Author’s response to reviews

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

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Author’s response to reviews:

Reviewer reports & Response to reviewers

Reviewer #1: 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.

Thank you. Additional sentences have been added at the beginning of the introduction to make this clearer.
2. Plain English summary: Was this written by PWD or alongside PWD? It would be helpful to ensure the summary is accessible to PWD.

- Thank you for this comment. We have approached PWD (through Dementia NI) and asked them to check and comment and the summary. As such, we have made a few minor edits.

“Empowerment is a useful term within health and social work to challenge stigma and enable greater freedoms to people with dementia (PWD). Within the dementia literature the term “empowerment” is commonly used. However, the term empowerment is rarely defined and if it is defined, that definition is produced by researchers. Furthermore, PWD are rarely involved in developing research ideas or in conducting the actual research. To address both these gaps, nine people with dementia and the research team undertook this current research. We searched for and reviewed all of the academic literature on empowerment within the dementia studies. Our findings suggest the term empowerment is used inconsistently within the literature. There is little research defining empowerment for PWD. We define empowerment by exploring its root word, power, in collaboration with PWD. This research article coproduces a definition of empowerment for PWD by PWD. Empowerment is: ‘A confidence building process whereby one is respected, has a voice and is heard, is involved in making decisions about their lives and has the opportunity to create change through access to appropriate resources.’”

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.

- The paragraph was moved to 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?

- We mention Table 4 in the results section as well. We feel it is important to have a reference to Table 4 in the Methods section to illustrate consensus and the terms agreed upon prior to PWD. The table then serves two functions: (1) co-production as a method toward consensus of terms and (2) the results of number of times terms were selected.

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

- Thank you, we have cut 3/4s of the words in the section and moved it to the background.
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.

We have reworded the aim/objectives and have used headings within the analysis section to make the links clearer.

Aim: The overall aim of this paper is to explore the development of an initial definition of empowerment specific to PWD. Key research questions research objectives are as follows:

1. To explore how empowerment is conceptualised within in the research literature about on dementia
2. To identify the core components of empowerment relevant to PWD
3. To coproduce an initial definition of empowerment with PWD

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.

- We agree, thank you. In the background section we have referenced a review by Millar et al regarding the involvement of PWD in care decisions. We have also added the following to the ‘Co-production in context section’ (under methods): “Members were in the early stages of dementia and usually joined Dementia NI within a few months of diagnosis. One member during our research left the empowerment groups due to their condition advancing and another member left because of misdiagnosis. Memory issues were not immediately evident—though this is not always how dementia manifests. The empowerment group members did not suffer from any obvious or normative associations of the disease, though some members suffered from delayed speech and would disclose that they were searching for words.”

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.

- We have expanded these sections, thank you.
6. **Methods:** What was the rationale for choosing 9 people with dementia? How exactly were they recruited into the study?

- This has now been clarified as follows:

“Nine PWD (between the ages of 47-73) who were members of the Dementia NI empowerment group programme (an organisation founded and led by people with dementia) were involved in this co-production research. Given the nascency of the Dementia NI empowerment group programme and the nature of the condition which limits long term participation, numbers of participants were low in 2017, though the number of members are continually growing.”

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

- See above to responses.

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.

- We believe that this project is very much in line with coproduction values and we are also wary of any attempts to narrow it down to a procedurally driven process. Coproduction, in our project involved three groups (1) academics; (2) PWD and a Service Provider Charity (Dementia NI). We all came together to use our unique and varied skill set to address this complex issue. As the project progressed Dementia NI played more of a facilitator role but at no point were PWD considered research participants or member of an advisory group.

Academic partners initially approached Dementia NI and, through this organisation, got in touch with PWD to be partners on the project. Following early discussions with PWD, the project was further refined and it was agreed that an initial review of literature was the first step. We were all
in agreement that this was to be conducted by the academic staff who had prior knowledge and experience. However, PWD were kept informed throughout and had access to the original data if requested. Once this was complete our coproduction partners (PWD) took a lead role in the second stage whereby they identified the core components of what empowerment meant to someone living with dementia. The final step was a coproduced statement defining what empowerment meant for PWD. Each partner inputted into this process and we each recognised the others skills, knowledge and experience.

In conclusion, we have made it clear that this is a co-produced piece of work, where PWD were offered the opportunity to be involved in all aspects of the manuscript preparation. We have also added how our co-production approach in this work was informed by key learning from a previous piece of co-production work (McConnell., 2018), most specifically the need to balance the desire for co-production partners to be involved in all aspects of the manuscript with the level of involvement that non-academic partners really want. Specifically, for this co-production project, we found that pushing involvement too far can actually disempower PWD who, by their own admission can tire easily. Therefore, we had ongoing negotiations throughout this project in relation to who was comfortable doing what.

We have now referred to the inclusion of PWD rather than referring to the research team separately from PWD.

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.

- We have changed this to “how the language of empowerment may facilitate confidence in the lives of PWD.” Given this change of language, we do bridge the literature on facilitative empowerment throughout the results.

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

- Ethics and other approvals are addressed under Declarations at the end of the paper to avoid the paper becoming too lengthy. Ethical Approval was granted by the University Ethics Committee.

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.

- This was part of an earlier draft but was not practical to include so we have removed reference to this to avoid conclusion.
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.

- AND, changed, thank you.

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?

- We wouldn’t have time to read 1498 papers in full. In “Phase 1 – Systematic Search and Narrative Review” we say “Searches were run between 6th June 2017 and 21st June 2017.” And “Documents were screened for inclusion independently by two reviewers based on titles and abstracts.”

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

-We have clarified that “Constructs and terms associated with empowerment were extracted from the final selection of papers into a data extraction table following discussions and guidance from our community partners.”

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?

-This figure was removed to avoid confusion, and we have clarified in the manuscript that community partners (PWD) discussed what the word’s meant to them, and whether or not the words helped define what empowerment meant for them as people living with dementia.

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
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?

-“The words were chosen and the academic research team aligned them into a sentence based on hierarchy of selection. A resulting ‘draft’ definition was presented to the Dementia NI members for refinement and agreement. All PWD did not disclose memory impairment and remembered our initial workshop.” Moreover, we also had the support of Dementia NI who were able to advise us in relation to memory deterioration which did not occur.

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?)

- We have added: “Ten paper were selected based on this criteria and were read in-depth for key terms related to empowerment (see Table 3).” In “Phase 1 – Systematic Search and Narrative Review” we say “Six databases were searched to ensure coverage of a substantive number of medical/health, social care and social policy based journals (1146 papers)... Google Scholar was also used to search citations of included papers (352 papers).”

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

- Sentence superfluous, erased. Thank you for catching this.

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

“While PWD were involved in the studies, they did not describe perspectives of PWD in empowerment, apart from one study where PWD felt empowered when they took steps to challenge biomedical perceptions of dementia through engaging in physical, mental and social activities.”

-Reference now included

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?
- Apologies for the confusion here. It was felt that it was not practical or appropriate to include every term in the definition. There were 15 relevant terms identified during the initial review. This increased to 18 after PWD added another 3 but data wasn’t collected on the number of others who agreed with this (i.e. we didn’t ask the other member to individually select whether they would have chosen it and the decision was made by consensus). The initial workshop focus was on quantity but this changed to ‘relevance’ as the project progressed. As such, not every term was included within the definition. It is also true that the team produced numerous draft definitions during the workshop which were debated, discussed and refined. Figure 1 has been removed.

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

- Reference now included.

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

-Reference to this has been removed.

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

- As stated in the response to comment 4, memory issues did not seem to affect members in any of the qualitative data. The response to comment 4 suffices to satisfy this query.

24. Results: Co-production workshop: Page 14 Line 30 - I think this section should also have a heading? "Being respected"?

- Headline added.

25. Results: Co-production workshop: Page 14 Line 51 title - "Having control" -which term does this relate to?

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

- Now explained and cited in text.

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)

- I’m not sure what they want here. The words are pretty self-explanatory… T and P?

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.

- The following has been added after the definition. This definition was agreed by consensus among co-production partners. This process included several draft definitions being written and debated by the team. It is important to note, that the focus here was on the relevance and ‘sense of meaning’ behind included terms rather than developing a definition that simply included a multiple different terms and phrases.

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.

- Thank you for catching this. The definition has been changed to: ‘A confidence building process whereby PWD are is respected, have a voice and are heard, are involved in making decisions about their lives and have the opportunity to create change through access to appropriate resources.’ We are not sure the change of tense necessitates another review by the members.

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.
- We have changed the sentence to reflect how the research co-production itself was a form of empowerment: “how empowerment initiatives through co-production of research can further empower them by facilitating agency and listening to their experiences”

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?
- Sentence erased, superfluous.

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?
- This has been deleted. The line should have read for measuring empowerment dementia

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

The table has been reformatted.

34. Grammatical/typographic errors noted:
   a. Intermittent use of PwD vs PWD - it would be helpful to be consistent throughout.
   - Changes to PWD, thank you for catching this inconsistency.
   b. Page 5 line 13 conceptualisation is spelled incorrectly
   - Corrected, thank you.
   c. Page 5 line 45 Typographical use of were instead of where …across Northern Ireland WHERE group members…
   - Changed, thank you for catching this.
   d. Page 16 line 39 NGO - state in full
- Changed to Non-Governmental Organizations (NGOs)

e. Page 17 line 22 extra quote marks included
   - Changed, thank you.

f. Page 26 Table 2 line 51 sentence is incomplete
   - Changed, thank you.

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

Reviewer #2: I draw the attention of the Authors to the following:

Co-production. This is usually involves lay people (with experience of health of social care) and professionals including academics in the involvement and management of a research proposal - that is, the lay people are an integral part of the research team - as distinct from 'tokens'. Here there are 7 senior academics and a total of 9 lay people (PWDs); The authors should explain the almost equal numbers of academics and lay people in what is really a simple exercise.

- The members of Dementia NI (PWD) were integral members of the research team, and we co-produced together this paper, the definition, and the research results. Given that there were more members than academics, we are not clear why this calls into question the validity of co-production. The sample size was small because Dementia NI is a nascent organization. We have now included the reasoning for the 9 members in the text.

The core team were four researchers, 2 did qualitative methods, and 2 did the literature review (this is stated in the paper). However, our grant consisted of a larger team, a total of 7. The other 3 academics gave input on drafts of the paper, helped us design our methodology, and helped guide the write up of our results. We don’t believe this longer explanation is suited to be included in the paper itself.

Although this is post research I would have thought non-PWDs could have provided a different and useful perspective - including but not exclusively carers- for instance I suspect that claims of disrespect, patronising, absence of being listened to etc would be challenged or least the evidence evaluated
Thank you for your comment. Interviewing carers was outside the remit of our study concerning PWD alone. While we have no doubt that carers would object to the some of the feelings and experiences of the PWD, that doesn’t invalidate their concern. Instead, we listened to the members and didn’t try to refute their concerns by talking to carers or nurses or social workers. In essence, doing so would be re-creating the unequal hierarchy of the biomedical model of giving medical practitioners power over (ie, instrumental power), the patients. Moreover, this is one definition based on the experiences of PWD. Another study might want to come up with a definition based on carer perspectives. That is not our study.

Even more problematical is the PWD statement about bed blocking; bed blocking is current problem in hospitals after medical treatment because patients can only be discharged if there is somewhere where the patient receives appropriate follow up care - usually with family or community.- which often it is not available hence the blocking. To say that 'no we are not bed blocking (wrt to hospitals and surgeries) our lives matter too’ hence inferring that in the health environment their 'lives are considered not to matter' needs to be challenged by evidence. NHS England is absolutely clear that some of the PWD negative claims, opinions, experiences have no place in today's health care - ref Dame Sally Davies, INVOLVE, PILAR, UNTRAP, CRNs. I have no experience of health care in Northern Ireland so cannot comment - please note I am a PhD graduate of Queens, for which I have the highest respect and remain in contact by the various Queens literature.

We have cited Davies in the text upon request from another reviewer. We do not feel this is problematic at all. This paper is not about refuting the validity of PWD’s claims. It is about listening to their experiences and trying to empower them to make change. We are trying to get away from the hierarchical model of say, the NHS telling the public there is no such thing as bed-blocking. That is not the experience nor feelings of our co-researchers. Either way, bed-blocking is not the issue here. We are co-producing a definition of empowerment from the perspective of PWD.

9 PWDs were selected to take part in the co-production team. I would be interested to know the demographics of people with dementia in N Ireland - numbers, age profiles, gender, stage of diagnosis, distribution - rural vs town/city living, hence to provide a perspective to help understand better this paper.

We worked closely with a Northern Ireland wide charity (Dementia NI) in which we asked them to try and give a representative mix of individuals from various different backgrounds (employment, education etc.) Nonetheless, this comment suggests that PWD were research participants rather than co-researchers. We do not feel it is fair that PWD are asked to provide
details that members of the research team are not expected to give about themselves. Nonetheless, we do recognise that individual backgrounds can be a factor in qualitative research.

Clarification is also needed on the selection criteria for the PWDs and including stages of dementia. The capacity to give informed consent implies 'early stage dementia'. So, I would have liked information on how the diagnosis was carried out; what gave rise to referral. Part of the diagnosis probably evaluated memory and a capacity for analysis of events, make decisions. The strong impression I get is that the PWDs are strong on these values; but how representative are these 9 PWDs of the rest of the N Ireland dementia population?

- We added this to the Co-production in context section: “Members were in the early stages of dementia and usually joined Dementia NI within a few months of diagnosis. One member during our research left the empowerment groups due to their condition advancing and another member left because of misdiagnosis. Memory issues were not immediately evident—though this is not always how dementia manifests. The empowerment group members did not suffer from any obvious or normative associations of the disease, though some members suffered from delayed speech and would disclose that they were searching for words.”

In terms of consent - that’s why input from dementia NI was important. We recognize the importance of consent and actively sought it. However, we also did not want to exclude anyone based on additional needs. This goes against are team values of inclusion and respect for everyone’s views and opinions. We believe further work is needed but this represents a first step.

I am not convinced that the inclusion of philosophy/sociology e.g. Foucault adds to the theoretical framework or ultimately to the outcome values of the project. For me they confuse understanding and evaluation.

- Other reviewers liked this section. Nevertheless, we have cut ¾ of the theory on power and significantly simplified it. We have also reduced the definitions to instrumental and facilitative. As we make clear in a comment to your review above re. including carers, there is confusion about how power functions and it is important for researchers to realize this, especially in co-production work where facilitative power is the thrust of what we should be doing, not top-down instrumental power that attempts to refute the claims of patients.

Nevertheless, we have clarified our engagement with the terms in the results section.

The inclusion of citations about ‘empowerment of one ...at the expense of another’ (Clegg; Davenport.) is out of step with today's world of financial stress in the health service and funding
for health care research; selection is done on the basis of 'best care' (NHS) and 'most promising research proposal' usually done by panels of professionals and lay people (PPI) e.g. RfPB.

- Indeed, that is why we advocate facilitative power. Evidenced in many papers and our co-researchers quotes, there is still a top-down model (ie, instrumental) when it comes to patient care. The example you have given (re. health care funding) does not eschew all other experience. That would be an instrumental conclusion: you are taking the power of experience away from the Dementia NI members.

Activism: I have no direct experience of the meaning of activism. I am actively involved in health research including with Alzheimer Soc.: this is the first time I have heard of 'dementia activist movement'. To avoid misunderstanding the authors need to provide clarification.

- We have now defined “activism” in the paper: “dementia activists—PWD publically and actively advocating change by themselves and for themselves”. Within the context of Dementia NI, which we make clear in the paper, this is an organization created by PWD for PWD to change social attitudes and change how they are treated in the health system. This is unique, and should be welcomed and respected. It is nothing short of activism, and they identify as activists.

Reviewer #3: This is a good article written in a straightforward manner that will, in my opinion, be of immediate interest to those active and interested in dementia issues but also of relevance to other fields grappling with the meaning and definition of empowerment.

I understand that the authors have already received feedback guiding them to bring the co-production methodology more to the fore in the text. Arguably there is still room to do this - e.g. in terms of noting in the discussion or elsewhere the challenges and opportunities of using this method, adherence to key principles etc. But personally, I feel they have got the balance about right to ensure this is still a paper about defining empowerment.

- Thank you. We made changes throughout based on your comments and that of other reviewers. Nonetheless, the authors may find that they receive more comments and feedback on this element than their published definition.

The authors do not say how the definition developed could and should be disseminated and adopted as standard. Or what sort of research might be helpful to build on their conclusions: i.e. larger workshops; events conducted in other parts of the country, greater diversity.

Thanks you. Additional text has been added to the discussion regarding next steps
Reviewer #4: This paper describes the process of co-producing a definition of empowerment specific to the situation of people with dementia, based on literature review and the perspective of end-users, in a collaborative research involving PWD. This paper treats of an interesting topic in an era where patient engagement and empowerment is promoted but for which few data regarding PWD are currently available. The approach combining literature review and coproduction workshop is very relevant and the theory section in the different definitions of power is well documented. However I have concerns regarding the reporting of methods and findings.

1- One of my main concerns regards the 1rst objective stated in the paper which is "1. How can PWD be involved in coproduced research to define empowerment relative to PWD?". To me the research has not been conducted to properly answer this question as first aim. It seems that the questions 2 and 3 are more consistent with the project that has been conducted. The authors did not study the mechanisms, the process nor the impact of engaging PWD in research, no endpoint regarding how PWD were engaged (level of engagement, activities, perceptions, barriers/enablers, impact… for instance) were studied and reported, thus I would only state this as secondary objective. In line with this remark, the first sentence of the discussion should be removed. I propose to begin the discussion on the definition, and to rather mention later that this study showed that PWD engagement in research is feasible, since PWD participated to the workshops and gave valuable insight.

- Thank you. We agree and (a) we have made the first question has been made a secondary objective. (b) we have erased the first sentence of the discussion section and now state: “We have found that through PWD participation in workshops engagement with early-stage PWD in the co-production of research is feasible and valuable.”

2- The literature review is described as a "systematic search and narrative review". The number of databases screened is correct, but some data are missing to fit with the definition of a systematic approach.

- Some helpful comments here and below – thank you. We are confident in the robustness of our searches given that a number of our team have published extensively on this methodology. The additional information required has been added and we have removed reference to ‘systematic’ so as to avoid confusion.


- The questions addressed by the review are not explicitly defined, for instance in the abstract emphasis is put on empowerment measurement which is not clearly addressed in the body of the manuscript as an objective and not presented in the result section.

- Regarding table 1: Where there any boolean operator between empowerment and concepts?
This has been changed

- Did you apply language restriction and date restriction regarding publication date?
English language. No date restriction

- Why limiting your search to peer-reviewed journals? Grey/unpublished literature on this topic, coming from patients associations or institutions would have been very relevant.

- The search focused on more widely available peer reviewed material rather than grey literature. We also searched reference lists to increase the range of our search. This has been made clearer within the paper

- No information is available in the methods on data extraction and analysis process of the review. I would suggest switching the first 2 paragraphs of the results from the results section to the design section because to me they provide information on these points. It would be interesting to present the items covered by the data extraction framework.

This framework is illustrated in Table 3 and this has now been made clearer in the paper

- The results section should begin by presented numbers of papers included. The flow-chart of inclusion of papers in the review is not presented and would be interesting as appendix for instance to gain in transparency of the review process (see PRISMA statement for example).

3- Regarding the co-production workshops:

Who are the 9 co-researchers mentioned p8 l18? Do they correspond to the 9 PWD mentioned previously? Additionally to PWD, how many professionals/researchers participated to the workshop? Who facilitated the workshops?
Yes, this is the same group of PWD. We have added (PWD) after the reference to 9 co-researchers in keeping with the practice and labelling of co-production research. Thank you for this clarification.

Description of PWD involved in workshop could be enhanced by presenting briefly their previous experience of involvement in research or their history of participation in the Dementia NL. This would help to appreciate how they are representative of "all" PWD. The authors mentioned it as a potential limitation of the study but additional description of the PWD could help to appreciate this potential bias.

- Thank you, we have done this based on another reviewer comment. Thus:

“Members were in the early stages of dementia and usually joined Dementia NI within a few months of diagnosis. One member during our research left the empowerment groups due to their condition advancing and another member left because of misdiagnosis. Memory issues were not immediately evident—though this is not always how dementia manifests. The empowerment group members did not suffer from any obvious or normative associations of the disease, though some members suffered from delayed speech and would disclose that they were searching for words.”

We also now say: “These nine members (between the ages of 47-73) were recruited through the Dementia NI empowerment groups in Belfast and Holywood. Given the nascency of the Dementia NI empowerment group programme and the nature of the condition which limits long term participation, numbers of participants were low in the 2017, through the number of members are continually growing.”

It seems that no clinician has been included in the process. Why did you choose to not include clinicians/health professionals? This has to be discussed in the paper since, as mentioned in the results from the literature review, they are involved in the design of programs to empower PWD. Co-production usually involves all end-users representatives and professionals could be considered as end-users of the definition.

- Thank you for your comment and question. Interviewing carers was outside the remit of our study concerning PWD alone. We didn’t want to include clinicians/health professionals/carers because they may undermine and attempt to invalidate the legitimate concerns, experiences, and feelings of PWD. In essence, doing so would be re-creating the unequal hierarchy of the biomedical model of giving medical practioners power over (ie, instrumental power), the patients. Moreover, and crucial to the design of the study, this is one definition based on the
experiences of a set of early-stage PWD. Another study might want to come up with a definition based on other perspectives from clinicians/health professionals, etc. That is not our study.

This is why input from dementia NI was important. We believe further work is needed but this represents a first step exclusively representing the PWD. We would also note that members of our research team (PB) do have clinical experience (social work) working in dementia settings.

4 - In the final definition of empowerment, the specification 'about their life' seems to refer only to an individual perspective. Did the members of the workshops talk about organizational or even societal levels?

- Yes, our co-researchers often spoke about challenging organization hierarchies, especially instrumental power relations, and social stigma. We feel we have captured both in the definition without making it too long and cumbersome. We say: “involved in making decisions about their lives [their lives are holistic, this includes, family, social, political, etc] and has the opportunity to create change through access to appropriate resources [the message here is institutional access to resources, beds, care, knowledge, etc].”

5- The discussion does not clearly compare the proposed definition to others available in the literature in general or specific of patients with other diseases. Did the authors identified specificities linked to dementia in the proposed definition

- We feel this is an important first step and this important comment may represent the next phase of our work in this area. Unfortunately, given the length of the current paper we feel this is outside of the scope of the current paper. As such, a line has been added to the paper to reflect this.

Minor remarks:

"people with dementia" is inconsistently abbreviated as PWD or PwD, please revise the manuscript to be consistent.

- We have made it consistently “PWD” now. Thank you.

p16 l39: I think NGO has never been used before in the manuscript so I propose to write it in full length.

- We have done that now, thank you.
Reviewer #5

Comments were made within the manuscript text as track-changes and we therefore addressed and responded to those comments within the manuscript revision text.