Reviewer’s report

Title: Integrating patient perspectives in medical decision-making: A qualitative interview study examining potentials within the rare disease information exchange process in practice

Version: 0 Date: 08 Feb 2019

Reviewer: Reviewer 2

Reviewer’s report:

PEER REVIEWER ASSESSMENTS:

OBJECTIVE - Full research articles: is there a clear objective that addresses a testable research question(s) (brief or other article types: is there a clear objective)?

No - there are minor issues

DESIGN - Is the current approach (including controls and analysis protocols) appropriate for the objective?

Not sure - key details are missing from the manuscript

EXECUTION - Are the experiments and analyses performed with technical rigor to allow confidence in the results?

Not sure - key details are missing from the manuscript

Statistics - Is the use of statistics in the manuscript appropriate?

N/A - there are no statistics in this study

INTERPRETATION - Is the current interpretation/discussion of the results reasonable and not overstated?

No - there are minor issues

OVERALL MANUSCRIPT POTENTIAL - Is the current version of this work technically sound? If not, can revisions be made to make the work technically sound?

Probably - with minor revisions
PEER REVIEWER COMMENTS:

GENERAL COMMENTS: This qualitative study explored how elements of shared decision making may be involved in consultations with people who have rare diseases. It is an indepth exploration of this issue, but some aspects of the methods are not clearly described which hampers interpretation of the results.

REQUESTED REVISIONS:

The aims of the study are not clearly articulated.

Many aspects of the methods are not clear. For example, the sentence about choosing 3 comparison groups (pg 5, line 23); considering the hierarchy level (pg 6, line 20); avoiding overestimating SDM effects (pg 6, line 44); approving quotations by a native speaker (p 7, line 32)

Please provide more detail about the interview guide (and the actual guide), including how it was developed. How do the authors know that piloting the guide with 1 patient and 1 family member was enough? How many physicians were involved in the piloting of the physician interview guide?

More details are needed about the standardized transcription booklet, and the process used for triangulation.

It's very unusual for the term 'inter-subjective reliability' to be used in qualitative research. Can the authors please consider whether this is appropriate and if so, elaborate about its use.

Without more clarity in some of the methods, it is difficult to assess the trustworthiness of the results.

ADDITIONAL REQUESTS/SUGGESTIONS:

The paper is difficult to follow in many places and could it be written more concisely in some sections (such as the history of shared decision making in the background). The background section is also quite disjointed and some sentences are not clear (e.g. pg 4, lines 8-10;pg 4, lines 54-60).

I also suggest that the paper is edited with the assistance of a native English speaker. There are many unfamiliar terms and/or terms used in an unconventional manner - for example, p8 , line 35 "stationary setting"

Note: This reviewer report can be downloaded - see attached pdf file.

Are the methods appropriate and well described?
If not, please specify what is required in your comments to the authors.

No

**Does the work include the necessary controls?**
If not, please specify which controls are required in your comments to the authors.

No

**Are the conclusions drawn adequately supported by the data shown?**
If not, please explain in your comments to the authors.

No

**Are you able to assess any statistics in the manuscript or would you recommend an additional statistical review?**
If an additional statistical review is recommended, please specify what aspects require further assessment in your comments to the editors.

Not relevant to this manuscript

**Quality of written English**
Please indicate the quality of language in the manuscript:

Needs some language corrections before being published

**Declaration of competing interests**
Please complete a declaration of competing interests, considering the following questions:

1. Have you in the past five years received reimbursements, fees, funding, or salary from an organisation that may in any way gain or lose financially from the publication of this manuscript, either now or in the future?

2. Do you hold any stocks or shares in an organisation that may in any way gain or lose financially from the publication of this manuscript, either now or in the future?

3. Do you hold or are you currently applying for any patents relating to the content of the manuscript?

4. Have you received reimbursements, fees, funding, or salary from an organization that holds or has applied for patents relating to the content of the manuscript?

5. Do you have any other financial competing interests?

6. Do you have any non-financial competing interests in relation to this paper?
If you can answer no to all of the above, write 'I declare that I have no competing interests' below. If your reply is yes to any, please give details below.

This reviewer has been recruited by a partner organization, Research Square. Reviewers with declared or apparent competing interests are not utilized for these reviews. This reviewer has agreed to publication of their comments online under a Creative Commons Attribution License attributed to Research Square and was paid a small honorarium for completing the review within a specified timeframe. Honoraria for reviews such as this are paid regardless of the reviewer recommendation.

I agree to the open peer review policy of the journal. I understand that my name will be included on my report to the authors and, if the manuscript is accepted for publication, my named report including any attachments I upload will be posted on the website along with the authors' responses. I agree for my report to be made available under an Open Access Creative Commons CC-BY license (http://creativecommons.org/licenses/by/4.0/). I understand that any comments which I do not wish to be included in my named report can be included as confidential comments to the editors, which will not be published.

I agree to the open peer review policy of the journal.