

Living With and Beyond Cancer: Top Research Priorities in the UK



Feng Li¹, Mariano Kalfors¹, <u>Alexander Renziehausen</u>¹, Patricia Ellis², Stuart Griffiths¹, Ian Lewis¹, NCRI LWBC Steering Group³

¹The National Cancer Research Institute, London, United Kingdom, ²James Lind Alliance, Southampton, United Kingdom, ³https://www.ncri.org.uk/lwbc/about-psp/steering-group-and-partners/

Background

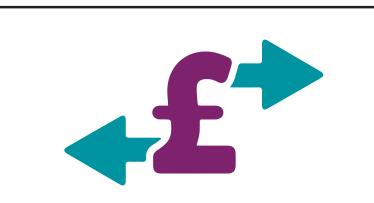




2.5 million



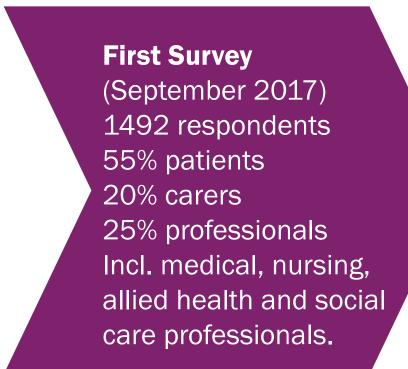
5 million people expected to be living with



1.4% estimated UK academic cancer research funding that went towards LWBC research in 2017-18*

The 2015 NHS England Independent Cancer Taskforce report** recommended identifying research priorities on long-term patient needs and survivorship issues to address this. Subsequently, the National Cancer Research Institute (NCRI), a partnership of major UK cancer research funders, formed a Priority Setting Partnership (PSP) with the James Lind Alliance to develop a list of priorities for Living With and Beyond Cancer (LWBC) research.

Method



Data analysis Questions were checked against systematic reviews and guidelines 54 questions longlisted

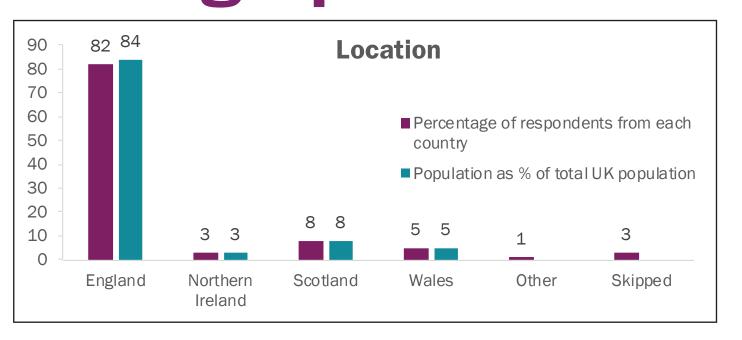
Second survey 1918 patients, carers and professionals ranked the 54 questions.

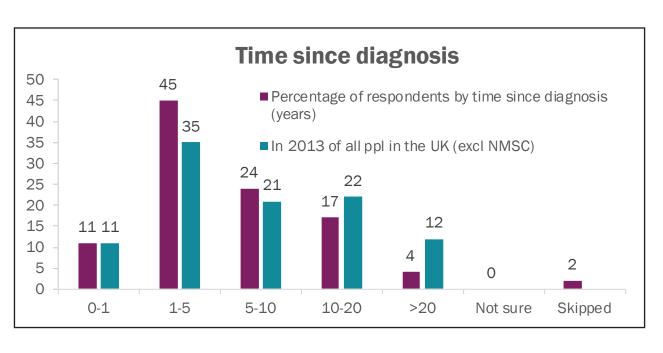
Data analysis 26 questions shortlisted

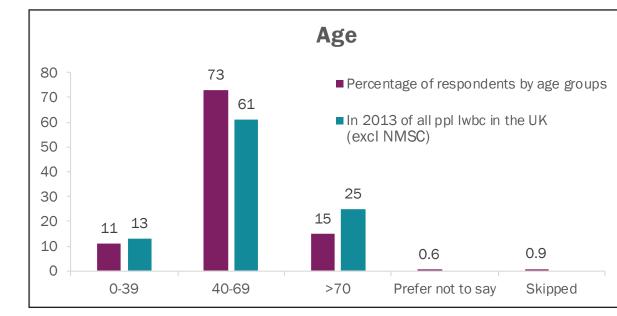
Workshop 32 participants ranked the 26 questions

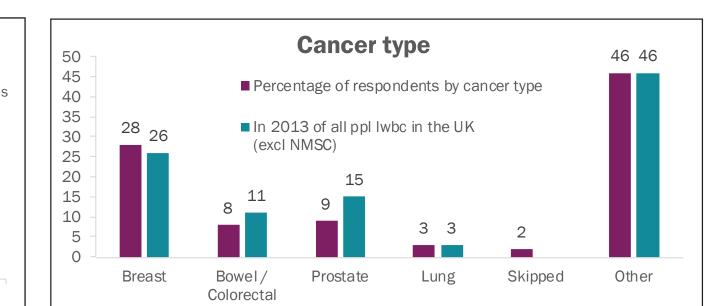
TOP 10 PRIORITIES LAUNCHED (November 2018)

Demographics









Conclusion and next steps

This is the first time that clear research priorities have been identified in the UK to help improve the lives of people affected by cancer.

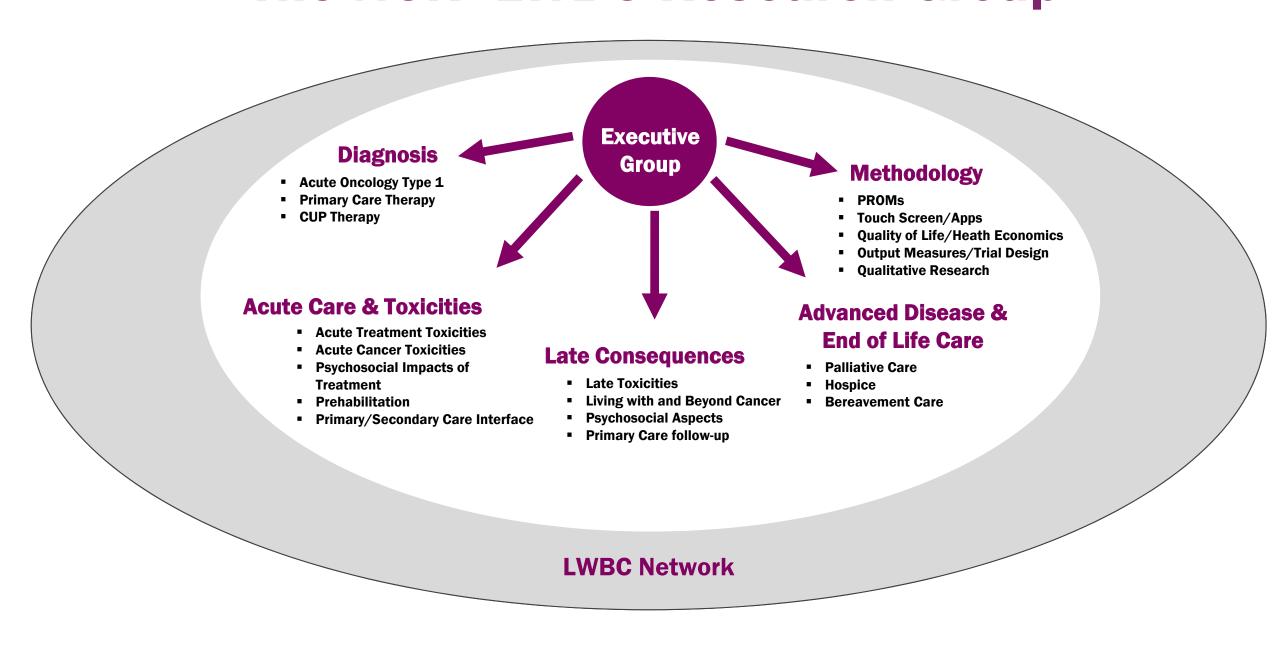
The NCRI is working with funders, researchers, the NHS and others to translate the priorities into research and patient benefit.

This includes establishing the world's first and most comprehensive multi-disciplinary research group on supportive care for cancer at all stages: The NCRI LWBC Research Group.

To find out more about this group and its work contact ncrigroups@ncri.org.uk



The NCRI LWBC Research Group



UK Top 10 living with and beyond cancer research priorities*

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

*Priorities relate to adults living with and beyond cancer

*.National Cancer Research Institute (NCRI) Cancer Research Database [Online]. [Last accessed 18 March 2019]. Available from: https://www.ncri.org.uk/ncri-cancer-research-data



