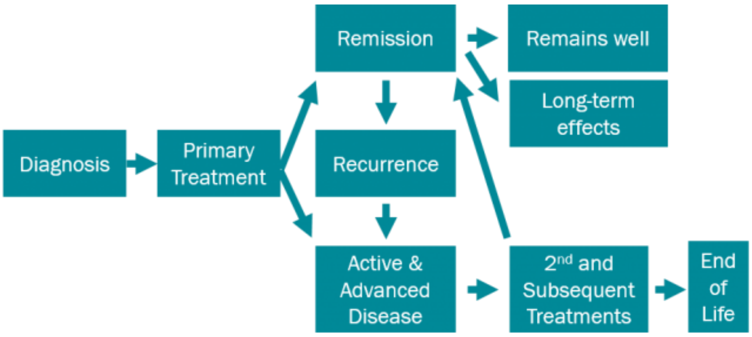
NCRI conference in Glasgow announces its 'Living with and beyond cancer' research priorities

The 2018 National Cancer Research Institute (NCRI) conference, traditionally held in Liverpool, was convened for the first time in Glasgow, at the exciting Clydeside SECC venue. The programme was, as ever, varied and multidisciplinary with a strong emphasis on patient and public involvement. The latter was most evident in a well-attended session on Day 3, entitled *"Spotlight on NCRI activities: Living with and beyond cancer initiative"*. Fittingly, it was chaired by Richard Stephens, chair of the NCRI Consumer Forum.

First, what is meant by 'living with and beyond cancer'? Work done by the NCRI has shown that the term 'survivorship', which has become widely used to describe this area, means different things to different people. Some consider it to be the part of the journey from the end of primary treatment up till, but not including, the end of life. Others consider it to be the period from the start of treatment and including advanced progressive disease which slides into end of life care. Going forward, NCRI intends to use 'living with and beyond cancer' rather than 'survivorship' to describe this whole area.

NCRI has considered academic sources and consulted relevant stakeholders and defined what it means as 'living with and beyond cancer' (LWBC) research, as shown below. The subtopics that constitute the 'living with and beyond cancer' scope align with all the stages of the patient journey.



Subtopics apply to the various stages of the patient journey

Psychological impact of cancer	■	■	■	▨
Symptom prevention and management	■	■	■	▨
Late effects and long-term outcomes of treatment			■	▨
Enablers to live 'normal' life	■	■	■	▨
Instrument for research and outcome measures		■	■	▨
Social and economic consequences of cancer		■	■	▨
Research into health economics and health services		■	■	▨

Source: NCRI 2018

One of the main purposes of this conference session was to announce the results of the NCRI's collaboration with the James Lind Alliance (JLA) in a 2 year programme of work called the 'Priority-setting Partnership (PSP) on research in the space described above as LWBC. Henceforth abbreviated as 'NCRI JLA PSP on LWBC'!

The main ingredient of a JLA PSP in any healthcare topic area is to work with a panel of consumers (in this case cancer patients, survivors and carers of current and former patients), healthcare professionals of all relevant disciplines and academics. During the collaboration, research priorities are sought from all of these constituencies, and repeatedly 'reality-checked' by national open consultations. One thousand five hundred people (55% patients, 20% carers and 25% professionals) completed the first survey and raised a total of 3500 questions. Gradually these were sifted, merged or discarded (eg if the question had already been answered) to yield a final set of 26 priorities. These were announced in the conference session by Ceinwen Giles, from the charity Shine Cancer Support. The full list of topics can be found by clicking this link: https://www.ncri.org.uk/lwbc/all-questions/ .

The 'top 10' of the 26 priorities are as follows:

1. What are the best models for delivering long-term cancer care including screening, diagnosing and managing long-term side effects and late-effects of cancer and its treatment (e.g. primary and secondary care, voluntary organisations, self-management, carer involvement, use of digital technology, etc)?

2. How can patients and carers be appropriately informed of cancer diagnosis, treatment, prognosis, long-term side-effects and late effects of treatments, and how does this affect their treatment choices?

3. How can care be better co-ordinated for people living with and beyond cancer who have complex needs (with more than one health problem or receiving care from more than one specialty)?

4. What causes fatigue in people living with and beyond cancer and what are the best ways to manage it?

5. What are the short-term and long-term psychological impacts of cancer and its treatment and what are the most effective ways of supporting the psychological wellbeing of all people living with and beyond cancer, their carers and families?

6. How can the short-term, long-term and late effects of cancer treatments be (a) prevented, and/or (b) best treated/ managed?

7. What are the biological bases of side-effects of cancer treatment and how can a better understanding lead to improved ways to manage side-effects?

8. What are the best ways to manage persistent pain caused by cancer or cancer treatments?

9. What specific lifestyle changes (e.g. diet, exercise and stress reduction) help with recovery from treatment, restore health and improve quality of life?

10. How can we predict which people living with and beyond cancer will experience long-term side-effects (side-effects which last for years after treatment) and which people will experience late effects (side-effects which do not appear until years after treatment)?

We are delighted that priority 9 explicitly includes reference to diet, along with exercise and lifestyle – these three are regarded as inextricably linked by the NIHR Cancer & Nutrition Collaboration. Priority 9 is a broad one, as it is not restricted to any particular stage of life after cancer treatment, and it focuses on wide concepts of 'restoring health' and 'improving quality of life'. We should point out that our Collaboration also has an interest in nutritional, activity and lifestyle in the period after diagnosis and before cancer treatment (so-called 'prehab').

Apart from priority 9, it is clear that nutrition and activity will feature in several other priorities, such as self-management in longterm cancer care (#1), fatigue management (#4), the prediction and management of late and chronic side-effects of cancer treatments (#6, 7 and 10) including abdominal surgery, pelvic radiotherapy and colitis after immunotherapy – all of which can impact on nutritional needs of patients. Of the total set of priorities, many of 11-26 also have nutritional implications. As with previous JLA PSPs, it is very likely that many of these priorities will now be taken up by cancer charities and put out as commissioned research calls. Our Collaboration is already actively working up studies that respond to the topics mentioned above.

It is no coincidence that one of the research workstreams in the Collaboration is also called 'Nutritional care in people living with and beyond cancer'. Many members of the Collaboration who took part in the surveys for the NCRI's JLA LWBC project are also active contributors to the NCRI clinical studies group on Supportive & Palliative Care, and so our thinking on this aspect of cancer care is closely aligned. In the conference session *"Spotlight on NCRI activities: Living with and beyond cancer initiative"*, there were two further presentations on how the NCRI clinical studies groups (CSGs) would engage with these priorities. One was given by Dr Galina Velikova, chair of the Psychosocial Oncology and Survivorship CSG and she focused on that group's expertise in patient reported outcome measures (PROMs) and quality of life evaluation; and on existing and planned work on lifestyle interventions in post-treatment rehabilitation.

The second presentation was by myself, as chair of the Supportive & Palliative Care CSG. This group has a multidisciplinary mix of oncologists, supportive and palliative care clinicians, cancer nurses, allied health professionals, health service researchers and methodologists – as well as, of course – two consumer representatives. The CSG's members have expertise in qualitative and quantitative study design, observational cohorts and randomised controlled trials, and increasingly we are incorporating translational aspects to our studies, such as validating biomarkers of clinical outcomes and use of molecular targeted interventions. So it will be no surprise that the Supportive and Palliative Care CSG – with input from colleagues in the Psychosocial Oncology and Survivorship CSG as well as the disease site-specific CSGs – will be closely working with the NIHR Cancer & Nutrition Collaboration in coming months and years to convert the JLA LWBC priorities into specific research questions and grant applications. Watch this space!

Sam H Ahmedzai

Chair, NIHR Cancer & Nutrition Collaboration

Chair, NCRI Supportive & Palliative Care clinical studies group