Living with and beyond cancer
Top research priorities
Living with and beyond cancer – a research challenge

- Increasing number of people living with the consequences of cancer and treatment.
- Amount of research looking into living better with and beyond cancer has been consistently less than other areas of cancer research.
- Several cancers have become or are becoming chronic conditions, both through better treatments and because of the ageing population.
- Living with and beyond cancer research is very broad and a lack of clear research priorities (and definition) has been a barrier to research funding.
- Cancer Strategy (England) 2015 recommends identifying research priorities in living with and beyond cancer and to make the research happen.
Priority setting method

First survey (Sep 2017)
1492 respondents proposed 3500 unanswered questions for research. Respondents: 55% patients, 20% carers and 25% professionals, including patients across all ages (16+), pathways and cancer types, 4 nations and a broad range of medical, nursing, allied health and social care professionals.

Data analysis
Questions checked against systematic reviews and guidelines. 2000 Qs compiled to form 54 research questions.

Second survey
1918 patients, carers and professionals ranked the 54 questions.

Data analysis
Created shortlist of 26 questions.

Workshop
32 participants ranked the 26 questions.

TOP 10 PRIORITIES IDENTIFIED (June 2018)
Top 10 living with and beyond cancer research priorities

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)?
This is the first time that clear research priorities have been identified in this area. They are the most impactful research questions that will help improve the lives of people affected by cancer.

Next steps

- NCRI is working with funders, researchers, NHS and others to translate the priorities into research and patient benefit.
- Promote awareness of the top research priorities.

Find out more and register your research at [www.ncri.org.uk/lwbc](http://www.ncri.org.uk/lwbc)

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