Reviewer’s report

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

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Reviewer: Richard Milne

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This is an important approach that has been relatively neglected. It is very important that we understand who, how and why people - whether patients or community based - take part in medical research including over long time periods. This particular study has been ongoing for many decades and provides particular insights.

The paper sets out to examine how participants understand and engage with the research process within cohort studies of older adults. It makes a valuable contribution to considering how older adults experience research, and how these experiences might contribute to the future development of research. The paper is a pleasure to read, analytically clear and methodologically sound. I have few significant suggestions or 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.

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.

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.

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.

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.

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.

One major area for careful consideration is the cultural context - to what extent might the cohort's location in a relatively stable Scandinavian 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?

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.

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

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.

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.

Yes

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

Yes
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