and Nutrition NIHR infrastructure collaboration conducted Phase One of its remit in 2014-15. This included the mapping of cancer and nutrition research activities in the UK, a patient experience survey, a clinicians' survey, and stakeholder engagement. A full report of Phase One work was published in late 2015 and is available at <http://cancerandnutrition.nihr.ac.uk/>. A key recommendation of Phase One was the identification and setting up of five work streams to take the collaboration's work onto the next stage. Therefore, the Steering Group agreed to hold a workshop in early February 2016 to further develop four out of the five work streams:

1. Information provision and communication with cancer patients and the public.
2. Creating a skilled community of practice.
3. Identifying major research priorities.
4. Characterising nutritional status in cancer.
5. Opportunities for engagement with the commercial sector.

The fifth work stream was not addressed specifically at this event, although participants were asked to consider potential engagement with industry and the commercial sector as part of their discussions. A range of stakeholders from across the UK were invited to participate in the workshop, representing patients, clinicians and researchers in the fields of both cancer and nutrition. Forty people attended the workshop, See Appendix 2 for a list of all participants and their affiliated institutions or organisations.

Participants were assigned to work streams according to relevance and expertise, to discuss and agree a work plan. Participants were asked to make decisions on membership, scope of work, deliverables and targets for each work stream. These were to be drafted in breakout sessions and agreed in plenary at the end of the day.

Summary

Two key themes underpinning the day were translational research facilitation and the involvement of patients and the public (PPI) at all stages, in all work streams. Issues of funding for PPI were discussed and recognised to be a high priority.

Following work stream break-out sessions, feedback and discussion took place, allowing for a full debate of the many points raised. The atmosphere was one of open, honest communication, with the aim of capturing wide engagement from all participants. Each work stream leader summarised their groups' discussions, including issues of membership, key objectives, and other activities such as mapping current practice.

Common themes identified across work streams were the need for standardisation of routine care for cancer patients, competency-based training for practitioners, quality assurance, educational and research resources, and data management. The development of research priorities was broken down into five sub-themes, with exploration of funding models and 'quick win' ideas also identified as important. In addition, the potential for self-completion of routine data collection was highlighted as worth exploring by more than one work stream.

Next steps

Following from the workshop, work streams are developing their work plans according to the template provided. Outputs will be identified, with named responsible people and timelines attached. A preliminary action plan from each work stream will be presented to the Steering Group at the end of March, for further development and action over the next twelve months. Wide participation and ownership are encouraged, in order to achieve tangible objectives that deliver improved cancer prevention and care for patients, for clinicians and for researchers.

Appendix 1 – Full workshop report

Summary report of Cancer and Nutrition NIHR infrastructure collaboration Workshop on Tuesday 2nd February 2016, London

Background

The event was planned as a result of the collaboration's Phase One findings, as a starting point for developing work plans for four out of the five identified work streams:

1. Information provision and communication with cancer patients and the public.
2. Creating a skilled community of practice.
3. Identifying major research priorities.
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Forty people attended the event, including patient representatives, specialist oncology dietitians, clinical oncology practitioners, lead researchers in the field of cancer and nutrition, public health experts, statisticians, nutritionists, epidemiologists, and others identified as important contributors to the development of the collaboration's work.

Organisations represented at the workshop included:

- National Cancer Research Institute (NCRI) Clinical Study Groups (CSGs)
- National Institute for Health Research (NIHR) Central Commissioning Facility
- NCRI Patient Forum
- NIHR National Office for Clinical Research Infrastructure (NOCRI)
- Independent Cancer Patient's Voice (ICPV)
- NIHR Biomedical Research Centres (BRCs) including Southampton, Royal Marsden, Imperial
- Cancer Research UK
- Macmillan
- World Cancer Research Fund UK
- Hospital/University Trusts including Addenbrooke's, Brighton and Sussex, Cardiff, UCLH, Queen's Belfast, Guy's and Thomas' London, Nottingham
- Centre for Research into Cancer Prevention and Screening, Dundee University
- Experimental Cancer Medicine Centres (Leicester)
- Wales Cancer Trials Unit
- Nutrition Society
- British Dietetic Association (BDA)

Professor Jackson, Chair of the collaboration welcomed everyone to the workshop event, marking the beginning of Phase Two of the collaboration. Overall aim is to start putting together an agenda and work plan for each work stream that can be prosecuted over the coming year. The collaboration team is currently funded until April 2017. Each work stream will develop its own work plan, but will also be reviewed by the Steering Group to ensure the approach to each work stream is consistent

and complementary. The level of commitment from those attending was recognised and appreciated, with many people travelling from other parts of the UK and the devolved nations.

Martin Wiseman, Medical and Scientific Advisor at WCRF UK made some opening remarks and set out the aims for the day. Key points included:

- Translational research facilitation
- Nutrition as a fundamental modulator of the cancer process
- Key activities of the collaboration to date (completion of Phase One)
- Main findings of Patient Experience Survey including the gap in evidence
- Main findings of Clinicians' Survey
- Mapping exercise: 1.8% of cancer research spend was on nutrition (2009-2013)
- Aim for today: work stream development, begin to fill in NOCRI template and report back to Steering Group at end of March with Action plan and progress

Steve Wootton then spoke about the wider framework and context of the collaboration and workshop event. Key points included:

- Translational research is poorly defined
- The NIHR places the benefits for patients and people at the heart of translational research, therefore the patients' perspective is central to taking the work forward, not just in PPI work stream but across all five work streams
- From NIHR's perspective, translational research is used to translate the findings of basic research more quickly and efficiently into medical practice, and thus meaningful health outcomes, whether these are physical, mental, or social outcomes i.e. 'bench to bedside'
- Perceived gaps in the research pathway (Basic, Clinical, Applied, Service Delivery) and the need to ensure these road-blocks are overcome.
- NIHR emphasises the need to 'pull-through' the science in order to achieve benefit to patients, their families and carers, and the healthcare system as a whole, as a demand-led process.
- We know there is variability in response to treatment depending on nutritional status, but we don't understand enough about the processes involved
- Importance of the 'terroir' i.e. the host, and the effect that host nutrient availability has on underlying tumour biology and response to therapies
- Opportunities exist to apply new technologies around bio-informatics and data science, biomarker development and genomics.
- Our challenge is to build a professional workforce in the field of nutrition and cancer, and to work out what tools are needed for use in clinical practice to benefit cancer patients at all stages of the cancer process.

The four work stream leaders then gave a five minute introduction to their theme. Key points are highlighted here.

1. **Lesley Turner: WS1: Information provision and communication with cancer patients and the public.**

- Key points from Phase One patient survey were highlighted e.g. lack of consistent nutritional advice, side effects of chemotherapy being the most commonly reported nutritional problems
- Need for patients to help identify priorities for future research
- Funding is a key issue if we are to have meaningful patient and public involvement

2. Ramsey Cutress: WS2: Creating a skilled community of practice (professionals and professional groups)

- Aiming to agree and develop the remit and constitution of the work stream
- Aiming to identify what evidence is needed and who should be involved
- To identify gaps in current evidence base for good nutritional support for cancer patients
- Recommendations for best practice and quality assurance for training and competency: what do we expect the workforce to know and do, how can we help them develop the necessary skills and understanding to assure quality care?

3. Karen Brown: WS3: Identifying major research priorities

- Good evidence for how nutritional factors relate to incidence of cancer, but not for management or outcomes post diagnosis, this constitutes the research gap
- Mechanism to collect this data is needed
- Lacking research also on what turns a normal cell into a cancer cell
- Mice trials are showing better response to treatment when nutritional status is better e.g. trials using curcumin, resveratrol and aspirin
- Links with industry are probably essential, although controversial
- Large scale trials are needed, multicentre, flexible models
- Many practical considerations - including cost

4. Bernard Corfe: WS4: Characterising nutritional status in cancer

- Key points from Phase One patient survey highlighted with a focus on the inadequate nutritional advice to patients
- Advice to eat a 'balanced diet' is not fit for purpose for all cancer patients, advice should be tailored to each person's situation (e.g. post-surgery colorectal patient)
- Many factors to consider when assessing nutritional status of patient e.g. appetite, stress, dietary intake, physical activity etc.
- Tools exist for quantifying these features, but are they fit for purpose and are they acceptable to the patient and professional community?

After the introductions to each work stream, everyone broke off into their smaller groups to develop the work plans as outlined above. The afternoon session began with work stream leaders feeding back to the larger group, followed by discussion of issues raised.

Lesley Turner: WS1: Information provision and communication with cancer patients and the public

- The group does not wish to be separated from the other work streams and would like to see patient/public representation across all streams (Steering Committee already agreed this prior to event)
- Questions raised about how formalised the process will be, what is the level of input from the Steering Group?
- Recognised that patients and public are two different groups and public is not represented at present
- Wish to identify achievable outputs
- Wish to involve younger people, unsure how best to do this
- Wish to engage relevant patient groups, will share slides to present to other CSGs (Clinical Study Groups) first and foremost
- NCRI Conference in Liverpool as an opportunity to showcase the collaboration's work
- Phase One report should be shared more widely with patients and public
- Possible patient group mapping exercise
- ICPV (Independent Cancer Patients' Voice) and WCRF UK to put a link in their newsletter to the Phase One report as a way to raise profile of the collaboration
- Nutritional data collection – could this be patient-led, use of a mobile app, engagement with commercial sector?
- Funding for PPI – where do we stand? Travel costs are the minimum that must be covered, clearer guidance needed for future, expertise is vast and valuable, funding needs to be embedded in bids and budgets to ensure cover
- Three main objectives: funding; representation on all five work streams; raising profile of collaboration to wider audience

Issued raised following Lesley's presentation:

- Top-slice funding from charities to cover PPI expenses
- Need to quantify what estimated costs will be, for attending meetings etc. Not talking about large sums.
- NOCRI model for PPI in collaborations does not exactly fit our model because some parties involved are not part of NIHR, therefore a wider discussion is needed.
- Need to engage PPI across different patient groups (i.e. different types of cancer) as needs can vary widely – aim to access NCRI CSGs to achieve this, Richard Stevens (Chair of NCRI Consumer Forum) to hopefully offer support
- Identified some common ground with other work streams – specifically the desire to create a network of patients to help set research priorities, and the idea of patients collecting their own nutritional data making it potentially quicker and cheaper than other mechanisms
- It was agreed that a set of slides should be made available on the website for anyone to use in order to raise the profile of the collaboration to a wider audience

Fehmida Munir: WS2: Creating a skilled community of practice (professionals and professional groups)

- PPI representation needed, as well as other specialisms e.g. nurses, GPs
- Professional competencies to include: recognition of role of nutrition in cancer incidence and progression; appropriate assessment of nutritional status; awareness of existing authoritative guidance and synthesis of evidence; application of 'best practice'; identifying research needs
- Three key objectives:
 - i) Identification of existing guidance (NCRI CSGs, NICE, RCN, BDA, AfN, Medical RCs, BAPEN, charities)
 - ii) Examine application of guidance by professionals, including consistency of application
 - iii) Examine consistency between and within different guidance
 - iv) Develop skilled community of practice
- Enabling activities: identify resources including patient groups, charities, AoMRC, student projects; BANS (potential data resource); liaison with other work streams especially toolkit and PPI

Issues raised following Fehmida's presentation:

- Clarity needed around training for different professionals
- Health Education England did fund attendance at training but this is stopping now, changing the workforce dynamic.
- Need to take advantage of new initiatives from NIHR infrastructure training forum to promote opportunities for developing clinical academic careers. New Clinical Academic Pathway (combined posts) and a need to match with translational research.
- Need to consider whether it is possible for cancer and nutrition to be identified as a future thematic call from NIHR.
- Kings College London is now offering an MRes in Translational Cancer Research.
- Need to remember devolved nations and different systems that may apply, although recognised that collaborations can exist across the nations, and there may be opportunities to engage with specific institutions in devolved nations
- Participants at the event from devolved nations included Annie Anderson, Professor in Public Health Nutrition, Centre for Research into Cancer Prevention and Screening at Dundee University; Rachel Barlow from Cardiff and Vale University and Rhiannon Whitaker from the Wales Cancer Trials Unit; and Marie Cantwell, Senior Lecturer in Nutrition and Cancer Epidemiology at Queens University Belfast
- Opportunity to develop further nutrition and cancer learning within undergraduate medical education – extent to which cancer considered within new ICGN undergraduate nutrition education implementation group curriculum guidelines?
- Further opportunities for learning would include foundation training for new nurses, doctors and dietitians (Professor Annie Anderson on education group for the BDA)

Karen Brown and Anne Helme: WS3: Identifying major research priorities

There were plenty of ideas and interests shared in the work stream. Three main objectives identified were:

- i) Develop research priorities, focusing on five sub-themes
- ii) Explore funding models
 - a. involving industry, bearing in mind any potential conflicts of interest involving commercial partners and type of research
 - b. involving other cancer funders
- iii) Start working on some 'quick win' research ideas

To take forward these activities, we need volunteers from the community to lead the activities listed below.

i) Develop research priorities

- Process: need to do a Delphi exercise (or a quicker type of survey) with a larger sample of the cancer and nutrition community, potentially focusing on five sub-themes reflecting cancer and nutrition across the life-course.
 - risk/causes/primary prevention
 - prehabilitation
 - acute/treatment
 - survival/survivorship
 - end-stage/palliative care
- Who we need to involve (NB not an exhaustive list): PPI, paediatricians, information scientists, statisticians, oncologists, clinicians, psychologists, biomarkers experts, basic scientists, clinical nurse specialist, systematic researchers, GPs, patients, other charities or special interest groups.

ii) Explore funding models

a) involving industry

- Can we provide something they can invest in, rather than research being led by them? Is the food industry reluctant to be involved in cancer research?
- KIT network as part of Imperial – two consortia on food and health including Nestle and Unilever, any potential opportunities here?
- Consider also insurance companies, gyms, translational research partnerships, health insurance companies like Bupa, celebrity chefs
- Public health/prevention research can't be funded by food industry, due to reputational risk.
- Can we learn from the [lung matrix trial](#), or [Horizon 2020](#)?
- Are any drug trials currently collecting information on patient nutrition?
- Many different models exist for engaging with industry, flexibility is needed, and expectations should be managed.

b) involving other cancer funders

- Large-scale intervention trials are expensive so need groups of funders.
- Consortium funding model could be used for cancer and nutrition, involving research charities and other funders. Explore how [National Cancer Research Institute](#) (NCRI) or [Association of Medical Research Charities](#) (AMRC) could help.

- Need to keep aware of work of [National Prevention Research Initiative](#) (NPRI), an initiative managed by the Medical Research Council (MRC) and involving multiple funding partners. The initiative [was reviewed in 2015](#) and there may be further funding opportunities that this collaboration could access.

iii) Start working on research ideas

Trial development groups should be established to take forward key research questions/studies suggested by participants, working with the [NIHR Biomedical Research Centres](#) (BRCs) and the [NCRI Clinical Study Groups](#):

- Primary Care optimisation - early signs of cancer can lead to physiotherapy referral.
- Collecting and synthesising what is known about nutritional status and clinical outcome in cancer patient outcomes/survivorship. (This works well in the prevention area e.g. [WCRF's Continuous Update Project](#)). Not known if same risk factors for incidence and survivorship.
- Does invasive feeding lead to better outcomes for patients undergoing chemotherapy?
- Does assisted feeding give better outcomes for patients having stem cell transplants?
- Does implementing a diabetes-type intervention for patients with breast or bowel cancer lead to better survival rates?
- What is the relationship between obesity, physical activity and breast cancer diagnosis/recurrence, for pre- and post-menopausal women?
- Establishing a prospective cohort with accurate capture of routine anthropometric measurements.

It was also noted that methodological research would be important to underpin effective research in cancer and nutrition – how could new trial designs help reduce the time and cost of large intervention trials?

- Eg use of routine data (could cancer registries collect data on nutrition? Nutritional phenotyping in biobanks?), cluster randomisation, 'piggy-backing' on drug trials, adaptive designs that allow additional arms to be added, use of surrogate markers for recurrence/progression.
- Could we persuade a trials unit to work on methodological issues? And a sub-group to consider health economics?
- How could nutrition be incorporated into patient outcomes/core outcomes from trials?
- Look at working with [Farr Institute](#) and [MRC Methodology Hubs](#).

Bernard Corfe: WS4: Characterising nutritional status in cancer.

- Current situation: many different tools, no standard practice, lack of consistency in training or application of tools across regions, Trusts, specialisms etc.
- Currently a two-step process includes screening and assessment:
 - i) Screening – according to NICE guidelines, carried out by nurses, use tools such as MUST to identify risk of malnutrition, either identified as not at risk, or signposted for assessment
 - ii) Assessment – dietitian-led, anthropometry, biochemistry, clinical and diet (ABCD), vast array of tools are used, recording of data is inconsistent

- Concern identified around lack of follow-up with patients not identified as “at risk” in screening, missed opportunity to provide information, advice and signposting at this point, also to encourage self-management
- Anthropometric data should be collected at primary care and made available to dietitians later
- BDA developing a dietetic outcomes framework, pilot Phase Two to start March 2016, and launch in October
- Holistic Needs Assessment currently within 31 days of diagnosis, includes questions around appetite, any concerns, a 0-10 scale of distress, no anthropometry or questions about physical activity
- Many other tools also used, e.g. PG-SGA (Patient-Generated Subjective Global Assessment)
- Key aims of work stream: build a team (identify who else is needed); collate current activities (mapping exercise); identify best practice in clinical care; identify the gaps and explore why certain things are not done; ensure basic routine collected data and explore use of patient-completed data (e.g. through use of iPads in waiting rooms); explore use of biochemistry and Biobank as potential way-in
- Consider best way to engage patients, ensure PPI representation on work stream
- Recognise specific needs of specific populations, may depend on cancer site, stage, age etc.
- Others to engage with: patients, nurses, oncologists and surgeons, speech and language therapists (work on taste), others
- What does our best practice nutrition toolkit look like? Who is it for?
- Do not want to reinvent the wheel, main aim is to standardise current practice and improve patient care at all stages of cancer process

Issues raised following Bernard’s presentation:

- Nutrition assessments need to have standardised and quality assured protocols for the over-nourished as well as the under-nourished, different tools for different people, minimum core with add-ons
- Self-completion by family or patient should be considered – current and critical
- Consider what are the obstacles to standardisation – the crux of the matter? Is this a clear objective for all work streams, as well as to be considered a standalone challenge?
- Professional groups (BDA, Nut Soc) represented in work stream, others needed?
- Data management and implementation is as important as data collection, statistical input needed to ensure appropriate use of data
- Data Science is on the need list, but no input now, Royal Statistical Society may have a role to play
- Nutrition community is lagging far behind others in terms of big data management
- Bio-informatics Centre is an important recent initiative, based at Imperial, owned by the MRC
- Cancer registers also valuable source of information for the UK, we have huge experience in the UK on collecting and using routine data
- Registers can be adjusted to meet needs for data collection
- Recognise that conflicting information can be given even within one hospital

- CRUK Patient Data Access Reference Group is working with the British Heart Foundation to identify priorities around access to patient data. There may be benefit in making a link with this group in the future to discuss issues of patient data access.
- Discussion around banking of patient tissue and expense involved, need to add nutritional measures to new studies collecting tissue in cancer patients e.g. piggy backing onto existing biobanking activities to save time and money

Summing up

After feedback and discussion around the four work streams, Martin Wiseman summed up some common themes including: the desire for more patient involvement, the standardisation of routine care, training needs, routine tests, educational and research resources, and data management.

Professor Jackson closed the day by thanking everyone for their creativity and participation in the day's discussions. Our challenge is now to capture that creativity, and develop the work streams in such a way that outputs are delivered. It was suggested that we may schedule another meeting at the end of the year to reflect on progress.

Next steps:

All work streams will be working on their work plans over the coming weeks, and will **feed back on progress to the next Steering Group meeting on 29th March 2016**. It is expected that each work stream will have completed the NOCRI template/ identified one or two deliverable outputs by this time, with further outputs identified for the future.

The deadline for submitting documents for circulation to the Steering Group is **Friday 18th March**.

Please send any documents for circulation to: millie.barrett@nihr.ac.uk

Appendix 2 – List of participants at the workshop

Workstream 1 – Information and communication with public and patients	Job title	Association
Lesley Turner	Lay advocate on Collaboration Steering Committee	NCRI Palliative and Supportive Care CSG; ICPV NCRI Consumer Forum
Louise Worswick	PPI Senior Programme Manager	NIHR Central Commissioning Facility
Natasha Jones	Advanced Specialist Dietitian; Haematology/TYA	Cambridge NHS (Addenbrooke's)
Ann Russell		NCRI Primary Care CSG; NCRI Colorectal CSG Adjuvant and Advanced Disease sub group and Surgical sub group
Elspeth Banks		NCRI Psychosocial Oncology Survivorship CSG, lifestyle and behaviour subgroup; NIHR consumer forum; Trustee of ICPV
Dimitrios Koutoukidis	Health Psychology, Clinical Trials, Nutrition and Dietetics	UCL
Kate Allen	Executive Director, Science and Public Affairs	WCRF UK
Victoria Iyamide Nnatuanya		NIHR CRUK Consumer Forum
Hilary Stobart		ICPV and NCRI
Min Cheung	BRC PPI Manager	Royal Marsden
Justin Webb	Physical Activity Engagement Manager	Macmillan
Workstream 2 – Creating a skilled community of practice		
Ramsey Cutress	Associate Professor in Breast Surgery	Southampton BRC
Mhairi Donald	Macmillan Consultant Dietitian	Brighton and Sussex University Hospitals Trust
Martin Wiseman	Medical and Scientific Advisor	WCRF
Fehmida Munir	Reader in Health Psychology	Loughborough University
Alan Jackson	Chair of Cancer and Nutrition NIHR Collaboration	UoS/ NIHR
Caroline Shriver	BRC Training and Education Manager in Clinical	Royal Marsden BRC

	Research	
Workstream 3 – Research priorities		
Karen Brown	Co-chair	Leicester ECMC
Anne Helm	Senior Research Funding Manager	CRUK
Clare Shaw	Consultant Dietitian	Royal Marsden
Rachael Barlow	Lecturer	Cardiff and Vale UHB/Cardiff University
Rhiannon Whitaker	Statistician and researcher	Wales Cancer Trials Unit
Elio Riboli	Director, School of Public Health	Imperial College London
Lucy Allen	Head of Research Infrastructure	NOCRI
Lauren Chapman (Observer)	Research Collaboration Manager	NOCRI
Annie Anderson	Professor in Public Health Nutrition	Dundee University, Centre for Research into Cancer Prevention and Screening
Sam Ahmedzai	Professor in Oncology and Metabolism	NCRI Supportive and Palliative Care CSG; University of Sheffield
Karen Phekoo	Manager	Southampton BRC
Workstream 4 – Characterising nutritional status in cancer (toolkit)		
Bernard Corfe	Molecular Gastroenterology Research Group	University of Sheffield; Nutrition Society
Steve Wootton	Associate Professor in Human Nutrition	University of Southampton; NIHR
Theresa Wiseman	Lead for Health Service Research	Royal Marsden
Margaret MacRae	Dietitian	UCLH
Sian Lewis	Chair of BDA Oncology group and Macmillan Clinical Lead Dietitian	BDA Specialist Oncology
Rhys White	Principal Oncology Dietitian at Guy's and Thomas'	BDA Oncology Group
Millie Barrett	Collaboration Project Manager	NIHR
Marie Cantwell	Senior Lecturer in Nutrition & Cancer epidemiology	Queens University Belfast
Laura Miller	Clinical/team lead oncology dietitian	Nottingham University Hospitals

End