

# LONG-TERM QUALITY OF LIFE

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CANCER SUPPORT

## Developing an effective approach to collecting and using long-term quality of life data

Rebecca Nash<sup>1</sup>, Sarah Benger<sup>2</sup>, Michelle Mackie<sup>3</sup>, Sylvie Hobden<sup>3</sup>, David Hills<sup>3</sup>, Galina Velikova<sup>4</sup>, Robyn Casey<sup>1</sup>, Jon Ardill<sup>1</sup>, Georgina Smerald<sup>1</sup>, Rebecca Robertson<sup>1</sup> and Rafael Goriwoda<sup>2</sup>

1. Macmillan Cancer Support, 2. NHS England, 3. Ipsos MORI, 4. University of Leeds

## Background

The Independent Cancer Taskforce set an ambitious task for the NHS: to make significant progress in reducing preventable cancers, increasing cancer survival and improving patient experience and quality of life by 2020. **There is no nationwide systematic collection of quality of life data from people living with and beyond cancer.** A national quality of life metric will play a vital role in helping us to understand how well people are living after cancer treatment.

As part of the Cancer Dashboard<sup>1</sup>, this metric will provide a high-level view of quality of life after cancer treatment. It will sit alongside survival rates and other national indicators at a Cancer Alliance, clinical commissioning group (CCG) and provider level. It will therefore act as a flag that will focus attention and service improvement discussion wherever poor quality of life outcomes are reported.

'Sometimes we [hear] that this hospital seems to have worse long-term side effects than other hospitals. It would be really useful to have hard data so that we can see whether that is the case.'

**Breast surgeon, District Hospital<sup>2</sup>**

Evidence was needed to understand how best to develop an approach that will meet key criteria. These include being feasible, meeting the needs of patients and professionals, and having the potential to support improvement within the current context.

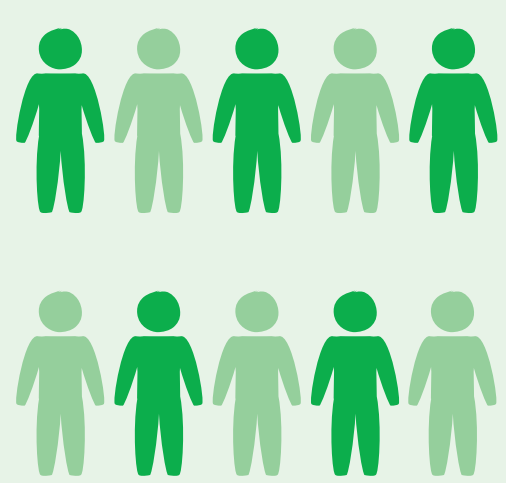
## Methods

NHS England and Macmillan Cancer Support worked together to commission Ipsos MORI and the University of Leeds to ...



... collect evidence on existing options and approaches (including methods of data collection and validated tools) using a literature review and interviews ...

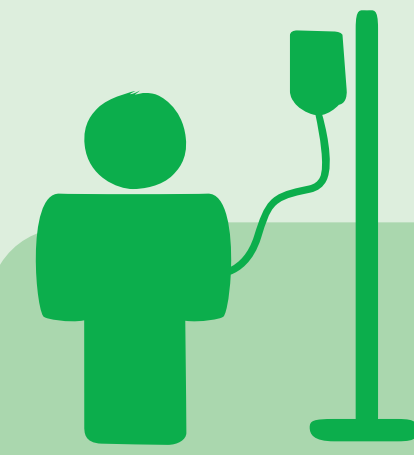
... and ...



... understand the different perspectives and learn from the expertise of people living with cancer, healthcare professionals, academics, and other stakeholders via qualitative depths, groups and online feedback.

## Results

People living with cancer and providers felt the systematic collection, analysis and use of quality of life aggregate data could provide significant benefits.

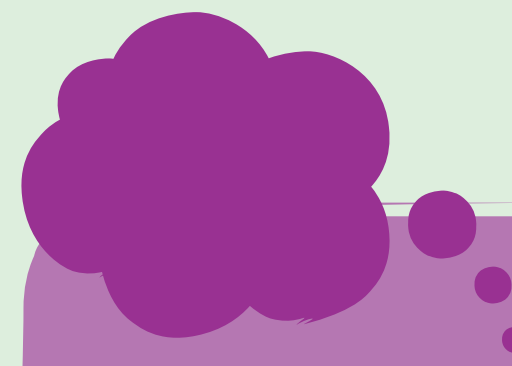


People living with cancer could use the data to inform their **treatment choices** and understand their **likely quality of life trajectory**.



Providers could use the data to understand the **level of need by area or patient group**, to **benchmark against other providers**, to evaluate the **economic costs of treatment**, and to **educate clinicians**.

The research identified and described the decisions that need to be considered when developing and delivering the metric and the associated challenges that need to be addressed.



Key considerations include **selecting a suitable instrument**, deciding **when and how often** the survey should be carried out, and deciding **how the data should be collected**.



Key challenges included the capacity and infrastructure needed to **collect and analyse the data**, the extent to which **meaningful comparisons** could be made between providers, and the need to **create buy-in and manage expectations** among a wide range of stakeholder groups.

## Conclusion

The research has extended and summarised our existing understanding. It has also provided actionable insight that will help us to progress the project and deliver a meaningful metric that can drive improvements in quality of life for people living with and beyond cancer. The findings are currently being used to design a pilot approach, identify key stakeholders, understand future opportunities and challenges, manage risks, and inform future consultation and communication activities. The pilots are due to begin later in 2017 and the results of these will inform national roll out.

'Quality of life comes into all aspects of cancer care, and the whole journey through it. I think it's really important to measure, and I think it's been increasingly recognised that it's important to measure.'

**Macmillan GP<sup>3</sup>**

## Working together



Ipsos MORI  
Social Research Institute

UNIVERSITY OF LEEDS

## References

1. <https://www.cancerdata.nhs.uk/dashboard/#?tab=Overview>
- 2,3. NHS England and Macmillan Cancer Support, 2016, *Research to Support the development of a quality of life metric*

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