Reviewer's report

Title: Values and value conflicts in implementation and use of preconception expanded carrier screening - an expert interview study

Version: 0 Date: 17 Jan 2019

Reviewer: Jenny Krutzinna

Reviewer's report:

Thank you for this interesting article on an important topic. Your research addresses a very relevant and timely issue of the different values influencing health policy-making. However, I have some major comments and questions about some aspects of the paper, which may need to be addressed before publication.

General comments:

- The structure of the paper could be improved by guiding the reader to the next sections. At present, individual sections appear disconnected from each other and it is not clear where the article is going.

- The findings could be more effectively presented, for instance, with a clearer structure and explanation of the categorisation at the outset.

- It is sometimes not clear if a statement came from a study participant or if it is the authors' view. Please check that all responses are clearly attributed to study respondents or indicate where you are commenting as authors.

- My main concern is the lack of clarity with regard to the conceptual framework (see below).

Background

This section provides a brief historical overview of some developments in bioethics with regard to values. However, no mention is made of the relevance of this to the current research question / study. The topic of ECS or similar modern health technologies that raise particular ethical questions is not mentioned or discussed in the background, although in the abstract it is referred to under the heading "background".

It may be a good idea to providing some information on the motivation for the study in this section, as well as an explanation of ECS and its relevance for ethics. Maybe the "Rationale for the study" could be moved up into this section to inform the reader at the outset what this article is about.
Theoretical background

This starts out of the blue - please link to the first part of the background section and explain to the reader where you are going (e.g. provide some guidance on the structure of the article).

This sub-section is not very clear. Under the heading, value theory and theories of rights are mentioned as the main branches of ethical theory, followed by a brief description of the two. It is not clear to me what this section is supposed to achieve, as there is no conclusion as to the theoretical framework to be applied in this study and the text is merely descriptive of some theory. A very limited selection of views on values are discussed superficially with no connection to the present context. To strengthen the overall article, this section would need to be re-written, to explain to the reader which theoretical framework was used to inform the study and why.

Methods

In the methods sections, I am missing information on how the theory was used to inform the study. While there is sufficient information on participant selection, no explanation is provided about the role of theory in the study. The reference to Bogner and Menz is not sufficient to explain the methodological approach to the study. A brief explanation of what theory-generating expert interviews are, and why this approach has been chosen, would be helpful.

Table 1 seems unnecessary, given that the same information is provided in the main text. Could you provide the Swedish names of the organisations in parentheses, so they can be more easily identified (esp. the National Board for Health and Welfare) or provide links to their respective websites?

Analysis

Please provide information on the set of values obtained after a thorough literature review. How was the literature review conducted (e.g. discipline, search terms, etc.), what were the results?

Results

How were the seven themes identified? Are these based on coding or on the literature review? How were the sub-themes identified - based on the authors' own views or on some theory? This section would benefit from more structure, which may of course be challenging, given that values are not always clear and may overlap. Given that one key aim of the paper is to discuss the value conflicts that may arise in ECS, it might be an idea to have a dedicated section on value conflicts.
One issue I have with this section is that the values are not explained or defined, either based on a theoretical approach or with an explanation from the authors on why they chose to group certain sub-themes together under one theme. The approach is also not consistent - e.g. under "solidarity" a comment on "human dignity" is provided, which is merely equated with equality. Can justice, equality and social care really be subsumed under solidarity - if we don't even know what is meant by solidarity in the first place? To make sense of these findings, it is important to understand the rationale behind the themes / sub-themes. Concerns for the disabled are also mentioned under solidarity and human dignity, and it is not clear how the categorisation was made.

Health as a value seems puzzling, as several things are subsumed under the heading, all of which would also fit at least under one other value.

Discussion

This first part of this section is helpful by setting out the Swedish context, which helps to explain the findings in the study. What I would like to see, however, is a more structured approach to the rest of this section. In particular, some signposting might help, e.g. an explanation of the challenges associated with trying to identify distinct values in such a study. This section is largely descriptive and some of the information would probably be better suited to the background section. Also, no critical literature is cited - notions such as "human dignity" and "solidarity" are very controversial in bioethics, but this is not even acknowledge. While a full literature review is not necessary for present purposes, it would be appropriate to start off by saying that the value conflicts expressed by the interviewees is echoed by the academic debate on the relevance / existence of certain values. No link is made to the theoretical framework in the earlier part of the article. Value theory is mentioned in the context of health, but is not applied to any other values - why? Finally, what is the analysis with regard to ECS? Going back to the aim of the study (values, weights, conflicts) - what did you find? The first point is addressed well, but the discussion of weighing between values and conflicts which may arise could be made stronger.

Conclusions

The values listed here are mentioned as the ones referred to by the experts - however, earlier it said that these arose from literature review. Is this list exhaustive or were there any others?
Are the methods appropriate and well described?
If not, please specify what is required in your comments to the authors.

Yes

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

Unable to assess

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

Yes

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

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