Author’s response to reviews

Title: Exploring the views of being a proxy from the perspective of unpaid carers and paid carers: developing a proxy version of the Adult Social Care Outcomes Toolkit (ASCOT)

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Version: 1 Date: 16 Mar 2018

Author’s response to reviews:

Sandra Bradley (Reviewer 1): An interesting study and one worth doing; however, I have the following comments:

> 1. In the Methods section, you have not described why some domains were tested on focus groups but not others and why the informal carers were subject to all domains? More details about why you chose to do it this way rather than testing the same domains for all is needed.

Authors’ comments: The reasons for using focus groups and interviews has been expanded (page 7 line 9-14). The reason for being unable to test all eight domains in each focus group has been added (page 8 line 11).

> 2. You have not adequately explained the theoretical framework that you used to do the analysis - please don't ask the reader to read your reference and figure it out - please identify whose framework you used, the steps involved and how you met the steps involved in your own research.

Authors’ comments: This has been added. Page 9 line 1. The framework method provides a systematic analytical framework with a series of steps that have been described. It is possible to use the framework method with inductive or deductive approaches to the data. In this study, we applied a combined inductive-deductive approach (i.e. the thematic framework combined pre-defined themes identified in literature and also those themes that emerged from the data).

> 3. What is the name of the national social care research ethics committee in England? I presume it has an official title?
Authors’ comments: The official title of the ethics committee is the Social Care Research Ethics Committee (SCREC). The SCREC was formally part of the National Research Ethics Service (NRES) and is now part of the NHS Health Research Authority (HRA).

> 4. I am most concerned that you have lumped carers of people with different diseases and disorders together to ask about social conditions - a person caring for a person with dementia will have a different experience as a carer than a parent who has lived with a child with disability. The same goes for paid care workers. A table illustrating which participants cared for which types of people and the responses they provided would help you to define if there were differences in responses based on the type and time of caring. This is important information for creating an ASCOT for different type of carer situations if you want to know what proxies will do and if you are trying to minimise bias between proxy and self-reporting.

Authors’ comments: Thank you for this comment. It has highlighted to us that we did not make clear the purpose of the study and what we were trying to achieve with ASCOT. ASCOT is a generic measure for social care service users and the aim of the study was to explore the feasibility of developing a proxy version for people with intellectual, cognitive and/or communication impairments. This has been clarified on page 4 line 30, and page 7 line 5. We have also amended the table to clarify the carers that took part in the study and the people they primarily cared for, which may have caused some confusion.

To clarify, we analysed the data from paid and family/friend carers separately; however, we report the findings together because many of the themes were generic across these two types of proxy respondent. Where there were specific differences between groups, we have amended the paper to explicitly acknowledge this. Where it applies to both groups, it is now also explicitly specified throughout the paper.

We have amended the use of terms to refer explicitly to each group (family/friend carers and paid carers), or both groups, where relevant and amended to ensure consistency throughout.

We have amended the methods section to clarify the data collection methods were similar between the groups.

> Results section:
> 1. You do not actually identify your themes and sub-themes. In lines 26-33, you say there are themes and then head into sub-themes which have not previously been discussed. Make your themes the headings with sub-themes as sub-headings.

Authors’ comments: Many thanks for highlighting this. On reflection, for this paper it made sense to remove the references to sub-themes and present the themes as standalone headings. These have been added on page 10 line 19 and are now addressed in order.

> 2. You are including discussion in your results (see top of p.9, first para). It is difficult for the reader to know whether the finding is your interpretation or has actually been derived from the data. This can be rectified by actually describing only the findings without comment about what they might mean and by including more commentary that justifies the sub-theme or theme.

Authors’ comments: The findings section has been amended to present these objectively and fairly,
based on the data. Any subjective language has been removed.

> 3. It is difficult to know which domains are being discussed within sub-themes without identification of the domains. It would be beneficial to actually provide a table of the ASCOT questions in the Methods section and then refer to the specific domain under discussion in the Results section.

Authors’ comments: Unfortunately we are unable to provide a table of the ASCOT questions as this as this would be in breach of the copyright and intellectual property for the ASCOT measure.

Some sections of the results have been edited to make it clearer which ASCOT domains are being discussed (see p.13, final paragraph).

A table of all the ASCOT domains along with definitions has been included.

> 4. The measurement bias difference (p.17, lines 38-40) may also be attributable to the psychological element of being cared for versus caring for someone - the stresses involved are different for both - you might like to discuss this within your considerations of measurement bias.

Authors’ comments: In the original paper, we referred to the difference between self-report and proxy-report of an individual’s quality of life as ‘measurement bias’. On reflection, this terminology may be confusing to the reader. We have edited the paper to remove this term.

In the literature, there is evidence that proxy experience of depression, stress and/or burden may influence the difference between self-report and proxy-report; however, it is unclear whether or how exactly this is influenced by the different stresses experienced by the proxy and the individual whose quality of life is being rated.

> 5. Language in Results section is subjective in parts rather than being based on the findings. Leave subjective interpretations for the Discussion.

Authors’ comments: The results section has been redrafted to avoid subjective interpretation.

> Overall:
> 1. Need more commentary to justify some of the author comments (p. 14, lines 37-42).

Authors’ comments: Unfortunately we were unsure as to exactly which section this referred to (p.14 has 25 lines our version). We have however amended the paper to remove any subjective comments and justify all findings based on the data alone.

> 2. Although I think the study is important, mixing two different types of carers with people caring for people with many types of diseases is not going to assist you in creating an ASCOT which is more subtle and refined. It may be better to present this data as separate information, particularly based on paid care workers.

Authors’ comments: We have amended the paper to clarify the purpose of the study and any differences between the groups, as well as the method for collecting data for these groups.

> 3. You have identified that perhaps the differences between paid and informal carers have not created enough subtlety to eliminate measurement bias. This is important to learn from but does not
necessarily warrant a published paper, as I would argue this should have been considered from the outset.

Authors’ comments: The objective of the work was not to eliminate measurement bias i.e. ‘the proxy gap’. This gap is influenced by a number of factors that are outside of the control of questionnaire design.

The objective of the paper is to (1) explore the challenges of acting as a proxy respondent and (2) seek to identify strategies to adapt self-report questionnaires into proxy-report format in a way that makes proxy response acceptable, feasible and minimise (what you might call) perception bias (i.e. potential bias due to systematic adoption of different proxy perspectives).

> Separating and reporting the findings differently would make a better published paper. Specifically if you have found differences in relation to the carers for specific disease states, e.g. dementia, Parkinson's vs spina bifida or other

Authors’ comments: This highlights that perhaps the purpose of the paper (and of ASCOT) was not clear. While some carers did indeed care for people who also had these conditions, ASCOT is not designed to pick up differences in these conditions. Primarily people had experience of caring for people with a learning disability; Autism or Asperger’s syndrome; and Dementia or Alzheimer’s. Table 1 has been amended to show this more clearly.

> Deirdre Fetherstonhaugh (Reviewer 2): This well written paper explores the views of being a proxy from the perspective of carers and care workers and then provides useful recommendations for the development of a proxy version of the ASCOT. It was pleasure to read and provides many insights about how to improve the process of using proxies to complete questionnaires and surveys for other people (in this case people who are receiving care).

> The only criticism (apart from a few edits) is a little confusion for the reader in some places as to who the authors are referring to when they use the terms participants, respondents, carers etc. Given that there were two groups of participants - unpaid carers and care workers - it would be better if these two 'names' were used consistently to ensure clarity. Technically, it could be argued that both participant groups are carers - one is paid and the other is not. For example, on Page 11 Line 32 does all carers refer to just the unpaid carers or the unpaid carers and the paid care workers. Page 11 Line 42 'some carers' - who is this referring to? Page 15 Line 51 'Participants' - is this referring to all participants? The authors need to go through the paper and check that they use consistent language.

Authors’ comments: Thank you for this comment. We have edited the manuscript to consistently refer to (family/friend) carers and paid care workers throughout.

> Suggested minor edits
> Page 2 Line 5 'for the value……..' rather than 'of the value…………

Authors’ comments: This has been amended as suggested

> Page 5 Line 10 'Many of these challenges are shared by the use………………. - this reads a little clumsily - suggest re-wording.

Authors’ comments: This has been re-worded. Page 5 line 5.
> Page 6 Line 26 - should 'a' be inserted i.e. '…….completed by a proxy………..'

Authors’ comments: No, this is a recognised use of the term proxy i.e. completed by someone else.

> Page 6 Line 50 ' …..what makes responses differ, and why.'

Authors’ comments: This has been amended as suggested

> Page 8 Line 19 It might read better to say that advertisements were placed with a University Adult Mailing Unit mailing list and on the University staff intranet.

Authors’ comments: This has been amended as suggested.

> Page 11 Line 5 'arise' rather than 'stem'

Authors’ comments: This has been amended as suggested

> Page 11 Line 12 reflect on what had been their personal preferences………………

Authors’ comments: This has been amended as suggested

> Page 15 Line 20 '……..and this view was not shared by all carers.'

Authors’ comments: This has been amended as suggested