Living with and beyond cancer
Top research priorities

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Living with and beyond cancer – A research challenge

In the UK alone there were 2.5 million people alive following a cancer diagnosis in 2015\(^1\).

The number has grown by this extra 400,000 people in just five years and this is predicted to rise to 4 million by 2030.

Living with and beyond cancer – A research challenge

Annualised spend (£ Millions)

- Prevention: £28m (£28m)
- Early detection, diagnosis and prognosis: £84m (£109m)
- Treatment: £173m (£238m)
- Care and survivorship: £7m (£9m)

2013

2017
• 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.
Definition of living with and beyond cancer research

- Psychological impact of cancer
- Symptoms & side effects - Prevention and Management
- Late effects & long-term outcomes of treatment
- Social and Economic Consequences of Cancer
- Enablers to live “normal” (or “usual”) life
- Research into Health Economics and Health Services
- Instruments for research and outcome measures

Find out more at www.nrci.org.uk/lwbc
• NCRI launched a **UK-wide** Priority Setting Partnership with the James Lind Alliance (NIHR), involving **people affected by cancer and front-line health and social care professionals**, and patient/carer groups/charities.

• The aim was to identify the priority questions for **research on the impacts of cancer and cancer treatments and how best to manage them, from diagnosis through remaining lifespan**.

• Then work with researchers, funders and health care providers to **find answers to benefit patients and carers**.
• All aspects of living with and beyond cancer including physical, psychological, social, financial, economic, and spiritual aspects.

• Interventions, care and support across all cancers. Includes supportive and palliative care, but not end-of-life care, which was covered by a separate PSP.

• People first diagnosed with cancer in adulthood (aged 16+) and those who care(d) for them, incl. health & social care professionals.

• Steering Group
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)
Priority Setting method – final workshop
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)?
Next steps and questions

• 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
Contact: lwbc@ncri.org.uk