Reviewer’s report

Title: Formation of a type 1 diabetes young adult patient and public involvement panel to develop a health behaviour change intervention: the D1 Now Study

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Reviewer: Sophie Söderholm Werkö

Reviewer’s report:

Review of "Formation of a type 1 diabetes Young Adult Panel to develop a health behavior change intervention to improve health service engagement: A patient-centred approach to improving care."

Overall, the topic of the article is interesting as young people with T1D indeed need to be interested in and taking responsibility for taking good care of their health, health care and health care planning. How this may differ from other age groups is however never unfortunately discussed, which is a shame as it would be interesting to read what similarities or differences the authors may have found had it been a comparative study.

Specific comments: The title is too long, it needs to be shorter. A suggestion could be to simply take out some words, e.g.: "Formation of a type 1 diabetes Young Adult Panel to develop a health behavior change intervention to improve health service engagement: A patient-centred approach to improving care."

In the abstract, background section, first paragraph, "young adults" with T1D are mentioned, but no ages defined. Later in the same section however it is stated that the members of the Young Adult Panel are 18-25 year olds. As a reader, I therefore assume the authors refer to the same age span earlier. Is this correct? This could be clarified.

In the Plain English summary p.2, first paragraph, the authors make statements about the lives, experiences and priorities of young adults with T1D. It is unclear whether this is a worldwide finding or whether it only applies to the western world? The second paragraph presents a "diabetes research team" of which we are told how many persons the are young adults and what ages they are between, but nothing is mentioned here about the other team-members, leaving the reader wondering how many researchers are included and what ages are they? What is the composition of the group, is one or the other group of actors outnumbered? This information is provided later in the article, but I think it should be presented consequently for both groups, i.e. when number and ages are presented on one part of the team, the same information on the other part should also be presented.

Under the heading Background on p.4, in the first paragraph there is reference to the "global" incidence. The following paragraph then state that "young adults with T1D often experience poor outcomes" - is this also on a global level? Later in the same section the authors refer to "a recent international comparison" with a reference, but in order to simplify for the readers, it would be
good to know here, without having to check the reference yourself, whether this international comparison refers to the western world or whether it is a worldwide finding.

At the beginning of page 6 it is stated "…only one young adult living with…" This makes the reader wonder: how was this person identified and selected?

Under the heading the Jigsaw model on p.6 there is first a typo (so using both singular and plural forms) "a strong links" and also no definition of what the authors think "a strong link" means. In that paragraph both youth mental health as well as young people are mentioned - what ages are those? Would be sufficient to just add this information in brackets.

Under the heading Involving young adults in PPI recruitment process on p.6, second paragraph, it is stated that 50 letters were sent. This leaves the reader wondering if this was to all persons those ages attending the clinic or if it was to a selection of persons? Also it is stated that flyers were used in local media, Twitter and Facebook campaigns - but I wonder if there also was a website on which information was posted? Under the heading Consultation on the same page, the process of group division is described: 3 groups of 6-7 people (n=19). Here questions arise: What is the division of gender; all males, all females or a mix? If so, what does the mix look like? Both overall, in these groups and also in the panel. The same question arise on p.7 when it is stated that "8 young adults were offered a place" - again you wonder about gender and age (if all are 25 year old males for example…) This information is presented later on in the paper, but it is too late, not until on p.9. The reader should not have to wonder about these issues, which is the case now.

On p.8, the almost last bullet point about introduction to the "think-aloud technique" is presented but not explained more than as "an approach used in many meetings". Instead of guessing what this means, I would like the authors to explain the technique. Later, on p.11, in the last paragraph of the Discussion, the authors talk about think-aloud sessions and then about brainstorming sessions - it is unclear to me what the difference is between these two techniques, in fact if there is a difference at all, I would like an explanation.

In the section under the heading Ensuring quality involvement and communication on p. 8, I have three questions:

1. where it says "…all opinions were listened to" - how was this controlled for or measured, i.e. how did they make sure all opinions were actually outspoken and listened to?

2. "Social events were organised" - How many social events and what different kinds?

3. "…some YAP members asked the clinical research team to write letters of recommendation…” - well, did the research team agree to do this? What were their answer to this request?
Under the heading Results on p. 9, the reader is left wondering how long a meeting would typically last? Apart from this lack of information, the meetings are well described. Please write out the abbreviation "diabetes HPC" as people not familiar with diabetes do not understand it.

Under the section of Acknowledgements, a study steering group funded by Novo Nordisk is first time mentioned. Unclear whether this means that employees at Nove Nordisk Ireland were participating in the steering group or why they did fund/sponsor this initiative? Please explain.

The Table 2 "Terms of Reference" provides good information but the title is a bit misleading - it is really not only ToR in my opinion.

Figure 1 - unclear whether the box "Letters sent to young adults with T1D attending clinic (n=50)" is the total or the sampling?

Figure 2 - Is it the piece in the middle T1DM which includes also the mental status/psychological well-being, i.e. the potential worry a person would have regarding his or her T1D?

Finally, a difficult word for non-native English speakers on p.10 - "surmounted" - please explain or change this word.

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