

## **PRESS RELEASE**

**Embargo: 00.01 hrs GMT Tuesday 6 November 2018**

### **Gap in research means millions living with long-term consequences of cancer: work needed in ten key areas**

**Glasgow, UK:** Millions of people are living with the long-term consequences of cancer and its treatment, but currently there is very little research on the problems they face and how these can be tackled, according to the UK's National Cancer Research Institute (NCRI).

Thanks to successes in research on diagnosing and treating cancer, more people are living longer with cancer and with the lasting side-effects of treatments. In the UK alone there were 2.5 million people alive following a cancer diagnosis in 2015 and this is predicted to rise to four million by 2030.

This growing population report side-effects that seriously affect their quality of life, but a combination of a shortage of funding, a lack of clear direction and relatively few researchers with expertise in this area have left a gap in cancer research.

New research presented at the 2018 NCRI Cancer Conference suggests that the issues faced by millions of people living with and beyond cancer could be identified and addressed with a set of ten new research priorities.

The new priorities have been developed by cancer patients, carers, doctors and nurses. Key questions include: how can treatment side-effects, such as fatigue, be prevented or managed; what is the impact on mental health; can lifestyle changes restore patients' health; and can we predict who will experience side effects?

The work was presented by Dr Feng Li of the NCRI. She explained: "The fact that millions of people are living with and beyond cancer is testament to the success of research on treatment and diagnosis. However, many of these people are living with the side-effects of cancer and treatment, and suffering from poor quality of life.

"There are not enough researchers studying these issues and there's very little funding currently available for this work. This is an enormous gap in our knowledge and it's one that can only begin to be filled if we have a starting point.

"We've looked at cancer research in the UK but the situation is similar around the world."

In response to the NHS's Cancer Strategy to achieve the best cancer outcomes, NCRI carried out this two-year project to determine priorities for research that will help people to live better with and beyond cancer.

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The work included UK-wide surveys which attracted more than 3,500 responses. The final ten priorities were chosen at a workshop involving patients, carers, and health and social care professionals. It is the first time that patients and carers have determined priorities in this area.

Ceinwen Giles was diagnosed with stage IV non-Hodgkin lymphoma six weeks after the birth of her daughter. She is now Director of Partnerships and Evaluation at Shine Cancer Support and took part in the research. She said: “It is vitally important to put money into researching these ten priorities because they reflect the reality of living ‘with and beyond’ cancer and they were developed by patients and their carers, alongside health and social care professionals.

“I hope this project will highlight this important gap in cancer research and influence funders to support more research in this area.”

Dr Li added: “There is a small amount of research going on in this area, supported by NCRI Partners and others, but we need to drastically increase the amount of research in the next five years and accelerate the translation of research into clinical practice.”

The NCRI is now working with its Partner organisations, other funders, researchers and the NHS to translate the priorities into research and patient benefit. As well as increasing support from funders they plan to engage with researchers working in other chronic diseases to develop large multi-disciplinary research projects. Macmillan Cancer Support and Tenovus Cancer Care say they are already considering the priorities for their future research funding. NCRI is working with a number of funders and expects they will be able to support this initiative in the near future.

Sam Ahmedzai is Emeritus Professor of Supportive Care at the University of Sheffield, UK, Chair of the NCRI Supportive and Palliative Care Clinical Studies Group, and contributed to the research. He said: “Funders should pay attention and respond to the priorities. We need to make sure they are translated into funded research programmes, so that we can make much-needed progress in improving health and quality of life for those people living with the consequences of cancer.”

**ENDS**

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## Notes to editors

**Abstract number 2015**, 'Living with and beyond cancer top research priorities in the UK – priority setting partnership'. **Spotlight session, Lomond Auditorium, 11.00-12.30, Tuesday 6 November.**

This research was funded by the National Cancer Research Institute Partners.

Read more about the project at: <https://www.ncri.org.uk/lwbc>

## UK 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)?

## About the NCRI Cancer Conference

The NCRI Cancer Conference is the UK's largest forum showcasing the latest advances in cancer research. The Conference provides a platform for researchers, clinicians, people affected by cancer and industry representatives to come together to discuss, present and showcase high-quality research. Informative and interactive educational sessions attract over 1,500 delegates each year and create the ideal setting to establish new collaborations with key stakeholders in cancer research. The NCRI Cancer Conference is taking place from 4-6 November 2018 at the Scottish Event Campus, Glasgow, UK.

For more information visit <https://conference.ncri.org.uk/>

## About the NCRI

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The National Cancer Research Institute (NCRI) is a UK-wide partnership of cancer research funders, established in 2001. Its 19 member organisations work together to accelerate progress in cancer-related research through collaboration, to improve health and quality of life.

NCRI works to coordinate research related to cancer, to improve the quality and relevance of research and to accelerate translation of research into clinical practice for the benefit of patients.

NCRI Partners are: Biotechnology and Biological Sciences Research Council (BBSRC); Bloodwise; Brain Tumour Research; Breast Cancer Now; Cancer Research UK; Children with Cancer UK; Department of Health and Social Care; Economic and Social Research Council (ESRC); Macmillan Cancer Support; Marie Curie; Medical Research Council (MRC); Northern Ireland Health and Social Care Public Health Agency (Research & Development Department); Pancreatic Cancer Research Fund; Prostate Cancer UK; Roy Castle Lung Cancer Foundation; Scottish Government Health Directorates (Chief Scientist Office); Tenovus Cancer Care; The Wellcome Trust and Welsh Assembly Government (Health and Care Research Wales). For more information visit [www.ncri.org.uk](http://www.ncri.org.uk)

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