WE ARE MACMILLAN. CANCER SUPPORT

DEVELOPING A NATIONAL METRIC FOR QUALITY OF LIFE

Authors: Rebecca Nash[1], Michelle Mackie[2], Sylvie Hobden[2], David Hills[2], Galina Velikova[3], Robyn Casey[1], Jon Ardill[1], Georgina Smerald[1], Rebecca Robertson[1], Sarah Benger[4] and Rafael Goriwoda[4]

1 Macmillan Cancer Support 2 Ipsos MORI 3 Univeristy of Leeds 4 NHS England

Background

As the survival rates of people diagnosed with cancer continue to increase[1], the need to understand longer-term quality of life becomes more important. Improved survival rates are a significant sign of progress. However, research indicates that many people with cancer live with its long-term physical and mental consequences for at least 10 years after treatment.[2]

In light of the growing population of people living with cancer, the Independent Cancer Taskforce recognised a need to understand the long-term quality of life for those with a cancer diagnosis. Subsequently it has recommended that a national quality of life metric for England, which will sit alongside existing survival metrics on the Cancer Dashboard[3], be developed.

This project is a first step towards ensuring that validated tools for measuring quality of life for people with cancer can be embedded within the NHS. It will also help drive improvement for people living with cancer.

Macmillan Cancer Support and NHS England have commissioned Ipsos MORI and the University of Leeds to conduct research to support developing a quality of life metric, to be agreed by 2017.

This study will result in a shortlist of up to three recommended approaches that could be used to measure long-term quality of life for people with cancer. These will include methods of data collection and validated tools. The research will also provide evidence around:

- the advantages and disadvantages of the potential approaches
- an understanding of what they will and will not be able to achieve
- options for implementation
- an understanding of the extent to which they meet stakeholders' aspirations.

This study will also inform piloting and testing the selected measure ahead of implementation.

Methods

The research will use a range of methods including:

- a review and appraisal of existing validated tools and approaches
- primary and secondary research aimed at understanding the feasibility of implementing a quality of life metric and learning from those with previous experience of using Patient Reported Outcome Measures in clinical practice
- research and engagement with a wide range of stakeholders to understand their aspirations for the metric.

Results

Preliminary findings from this study will be available by early 2017, with the final decision agreed in March 2017. The final approach will be the one that best meets these criteria and:

- takes account of what has been agreed in the Cancer Taskforce's report
- reflects what is important to patients and other stakeholder groups
- produces data that supports improvement at a CCG, provider and Cancer Alliance level
- is feasible for national roll-out
- is affordable
- involves the use of existing, validated tools.

Some of the research methods used include:

Interviews with providers to explore the feasibility and capability of measuring QoL

Interviews with patients and other stakeholders to explore aspirations around QoL measurement

Literature review of experiences of organisations in implementing patient experience surveys

Rapid evidence review of validated tools

Online data gathering exercise with a wider range of stakeholders

'What went wrong' workshop with those who have experience of implementing PROMs/QoL tools

References

1. Cancer Research UK. *Survival statistics for the most common cancers*. www.cancerresearchuk.org/cancer-info/cancerstats/survival/common-cancers (accessed 6 October 2016).
2. Armes J, et al. Patients' supportive care needs beyond the end of treatment: a prospective, longitudinal survey. *Journal of Clinical Oncology*. 2009. 27 36: 6172–6179.
3. NHS England. *CancerData. Dashboard*. www.cancerdata.nhs.uk/dashboard/#?tab=Overview&ccg=08K (accessed 6 October 2016).

Conclusions

This study will set the foundations for building a long-term recognised measure of quality of life that we can use to improve the lives of people living with cancer. The Quality of Life Metric at this stage will be used in England only.

You can access a digital version of this poster at
macmillan.org.uk/research-posters

NHS

Ipsos MORI
Social Research Institute

Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). MAC16399