Author’s response to reviews

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

Authors:

Ana Babac (anababac@yahoo.de)
Verena von Friedrichs (verena.vonfriedrichs@aekn.de)
Svenja Litzkendorf (sl@cherh.de)
Jan Zeidler (jz@cherh.de)
Kathrin Damm (kd@cherh.de)
J.-Matthias Graf von der Schulenburg (jms@ivbl.uni-hannover.de)

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Author’s response to reviews:

Landshut, 04.09.2019

Dear Sir or Madame,

Thank you very much again for your very helpful remarks. Indeed you are very right. We apologize and are very happy about the possibility to include your remarks into the manuscript.

Please see the section underneath for the point-by-point response to the comments. The changed sections were again included within the point-by-point answer.

Addressing the Reviewer report of Reviewer 2, requested revisions:

REQUESTED REVISIONS:

Requested revision 1:

There are just two remaining issues.

1) The following sentence that was added is not clear - suggest rewording it: "However, this also bears the risk that the concept may be relatively underrepresented in its extent, as it was not directly asked for."
Response 1:

Thank you very much for your note. We have tried to clarify the sentence further. Therefore, we have changed the sentence from “However, this also bears the risk that the concept may be relatively underrepresented in its extent, as it was not directly asked for.” into “However, this also bears the risk that the concept may not impose itself in its full extensity, as it was avoided to pinpoint participants towards the concept, by directly asking for it.”

Requested revision 2:

2) I worry that the use of the phrase ‘shared decision making’ in the title is not appropriate, particularly given that i) the questions asked are more about information gathering and informed decision making (which is different to shared decision making) and ii) this acknowledgement in the limitations that has been added: "Shared-decision making was not addressed as such within the interview guide. Participants were not directly asked about SDM, but rather indirectly about their experiences within healthcare systems and health management during the information-gathering process. This approach bears some risk, in that some interviews may involve situations in which SDM did not occur.”

Response 2:

Thank you very much for the comment and for the chance to straighten this out. To avoid irritations we have changed the title from “Integrating patient perspectives in medical decision-making: A qualitative interview study examining the potential of shared-decision making within the rare disease information exchange process” into “Integrating patient perspectives in medical decision-making: A qualitative interview study examining potentials within the rare disease information exchange process in practice”.

Thank you very much for your time spent on our paper.

Yours sincerely,

Ana Babac