

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Developing a dementia-specific preference-based quality of life measure (AD-5D) in Australia: Valuation study protocol
AUTHORS	Comans, Tracy; Nguyen, Kim; Mulhern, Brendan; Corlis, Megan; Li, Li; Welch, Alyssa; Kurrle, Susan; Rowen, Donna; Moyle, Wendy; Kularatna, Sanjeewa; Ratcliffe, Julie

VERSION 1 – REVIEW

REVIEWER	Janel Hanmer Assistant Professor of Medicine, University of Pittsburgh, Pittsburgh, PA, USA
REVIEW RETURNED	10-Oct-2017

GENERAL COMMENTS	I would like the authors to include their criteria for excluding respondents (if they will be excluding any respondents).
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REVIEWER	Elizabeth Goodwin Institute of Health Research, University of Exeter Medical School, UK
REVIEW RETURNED	26-Oct-2017

GENERAL COMMENTS	<p>This is a well-written protocol for an interesting and useful piece of research. I only have a couple of specific points that I would like to see addressed.</p> <p>Regarding research ethics, please could you specify when and how informed consent will be obtained from the dementia dyads participating in the interviews. At present, the text only refers to "able to provide informed consent" as an eligibility criterion (line 222). You've identified only one potential limitation of this study, which seems a trifle optimistic. In my experience, all kinds of things can go awry with valuation surveys. Just including one more potential limitation would sound more realistic.</p> <p>Overall, I have enjoyed reading this protocol, and I'm looking forward to hearing about the results.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

I would like the authors to include their criteria for excluding respondents (if they will be excluding any respondents).

Reviewer: 2

Comment: Regarding research ethics, please could you specify when and how informed consent will be obtained from the dementia dyads participating in the interviews. At present, the text only refers to "able to provide informed consent" as an eligibility criterion (line 222).

Response: We have added additional text to the paper to detail the process used

The recruitment process is guided by the Australia's NHMRC National Statement on Ethics Chapter 4.5. The statement articulates the right of people with a cognitive impairment to participate in research and outlines the considerations that need to be taken in this vulnerable population to ensure risks and burdens are justified. Recruitment follows a two-step process. First, the primary caregiver is phoned by a member of the research team after registration. A brief screening using set questions written for the study is used to assess suitability for inclusion into the study. The process of participation is explained and the caregiver is asked whether this is something that the PWD would be capable of and comfortable with. If during the telephone conversation it is clear that the PWD has severe dementia or is unable to respond to questions, or is likely to be distressed by an interview from an unfamiliar person, the person is excluded from participation. If preliminary eligibility is determined, a face-to-face interview is booked and information about the study is posted to the participants. Second, the research assistant checks on arrival for interview that the participant information sheet has been received and goes through this with the person and the carer, reminding them that participation is voluntary and they can withdraw or stop at any time. Consent to participate is then obtained (the person with dementia's consent is witnessed by the primary caregiver). Interviewers will be people with experience in working with people with dementia and have training to be alert for signs of distress and modify or discontinue the interview as appropriate.

also requested further limitations to be mentioned:

You've identified only one potential limitation of this study, which seems a trifle optimistic. In my experience, all kinds of things can go awry with valuation surveys. Just including one more potential limitation would sound more realistic.

Response: We have added the following limitation to the bullet points:

- The valuation methods used may not be readily understood by people with dementia, thereby limiting the ability to value quality of life from their own perspective.

We also modified one other bullet point to reflect uncertainty in obtaining value sets from people with dementia from:

- Preference value sets from both general population and dementia dyads will be available.

To:

- Preference value sets from both general population and dementia dyads will be modelled and compared.