Author’s response to reviews

Title: Was it worth it? Older adults’ experiences of participating in a population-based cohort study – a focus group study

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Author’s response to reviews:

Dear Editor-in-Chief,

We hereby submit a revised version of the paper “Was it worth it? Older adults’ experiences of participating in a population-based cohort study – a focus group study” (BGTC-D-18-00479). We are thankful for your positive reply and the reviewers’ most valuable comments. We have followed your advice and revised our paper according to the reviewers comments. We confirm that this manuscript has not been published elsewhere and is not under consideration by another journal. The authors have no conflicts of interest to declare. All authors have approved the manuscript and agree with submission to the journal of BMC Geriatrics.

Please address all correspondence concerning this manuscript to me at synneve.dahlin-ivanoff@gu.se

Thank you for your consideration of this manuscript.

Sincerely,

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Dorly Deeg (Reviewer 1):

Thank you for a very well done revision of the paper. We really appreciate all the work you have done. It has really improved the paper.

Regarding the sense of responsibility (my previous point 5) that I deduce from some of the description of the findings, remains a matter of interpretation. The authors write in their letter that none of the questions to the focus groups triggered a discussion of this theme (directly, my addition). But I keep thinking that it might be an underlying theme in some of the statements (see lines 281-285).
Author response: Thank you! You have totally right, it was an underlying theme. We did not indentified the theme as it was discussed within the context of their experience of H70 as an intense event. This has been clarified. See pages 11-12

The authors tend to use long sentences that not always flow correctly, and make for difficult reading. The very first sentence of the Abstract an lines 117-120 is an example. For one thing, it includes the word 'experience' twice. Please cut in two. There are more examples throughout the paper.
Author response: Thank you for your input. The text has been revised and changed accordingly.

2. In the Abstract, the Conclusions section is disproportionally long. Moreover, it includes new findings (lines 62-64), which should be moved to the Results section. (On the other hand, lines 50-51 in the Results section are basically a repetition of the previous sentence and can be omitted.) There is also a discontinuity in style, as in line 64 'you' is used, while elsewhere a more neutral phrasing is used. In line 65, it is not clear what 'It' refers to.
Author response: The abstract has been changed according to your comments. See page 2-3.

3. Throughout the paper, it is not made clear why the focus group approach is chosen. In lines 136-137 of the Design section it is only stated that this approach is based on 'a collective understanding of participants’ views.' In the Discussion section (lines 664 ff.) the focus group approach is critically discussed. Apparently, the authors found that this approach worked, but why did they choose it to begin with? What alternatives were considered?
Author response: Why the focus group approach was chosen has been reported as well as alternatives considered. See pages 5-6

4. In line 152, it would be good to state since when the H70 studies are running, as this is not common knowledge outside Sweden. Author response: This has been clarified. See page 6

5. The theme 'unpleasant examinations and key decisions' is not well-labelled. Do the authors mean: 'unpleasant key decisions'? If not, it would be better to separate the two parts. 'Key decisions about test outcomes' would be a better label for a subtheme, and in fact, would also apply to outcomes from not-unpleasant tests. Author response: Thank you for good suggestions. The theme has been re-labelled to 'Key decisions about test outcomes'. See page 17
6. In the description of the theme 'hidden agenda' it seems that it pertains to a self-completion questionnaire (line 473). However, how can this issue be solved by 'professionalism of research staff' and 'good relationships with research staff' (see Discussion)? Such staff is not present during the self-completion. Author response: Thank you for this comment. It is not only about self-completion questionnaire. This has been clarified. See page 20

7. Discussion, line 525: what 'risks' are meant? Author response: This has been clarified. See page 24

8. Discussion, lines 530-531: how can the motive of 'seeking health access through the "back door"' compromise the representativeness - what groups would be over- or under-represented? Author response: The discussion has been developed and clarified. See page 24

9. Discussion, line 599: 'health-literate organisation' is a new term, not further explained. Could the authors describe what they mean using common words? Author response: The term health-literate organization is further explained. See page 27

10. Discussion, lines 608-609: What is 'problematic', the conflict or the person-centredness? Please use two sentences. Also, what aspect of 'quality of the H70 study' may be affected? (See also line 614.) This needs some expansion. The discussion has been expended according to the comments. Author response: Thank you for this eye opener. This has been clarified. See page 27

11. Under 'Limitations', in the first two paragraphs it is not clear what limitation is exactly addressed. Author response: The first two paragraphs have been clarified, see page 27-28

12. Lines 652-653 are superfluous, as the 'very dynamic' nature of small focus groups has already been stated a few lines earlier. The more so, as reference (10) is from this same research group. Author response: We have deleted these sentences.

Richard Milne (Reviewer 2):
Thank you very much for the positive comments on the paper. We are extremely grateful for the time and engagement. We have really appreciated your comments

There's some wonderfully rich data here, and the presentation of the focus group extracts might be expanded. While it's important that they're presented at length to give a sense of interaction, as it stands there's little elaboration or discussion of what is going on in the discussions presented. Space permitting, the authors may wish to consider spending more time on these. Author response: We have added more citations. It is up to the editor to decide if the presentation of the focus group extracts should be expanded further. See page 13

In the study design, was there greater value in having heterogeneous groups of LP/non-LP participants, rather than having a group entirely made up of people who had rejected a key study procedure? This might have allowed a more detailed discussion of why the procedure was rejected. Author response: We do not know if we would have the same results if the focus groups were made up of people who had rejected / not rejected a key study procedure. The decision to include both groups of LP/non-LP participants insame the focus groups was based on the premise that the participants represented the whole H70 population per se. The purpose was to capture both groups. See page 8
The overall framing theme of the paper that "It was well worth the effort," needs some further justification and discussion. Whereas other themes are primarily descriptive, this is a judgement position on the value of research - rather than a motivation prior to the study, it suggests a reflection on what has come out of the study. This reflection and learning process is an interesting element of the paper which be drawn out and would distinguish its original contribution - for example in relation to the LP results, and the importance of prior experience in shaping future participation.

Author response: We totally agree that the overall framing theme "It was well worth the effort," is not a motivation but a core theme that frame how the participants in total felt about the H70 study. We have extended discussion from a reflective point" on "It was well worth the effort," focusing on both trust/mistrust. See page 21 for expended discussion.

The paper engages with a good body of literature around research participation. However, in addition to the work by Mein on older adults, further literature might provide useful insights into some of the positions and dynamics described here. For example, the discussion of the desire to perform research 'honestly' might be elaborated with reference to Morris and Balmer's work on research participation, as well as the Cox and McDonald paper cited. The limits of informed consent are also gestured to, and the work of Hoeyer around biobanking may be of particular interest here - as well as expanding the discussion of trust.

Author response: Thank you for this comment! We have considered your suggestion carefully and decided to expand the discussion of research participation and trust but not to discuss informed consent and bio banking as it is a little bit beyond the scope of the paper. See page 22.

In the discussion, it might also be worth pulling out tensions between the different motivations and experiences - most notably between the trust in researchers and the idea of a hidden agenda. This perhaps gestures to the point by Hallowell et al. that motivations for participation are not only complex but also dynamic and shifting.

Author response: We are very grateful for this comment. You made us aware of the possibility to discuss this in relation to" It was well worth the effort”. We have expended the discussion accordingly to that. See page 21.

The findings about return of results seem to take the paper in a slightly different direction, and need to be anchored more clearly to the other considerations - they're more about expectations than experiences. However, they do provide the opportunity to bridge to the reflective assessment above about the value of research participation - what is it that people are getting back? Was the discussion primarily related to Alzheimer's disease in this context, and if so, it would be worth referencing the growing literature about the return of amyloid biomarkers and research results.

Author response: No, the discussion was not primarily related to Alzheimer's disease in this context. The finding in this context relate the H70 participants' experiences of how they experience the information and the questions in all of the examinations. The results are discussed in the light of comprehension of health literacy and the major challenges that this poses for the H70 study in form o forganizational and educational challenges. This has been clarified see page 25.

One major area for careful consideration is the cultural context - to what extent might the cohort's location in a relatively stable Scandanavian socialised health and social care collective influence the finding. This is particularly relevant in light of the connection to Townsend and Cox's work on research participation as a means of accessing healthcare - how does this hold in a Swedish context? Are H70 participants a particularly excluded group?

Author response: Thank you very much for this comment! The results showed that the focus group participants experienced themselves as an excluded group, but whether they are a particularly excluded
The purpose of this study was to make the voice of older people heard and so we have. However, despite health care in Sweden being one of the best in the world, many older people do not receive appropriate health care. Today’s highly specialised acute care is poorly adapted to the care needs of older people and therefore exposes them to avoidable risks such as loss of functional capacities resulting in unnecessary health and social care needs, and increased mortality. Swedish health care has undergone dramatic changes during the last decades, with decreased number of hospital beds and shorter hospital stays, especially evident in geriatric hospital care. This are evidence that they could be an excluded group. This has been discussed see page 23-24

The responses in the study are high whereas in other cohorts with austerity and neoliberal social contexts those who respond may represent different sections of society.

Author response: The H70 population is a sample with high cognitive and social functioning. Reasons for declining included both being too ill and being too healthy. This may have generated a sample with diverse health status. However, this will be investigated in a coming drop-out analysis.

What does the study provide in terms of implication for research where data miners have a relationship with the population from whom the data are extracted.

Author response: In this study, the implications are negligible because the participants represent such a small proportion(n=38) compared to the entire H70 study (n=1203). The benefits of the study will hopefully be greater. See page 28-29

Finally, the conclusion of the paper about involving participants in study design and conduct might reference some of the growing body of work in this area, in both longitudinal studies of ageing (see Dementia special issue 2019) and in major initiatives like the AllofUs precision medicine initiative.

Author response: Involvement of participants in design and conduct has been referred to. See page 30

On behalf of all authors

Synneve Dahlin Ivanoff