Author's response to reviews

Title: Clinical guidelines contribute to the health inequities experienced by individuals with intellectual disabilities

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Author's response to reviews: see over
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Dear Dr O’Connor

1880340453589070 - Clinical guidelines contribute to the health inequities experienced by individuals with intellectual disabilities

Thank you for forwarding us the comments on our manuscript from the two reviewers and editor. These comments were very helpful and the suggested changes have been made in full, as outlined below.

We would like to comment on the point raised by one of the reviewers that perhaps the paper would be better placed in a specialist journal. We have discussed at length whether the manuscript should be submitted to an intellectual disabilities journal. However, as shown in our paper, very few guideline development groups involve intellectual disabilities stakeholders and the National Guideline Clearing House does not list any guidelines specific to the health needs of individuals with intellectual disabilities. Therefore, although academics and clinicians working in the field of intellectual disabilities may be involved in the implementation of clinical guidelines, we feel that the target readership for this manuscript is broader than the readership of specialist intellectual disabilities journals. As the reviewer states subsequently, Implementation Science is one of the leading journals publishing research relevant to clinical guidelines and we believe that if the revised manuscript is acceptable for publication in the journal it is more likely to provoke discussion amongst individuals working in the clinical guideline field.

Reviewer 1:

1. It is not 100% clear what the objective of this manuscript is. Typically the last paragraph in the Introduction will explicitly state the aim of the study that is being reported on, but this is not done here. The authors say that they “used the INCLEN equity lens to examine whether existing clinical guidelines address the health inequities experienced by people with intellectual disabilities”. I assume the objective is to investigate whether a set of clinical guidelines address inequities experienced by individuals who have intellectual disabilities, and that using the INCLEN-lens is not an objective as such, but rather a method for doing what they set out to do. If this is correctly understood, I would rephrase accordingly and move everything about the lens from the Intro to the methods.

As suggested, the aim of the study has been inserted at the end of the introduction, along with three specific research questions.

2. I find the “equity lens” itself confusing. I looked up the reference (Dans et al), and I realize that the reason I am confused is because of how the lens was presented in the original paper, thus I cannot blame the current authors for that, at least not entirely. The problem I have concerns the questions that the current authors list in the Background section, i.e. the five criteria. I find that it is difficult to understand how these are intended to be used and understood, by both the current and the original
We apologise that the description of the equity lens and its relevance to the study was not clearer in the previous manuscript. Since the equity lens is central to the methodology, the issues raised under points 2, 3 and 7 are important to address. We have made the changes suggested by the reviewer and believe this has strengthened the clarity of the paper.

As suggested in point two we have included the third column from Table 1 in the paper by Dans et al. This is now incorporated into a new table providing relevant details of the equity lens— Table 1 in the revised manuscript.

3. Adding the third column from the table in Dans et al is not sufficient, though. I think the authors—like me—need to clarify to themselves how exactly the lens should be applied in this case. I think the statement in the first paragraph under Methods illustrates that they also struggle with this: “the available evidence-base on these disorders meets equity lens criterion one.” I first assumed that the authors wrote this since they interpreted criterion one as I first did, i.e. if the topic is an important one for disadvantaged groups (in this case those with intellectual disabilities), the criterion is fulfilled. But, in other parts of the manuscript they consider criterion one fulfilled only if the specific needs of the specified disadvantaged group is explicitly addressed in the guideline. As mentioned above, I think the latter is in line with the intentions of Dans et al, though this is not well articulated in their or the current text. I suspect that the current authors also find this confusing, and I suggest they a) clarify to themselves how they think about this, and b) try to communicate this clearly to the reader.

To clarify this we have made several changes to the methods section of the revised manuscript:

a.) The order of sub-sections in the methods section has been changed so that the sub-section entitled Measurements now comes first. This includes the newly inserted Table 1 which we believe now makes the description of the equity lens clearer.

b.) In the sub-section entitled Selection of clinical guidelines we have revised the text to explain the relevance of equity lens criterion 1 to the methodology and inclusion of clinical guidelines.

c.) We have reiterated the relevance of equity lens criterion 1 in relevant sections of the paper— sub-section on Equity lens criteria (page 7); first paragraph of the discussion (page 9).

4. In the Methods, I found it very odd that the authors suddenly focused on countries as the unit-level they selected from, not guidelines which I would have expected: “Countries with available guidelines for two or more of the health problems selected were identified”. This makes little sense to me and does not fit the research question (maybe in part because the research question is also not 100% clear). If the authors had a reason for focusing on guidelines from a set of countries rather than just a set of guidelines (independent of origin), then they need to explain why they focussed on a set of countries and their guidelines, not just a set of guidelines (from anywhere in the world).
5. Also, it is unconventional to present the results of their search-strategy under Methods. Usually – and I would recommend sticking to the norm – the results (what they found) are presented under results, and the methods (how they looked for it) under methods.

We have moved the results of the search strategy to the results section.

6. A minor thing: In the first para of the Methods-section, it is stated the “We selected nine health problems”, but when I – for some strange reason– counted the number of health problems I found 10 (and I did count “injuries or falls” as one). I guess the easy way to fix that is to replace 9 with 10 all the way through.

We apologise for the confusion caused by the inclusion of the term “accidents, injuries and falls” to represent a single health problem. This has been changed to “accidents/ injuries and falls” which we hope now makes it easier to identify the nine health problems selected.

7. The sub-section “Equity lens criteria” also illustrates the previously mentioned problem with the equity lens: it’s not very clear how it can or should be used. Do you apply it on inequities generally, or on specific disadvantaged groups? This lack of clarity seems to stem from the original article by Dans et al. Again, I think it would be helpful if the current authors expanded on their discussion on this, possibly addressing it earlier in the manuscript, to avoid more confused readers like me.

A paragraph explaining this has been inserted at the end of the Data extraction sub-section. Along with the changes made in response to points 3 and 4 above we hope this clarifies the issues raised about the lack of clarity around the equity lens criteria.

8. In the same para: “ criterian” should read “criterion”.

This has been corrected.

9. In the last para under “Guidelines content”, the authors start off with “Interestingly”. I found that a bit misplaced. I would just delete that word.

This has been deleted.

The Discussion has not “Limitations” or “Study-weaknesses”-section. I think it is obligatory for the authors to reflect on and share the possible weakness of their work.

A new sub-section to the Discussion has been inserted, entitled Strengths and limitations.

10. I find that the logic behind the following statement is flawed (at least I don’t follow it): “Since there is available evidence to allow guidelines to meet equity levels criterion one – as evidenced by the six guidelines that met this criterion – we believe that the current guideline development process, used by national organisations with the responsibility for clinical guideline development, may be adding to the health inequities experienced by individuals with intellectual disabilities.” Firstly, the available evidence concerning special considerations for people with intellectual disabilities will likely vary much from topic to topic, so using the six guidelines as proof that there is evidence available to inform recommendations across all topics, does not seem to make sense. Apart from that, the authors seem to argue that evidence is needed to make recommendations, however, even when convincing scientific
evidence is lacking recommendations can (and often should) be made anyway, e.g. based on expert opinion. Secondly, although the authors may be correct in their assertion that lack of attention to disadvantaged populations “may be adding to the health inequities” (in this case for people with intellectual disabilities), think it would wise to expand a little and walk the reader through why this is likely to be the case (alternatively, this line of reasoning could be presented in the Introduction-section).

We have rewritten this opening section to the Discussion and linked it to an example of how clinical guidelines may be missing opportunities to address the inequities experienced by individuals with intellectual disabilities.

Reviewer 2:
Major Compulsory Revisions
1. My main concern about the paper is Figure 2 and the use of the word ‘Reasonable’. Not that I am suggesting that these are not reasonable, but the inclusion of the proposed actions for all disadvantaged groups, when they are defined as widely as place of residence, sexual orientation, occupation etc, would be extremely resource intensive and runs the risk of being ignored because of this fact. I wonder if the authors should concentrate in this particular case on providing a shorter, more focused list of recommendations to prevent the disadvantage of those with intellectual disabilities.

We agree that Figure 2 in the original manuscript was overly inclusive and have amended this in table 6 to limit our suggestions to intellectual disabilities.

As we have made clear in the discussion, our groups lack of experience of clinical guideline development processes internationally is a potential weakness of the study. We appreciate the comment on the feasibility of our suggestions from an expert on guideline development, which has helped us reflect on the overall tone of our paper. To address this we have tried to emphasise the exploratory nature of the study, and our recognition that it is for guideline development organisations to make decisions about practical steps to improve the equity of guidelines.

Minor Essential Revisions
2. The basis of this paper is the equity lens developed by INCLEN. It would be helpful to have some indication as to how the work of INCLEN has been disseminated to guideline development agencies.

We have investigated this as best we can, since none of the members of the research group are involved with INCLEN. Unfortunately, we have not come up with any information about how INCLEN disseminated their work on clinical guidelines to relevant agencies.

We have inserted a sentence on page 4 explaining that the equity lens paper was one of a series of papers on clinical guidelines to provide advice to the WHO Advisory Committee on Health Research. We have also suggested in the Discussion that one way for GIN and AGREE to take the issues forward would be to disseminate the work of INCLEN (page 12)

3. It is unclear how guideline agencies should apply the PROGRESS-PLUS framework in choosing the topics for guideline development. Development of this point would enhance the paper.

In recognition that our research group has limited knowledge of the processes used to choose topics and the multiple influences on topic selection we have decided to remove this suggestion from the manuscript.

4. The authors should clarify what they mean by ‘..organisations should look at ways to include evidence relevant to intellectual disabilities ... even in situations where it does not meet the required hierarchical grading recommendations’. The authors go on to say that ‘Without such an adjustment to
allow inclusion of a broader evidence base, guideline recommendations ...will be limited to consensus opinions’. It is totally unclear to me what type of evidence is being recommended. At my own organisation we use lower grade evidence and consensus reports where high quality evidence is not available. What is the difference?

Thank you for making this point, which again reflects our limited knowledge of the procedures that guideline organisations already use. We have removed this paragraph from the manuscript.

5. As far as I aware the G-I-N Search Group is no longer functioning. The authors could rephrase this section to recommend that G-I-N or the AGREE Trust take this whole issue forward as an area of activity.

We have reworded this section (pages 12-13).

As suggested by the editor the two figures in the original manuscript have been changed to tables, reference has been made to the additional file in the text and the abstract now includes details of the number of guidelines included in the study.

We would like to thank the reviewers and editor for taking the time to read our original manuscript in detail and provide such thoughtful and useful comments. The changes we have made in response to the comments and suggestions have strengthened the manuscript and helped us recognise the challenges involved in the development of clinical guidelines.

We would be grateful if the revised manuscript could be considered for publication in Implementation Science.

Yours sincerely

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