Living with and beyond cancer
Top research priorities

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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.

NCRI Cancer Research Database
Overall Research Spend (2002-2018)

Data from: https://www.ncri.org.uk/ncri-cancer-research-database-old/spend-by-research-category-and-disease-site/

CSO\(^1\) codes:
- 1 Biology
- 2 Aetiology
- 3 Prevention
- 4 Detection/Diagnosis
- 5 Treatment
- 6 Control, survivorship, outcomes

\(^1\) For Common Scientific Outline (CSO) code definitions visit: https://www.icrpartnership.org/cso
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1. Biology
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6. Control, survivorship, outcomes

CSO 6: Control, survivorship & outcomes
[£44m/£683m or 6.4%]

CSO 6.1: Care & Survivorship
[£9m/£683m or 1.3%]

\textsuperscript{1} For Common Scientific Outline (CSO) code definitions visit:
https://www.icrpartnership.org/cso
Living With and Beyond Cancer
Priority Setting Partnership
Priority Setting Method

First Survey (September 2017)
1492 respondents proposed 3500 unanswered questions
55% patients, 20% carers and 25% professionals

Data analysis
Questions checked against systematic reviews and guidelines
Compiled to form 54 research questions.

Second survey
1918 patients, carers and professionals ranked the 54 questions.
54% patients, 17% carers, 19% professionals

Data analysis
Created shortlist of 26 questions

Workshop
32 participants ranked the 26 questions
18 patients and carers, 14 professionals

TOP 10 PRIORITIES LAUNCHED (November 2018)

Key documents including engagement summary, all survey questions and evidence search available from: www.ncri.org.uk/lwbc/resources
Out of scope questions – patients and carer information requests

Of the 3,500 questions, over **1,500** were analysed as non-research and asking about/for:

- advice (503)
- cancer treatment (128)
- care quality (125)
- access to services (108)
- causes of cancer (63)
- diagnosis (44)
- financial support (31)
- funding cancer services (27)
- end of life care (24)
- professional training (22)
- cancer prevention (21)
- employment (11)

A further 360 questions were analysed as “broad or off topic” and 94 as questions that could be answered by audit.

The full survey questions are available from: [www.ncri.org.uk/lwbc/resources](http://www.ncri.org.uk/lwbc/resources)
A gap in impact of research for patients – LWBC research questions already answered

Of 3,500 questions asked, 191 were analysed as having already been answered:

• How long do the side-effects of cancer treatment last? (46)
• What is the risk of an individual’s cancer coming back and when can people be certain that their cancer will not return? (60)
• Are people living with and beyond cancer at risk of developing another type of cancer, different from their first cancer? (17)
• Are people living with and beyond cancer at risk of developing another health condition (e.g. dementia and osteoporosis)? (11)
• How can patients be better informed about possible early signs of their cancer coming back? (26)
• Can treatments be developed with fewer side effects, including short-term, long-term and late effects? (15)

Plus 16 additional single/specific questions.
The top 26 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)?
The top 26 living with and beyond cancer research priorities

11. What are the most effective ways to stop cancer coming back (combining treatments and life-style changes)?

12. What are the social, financial and economic impacts of living with and beyond cancer – how does it affect families, relationships, finances, work and use of NHS services?

13. What are the best ways to cope with the fear and anxiety about cancer returning (combining self-management approaches, treatments and psychological support)?

14. How can we predict who is at risk of developing mental health conditions in people living with and beyond cancer (e.g. depression) and what are the best ways of supporting those with mental health conditions?

15. What are the best ways to support people living with and beyond cancer to make lifestyle changes to improve their health?
16. If people with cancer are involved in their own healthcare decisions (including participating in multi-disciplinary team meetings with health professionals), does this lead to better outcomes?

17. What are the psychological and social impacts on children who have a parent (or parents) with cancer, and what are the best ways to support those children?

18. What is the best form of rehabilitation and other support to help people living with and beyond cancer return to or maintain their usual activities (e.g. work)?

19. What are the best ways to manage the consequences of nerve damage caused by cancer treatments?

20. How do the support needs of people with rare and less common cancers differ from people with more common cancers, and how are those needs best met?
The top 26 living with and beyond cancer research priorities

21. What can be done to **reduce and manage the impact** of cancer treatments **on people’s sex lives**?

22. What are the best ways to **support people** living with and beyond cancer **who live alone**?

23. How is cancer perceived across multiple black and minority ethnic groups – what are the similarities and differences?

24. Can **lymphoedema** be prevented? If not, how is it best treated/ managed?

25. What is the **optimal follow-up approach** to detect whether a cancer has come back?

26. What are the **spiritual care needs** of people living with and beyond cancer?