

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Developing a new quality of life instrument with older people for economic evaluation in aged care: study protocol
AUTHORS	Ratcliffe, Julie; Cameron, Ian; Lancsar, Emily; Walker, Ruth; Milte, Rachel; Hutchinson, Claire; Swaffer, Kate; Parker, Stuart

VERSION 1 - REVIEW

REVIEWER	Erik Buskens University Medical Center Groningen, Faculty of Economics and Business, University of Groningen the Netherlands
REVIEW RETURNED	31-Jan-2019

GENERAL COMMENTS	<p>As such the attempt to develop an instrument that would adequately capture quality of life or rather utility among older individuals is in dire need. Therefore the study is timely, and appears well designed, deserving further dissemination. Having said that it would appear that the existing instruments and the mapping thereof on the new instrument would be very relevant. This is not foreseen or considered relevant? It would seem that the group is gathering all the relevant data, yet has not (yet) made clear plans as to a comparison with the 'standard' EQ5D (3-L of 5L? with and without cognition?) Why would an adaptation or new weighing scheme for the EQ5D based on a similar design not be appropriate? Why is a new instrument the way forward? This would help the reader better understand the rationale of the study. Finally, little attention seems to have been paid to cognition as a mediating or conditional domain/condition to be able to consider QoL. Ageing as such is one thing, but cognitive decline is another much dreaded phenomenon. How does the group think this will affect or determine QoL/utility? Drafting explicit plans and including those would be an interesting addition I think.</p>
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REVIEWER	Darshini Ayton Monash University, Australi
REVIEW RETURNED	17-Feb-2019

GENERAL COMMENTS	This study reports the proposed methods to develop a quality of life instrument for economic evaluation in aged care. Excitingly the methods aim to co-create this instrument with older people. This is a much needed instrument.
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	<p>This study protocol is well written.</p> <p>Introduction sets the context of the aged care sector and economic applications of quality of life. It would be helpful to identify or describe any other quality of life measure that would be applicable to aged care residents and maybe comment on why a new measure is needed over existing disease specific and generic QoL instruments. Later in the introduction it is commented that no existing instrument has the specific attributes of independence, mobility and control over life that can be used in the calculation of QALYs. This may need to be expanded as to why? Excellent overview of previous work by the authors in this area.</p> <p>Methods: Very well described. Minor suggestion is to include the topics of the interviews in a table. The questions guiding the interviews seem to get lost in the text. Is the analysis thematic or content? Which approach are you following? From the description the process sounds more like thematic analysis.</p> <p>Additional sub-headings will make navigating the text easier. For each phase I propose that you have subheadings on research design, data collection, data analysis.</p> <p>This is an excellent study and wishing you all the best with it.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

1. The attempt to develop an instrument that would adequately capture quality of life or rather utility among older individuals is in dire need. Therefore the study is timely, and appears well designed, deserving further dissemination.

Thank you for your supportive comments

2. Having said that it would appear that the existing instruments and the mapping thereof on the new instrument would be very relevant. This is not foreseen or considered relevant? It would seem that the group is gathering all the relevant data, yet has not (yet) made clear plans as to a comparison with the 'standard' EQ5D (3-L of 5L? with and without cognition?) Why would an adaptation or new weighing scheme for the EQ5D based on a similar design not be appropriate? Why is a new instrument the way forward? This would help the reader better understand the rationale of the study.

Thank you for this insightful comment. We have added a new section in the introductory section of the revised paper to elucidate why a new instrument is the way forward:

The findings from our large scale pilot study indicated that the preferences of younger and older people in relation to the relative importance of the attributes of quality of life embedded in health status and broader attributes of quality of life were not the same. The ability to be independent, physically mobile and have control over their daily lives were found to be the most important determinants of older people's quality of life. It is important to note that whilst existing preference based instruments, including the EQ-5D and the ASCOT incorporate some of these elements, no

currently existing preference based instrument incorporates all three of these quality of life attributes for the calculation of QALYs.

We have also added a new section in the Discussion section of the revised paper to highlight that the relationships between the new quality of life instrument and the EQ-5D-3L and the EQ-5D-5L will be investigated. Mapping algorithm will also be developed using recommended best practice methods to facilitate the estimation of re-weighted utility values from existing data-sets incorporating the EQ-5D-3L or the EQ-5D-5L.

3. Finally, little attention seems to have been paid to cognition as a mediating or conditional domain/condition to be able to consider QoL. Ageing as such is one thing, but cognitive decline is another much dreaded phenomenon. How does the group think this will affect or determine QoL/utility? Drafting explicit plans and including those would be an interesting addition I think.

We agree that cognitive impairment and dementia are particularly prevalent in populations of older people. Recent related research has found that with careful study design and an appropriate level of support, many people classified with mild or moderate cognitive impairment or dementia are able to provide a valid assessment of their own quality of life (see for example Ratcliffe et al AHEHP 2017). Our team will use sub-group analyses in every phase of the project to investigate the extent to which the presence of cognitive impairment impacts upon quality of life and the relative weights attached to the attributes included in the new quality of life instrument. We will also focus on the development of easy read resources and pictographs to assist in effectively communicating the content of the new descriptive system and facilitating understanding for older people with cognitive impairment and dementia. These additional details have been incorporated into the methods section of the revised paper.

Reviewer: 2

1. This study reports the proposed methods to develop a quality of life instrument for economic evaluation in aged care. Excitingly the methods aim to co-create this instrument with older people. This is a much needed instrument.

This study protocol is well written.

Thank you for your supportive comments

2. Introduction sets the context of the aged care sector and economic applications of quality of life. It would be helpful to identify or describe any other quality of life measure that would be applicable to aged care residents and maybe comment on why a new measure is needed over existing disease specific and generic QoL instruments. Later in the introduction it is commented that no existing instrument has the specific attributes of independence, mobility and control over life that can be used in the calculation of QALYs. This may need to be expanded as to why?

Thank you for these insightful comments which were also similarly raised by Reviewer 1. We have added a new section in the introductory section of the revised paper to elucidate why a new instrument is the way forward:

The findings from our large scale pilot study indicated that the preferences of younger and older people in relation to the relative importance of the attributes of quality of life embedded in health status and broader attributes of quality of life were not the same. The ability to be independent, physically mobile and have control over their daily lives were found to be the most important determinants of older people's quality of life. It is important to note that whilst existing preference based instruments, including the EQ-5D and the ASCOT incorporate some of these elements, no

currently existing preference based instrument incorporates all three of these quality of life attributes for the calculation of QALYs.

3. Excellent overview of previous work by the authors in this area.

Methods: Very well described.

Thank you

4. Minor suggestion is to include the topics of the interviews in a table. The questions guiding the interviews seem to get lost in the text.

Is the analysis thematic or content? Which approach are you following? From the description the process sounds more like thematic analysis.

The Interview questions have been dot pointed to make them stand out in the text.

We will be adopting a thematic approach to analysing the data. The process involves three stages as outlined: data immersion (reading, listening, re-reading), the initial round of coding will focus on descriptive content and the second round of coding will collate the first-round codes into broader themes.

A coding diary and coding map will be maintained to track the progression of the analysis until the research team has agreed the final themes for the descriptive system. This statement has been added to the text for greater clarity.

5. Additional sub-headings will make navigating the text easier. For each phase I propose that you have subheadings on research design, data collection, data analysis.

Additional sub-headings have been included for each phase in the methods section of the revised paper as recommended by the reviewer

6. This is an excellent study and wishing you all the best with it.

Thank you