Reviewer’s report

Title: Co-producing a shared understanding and definition of empowerment with people with dementia

Version: 1 Date: 14 Jan 2019

Reviewer: Katie Banister

Reviewer's report:

Thank you for your manuscript. In summary, this is a patient centred piece of qualitative research, to develop a definition of empowerment relevant to people with dementia (PWD), developed alongside PWD.

The results are interesting, in particular to PWD and people working with PWD. However there are some issues with the article which I feel would benefit from further proof reading and editing to ensure consistency and clarity throughout.

I have the following specific comments

1. Abstract: The abstract conclusions highlighted the added value in involving PWD in research - but this value is not described in the main discussion.

2. Plain English summary: Was this written by PWD or alongside PWD? It would be helpful to ensure the summary is accessible to PWD.

3. The manuscript was a little difficult to follow and would benefit from further editing to ensure the methods are collected together, then results, then discussion. For example:

   a. Methods: Page 6 line 7-46: This is not methods and would be better integrated in the background section.

   b. Methods: Phase 2: Table 4 is the results of the study so should be referred to there rather than the methods?

   c. Methods: Theory - this is background and should be incorporated in the background section not methods

   d. Results. In general it was hard to follow which of the results mapped onto which of the research questions. It would be beneficial to better link the elements of the research questions with the results and discussion.
4. **Background:** The background does not give any details of the condition of dementia, the likely issues with empowerment which have led to this research, nor an explanation of any issues/challenges in involving PWD in the research. I would suggest this would be an essential addition to make the paper much clearer to non-specialists in the field.

5. **Background:** Although three research questions are stated in the introduction (line 19-26 page 5) these are not all clearly addressed in the results/discussion? In particular Q3. What are the reported processes that have been used to empower people with dementia? This is partially addressed in page 13 line 20 but with not much clarity/explanation. Line 49-57 page 13 seems to suggest some input of PWD included in the evaluation of the findings but the sentence and results are not clear.

6. **Methods:** What was the rationale for choosing 9 people with dementia? How exactly were they recruited into the study?

7. **Methods:** Some further demographics of the PWD should be included, what was their age, length of disease etc.

8. **Methods:** It is not very clear when reading this manuscript whether this is a co-produced piece of work, or whether the PWD were actually participants in a qualitative focus group (research study). Were PWD offered the opportunity to be involved in any aspect of the manuscript preparation or just in the focus groups? You state that the work is a co-production and yet refer to the research team separately from the PWD which suggests the PWD are separate rather than part of the team. If this was co-produced I would expect more explanations of the research team as "including" PWD. The methods for involvement are not clearly stated in the manuscript and are not further described in the GRIPP2 short form attached. The GRIPP2 form should be used to explain further the methods you used to involve people with dementia - the present version just restates the methods/results of the paper. The GRIPP2 journal article [https://www.bmj.com/content/358/bmj.j3453](https://www.bmj.com/content/358/bmj.j3453) gives an example you can follow.

9. **Methods:** page 6 line 1: Point 2 seems a rather ambitious statement of intent compared to what was actually addressed in the paper - It wasn't clear to me how empowerment may be translated into practice.

10. **Methods:** Design: What ethical or other approvals were required for the project?

11. **Methods:** Phase 1. The abstract and table 1 mention measurement tools. These are not explained in the methods, nor dealt with in the results or discussion.

12. **Methods:** Phase 1. Table 1 - the search strategy is not clear - how are the first 2 terms in the search combined with term 3 - are they AND or OR? This is further described page 7 line 45 but again is unclear.
13. Methods: Phase 1: Some further methods relating to the search should be included. What were the included dates for the search strategy? Was screening for inclusion only performed based on the abstract or were full text also used to screen?

14. Methods: Phase 2: How were the constructs and terms extracted from the included studies?

15. Methods: Phase 2: It is unclear as to why figure 1 was presented in this way in the manuscript? The methods state that PWD were shown a series of cards to view the words, so how was this figure used? What is the rationale for the colours used as they could be construed as influencing the discussion as they are in different colours? Were any definitions of the terms included or did PWD discuss what the word meant to them?

16. Methods: Qualitative data analysis: This section line 18 does not give enough detail of how the final definition was developed/agreed after the initial choice of words presented in the table. Would there be any implications for PWD in having a separate meeting to further discuss the project? How did you deal with potential memory issues?

17. Results: Literature search. I would normally expect to see more detail of how many articles were screened, selected, rejected etc if this has been conducted as a systematic search as suggested in the methods. The number of included papers is missing (was this 10?)

18. Results: Page 11 Line 34 - this sentence is incomplete "evidence is typically...."

19. Results: Page 12 Line12 …apart from one study…please include reference to the study

20. Results: Definitions. It is rather confusing to understand which terms were included in the development of the definition. Page 12 line 23 illustrates 13 terms, the figure 1 included 18 terms and the final results which include 3 terms suggested by PWD has 15 terms. Were any other terms suggested by PWD and not included? What were the reasons given for not including 6 terms for figure 1?

21. Results: Page 12 Line27 …also referred to in one paper…please include reference to the study

22. Results: I could not find the findings of the review of tools/measurements for quantifying empowerment within the results?

23. Results: Co-production workshops. Were there any issues of memory/understanding with relating the third workshop to the previous 2?

24. Results: Co-production workshop: Page 14 Line 30 - I think this section should also have a heading? "Being respected"?
25. Results: Co-production workshop: Page 14 Line 51 title - "Having control" - which term does this relate to?

26. Results: Co-production workshop: Page 15 line 47 - add reference to Still Me campaign - this has not been explained

27. Results: Co-production workshop: several of the selected words in table 4 are not further described in the narrative (Stigma, Education, Self-determination, creating change)

28. Results: Empowerment definition: Page 17 line 32. As highlighted in methods section, not enough detail is given on how this final definition was agreed.

29. Results: Empowerment definition: Page 17 line 35. The definition is not grammatically correct. (Uses third person singular "ONE is respected" then later third person plural "Making decisions about THEIR lives". I would suggest that this is further reviewed and agreed with PWD.

30. Discussion: Page 18 line 16. You state that this paper has filled a gap in relation to "how impairment initiatives can further empower PWD. I don't feel this was covered in the results so this could be made clearer.

31. Discussion: Page 18 line 23-25: "In relation to empowerment initiatives, being empowered included all the elements from a general definition". This sentence is not very clear. What general definition. Which part of the results does this statement relate to?

32. Discussion: Page 18: line 46. You state "The fact that were unable to identify any studies measuring empowerment". Is this stated explicitly in the results? I could not find this. I'm also not clear how it relates to the study mentioned in the next sentence (Barr et al) which reported 19 different measures. Was this systematic review not included in your search?

33. Table 4 would benefit from reformatting as a standard table with headings rather than footnotes

34. Grammatical/typographic errors noted:
   a. Intermittent use of PwD vs PWD - it would be helpful to be consistent throughout.
   b. Page 5 line 13 conceptualisation is spelled incorrectly
   c. Page 5 line 45 Typographical use of were instead of where …across Northern Ireland WHERE group members…
   d. Page 16 line 39 NGO - state in full
   e. Page 17 line 22 extra quote marks included
f. Page 26 Table 2 line 51 sentence is incomplete

g. Table 3: Page 28: Gavan 2011 - Methodology states Theoretical/lit review???

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