Reviewer’s report

Title: PATIENT LED PROMs MUST TAKE CENTRE STAGE IN CANCER RESEARCH

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Reviewer: John Reeve

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* Important topic - widely recognised that QOL measures are outdated and unsatisfactory and not patient centred. Quality of life encompasses a range of factors that cancer patients report consistently as being under-represented and considered by clinicians and in cancer research.

* Timely - National Cancer Strategy - Achieving World Class Cancer Outcomes - putting patient experience on a par with clinical outcomes and safety

* Concept of designing patient pathways around PROMS and patient experience is important and deserves further work to develop and apply

* Recognises that a range of stakeholders and various strands of activity, both in the UK and across Europe.

* Highlights the need for a co-ordinating and integrating vision and strategy for measuring and reporting life quality via PROMS

* Writer shows his breadth of experience as a patient as well as someone with considerable knowledge and experience of patient involvement.

* Understandable focus on metastatic disease and treatment decisions for late-stage disease which may or may not consider properly life quality. However, 70% of cancer patients now
survive for 5 years and living with and beyond cancer is an under-researched area where life quality and PROMS have an important part to play.

* Opportunity to give more consideration to the development of patient experience pathways and how this might be taken forward via Cancer Alliances and the National Cancer Strategy

* Opportunity to leverage the world-leading insight available at the Yorkshire and Humberside based Haematological Malignancies Research Network which has information about patient experience and journeys for every blood cancer patient treated across 19 NHS Trusts over a period of over 10 years.

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