Reviewer's report

Title: The Patient Reported Outcomes, Burdens and Experiences (PROBE) Project: Development and Evaluation of a questionnaire assessing patient reported outcomes in people with hemophilia

Version: 0 Date: 07 Nov 2017

Reviewer: Helen Twohig

Reviewer's report:

Thankyou for this interesting and well written paper. I have a few comments as follows:

1. The title does not give a full picture of the subject of the study. It would capture the attention of readers interested in haemophilia and or PROMs work better if the title read something like “The Patient Reported Outcomes, Burdens and Experiences (PROBE) project: development and evaluation of a questionnaire to assess patient reported outcomes in people with haemophilia”.

2. A flow diagram depicting the stages of the project would be really helpful as it is quite a complex process and there are a lot of acronyms involved which can make it hard to follow when reading just text.

3. Were people with haemophilia (other than those in the investigators group) involved at the HERO summit in developing the outcomes of importance to patients? It is not clear whether these outcomes were put forwards by patients themselves or purely identified by professionals and the literature review process.

4. It would be interesting to know in what ways the focus groups influenced the design of the questionnaire. This seems to be the stage which involved PWH most directly but the 'results' of the focus groups and the refinement in response to the focus groups is not described.

5. Lines 182-184 mention full psychometric analysis upon successful completion of 'this proof of concept'. Does this mean after the feasibility testing? It would be helpful to state this if so.
Overall this is a well designed and ambitious piece of work, collecting data from a large number of countries to secure diverse patient input into the development of this measure.

Level of interest
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Quality of written English
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