Author’s response to reviews

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

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Author’s response to reviews:
Comments from the Editors.

1. The revised definition/distinction between QoL, HRQoL and PRO(M) is still not quite correct. Whilst the definition of PRO (please note this should not be PROM when reflecting the FDA definition) is accurate and reflects the FDA definition, the concepts of quality of life and health-related quality of life fall within this overarching concept of aspects of health and well-being that can be reported by patients. It may be helpful to indicate that PRO can reflect a wide range of constructs, such as quality of life and health-related quality of life. However, it is more usual in healthcare to focus attention on the assessment of health-related quality of life which is widely accepted to encompass concepts pertaining to symptoms, physical function, emotional well-being and social function or participation – and hence can be targeted by healthcare.

The much wider concept of quality of life may include aspects that cannot be addressed by healthcare. Measures of HRQoL, or patient-reported outcome measures which purport to assess HRQoL, are (mostly) multi-item questionnaires which seek to assess how patients feel, function and live their lives because of their health and associated healthcare. If well developed, the items, or specific questions should reflect those aspects of health that are important to people with (if a specific measure) a specific condition. A scoring system is then appointed to each question, which thus supports the calculation of a metric (as the author indeed suggests). However, as the author is very aware, often patients are not appropriately involved in item generation and many of the ‘legacy’ measures lack relevance to patients and hence are perhaps not appropriate for use in research or routine practice settings. Where the FDA guidance supports a greater transparency
in the process of item/question generation, it does not go as far as to explore PPI in measurement development.

Thank you. I have made appropriate modification using HrQol a little more often and replacing PROMs with PROs in a number of places. The description of the terms has been modified as suggested.

2. Please note that the Royal College of Nursing Research Institute no-longer exists at Warwick and should be replaced by ‘Warwick Research in Nursing, (WRiN) Warwick Medical School’ – and this could be added to the list of acronyms. Please also note that there are two workstreams in this group of relevance to this paper – both PPI and Patient Reported Outcomes.

Thank you. Modifications made.