









STUDY PROTOCOL

A protocol for the establishment and evaluation of an older adult stakeholder panel for health services research [version 1; peer review: 1 approved, 1 approved with reservations]

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V1 **First published:** 14 Jan 2020, 3:1
<https://doi.org/10.12688/hrbopenres.12979.1>
Latest published: 14 Jan 2020, 3:1
<https://doi.org/10.12688/hrbopenres.12979.1>

Abstract



Background: There has been a policy shift towards public and patient involvement (PPI) in population health and health services research in Ireland and internationally. Despite growing empirical evidence that PPI can have positive impacts on the quality and appropriateness of health research and innovation, little is known about the involvement and impact of older adults as research partners. The aim of this study is to 1) describe the process of establishing a PPI panel of older adults, family carers and ageing research academics and 2) to evaluate the impact of this research partnership on all members of the PPI panel.



Methods: A partnership-focused framework will guide the recruitment and establishment of a PPI panel of older adults, family carers and academic researchers. Between eight and ten older adults and four and six family carers with experience of using health services will be recruited through advertisement in community locations and through gatekeepers in a range of non-governmental, voluntary, and community organisations of older adults in the Mid-West region of Ireland. Academic researchers will be recruited through an established Ageing Research Centre at the University of Limerick. Data collected will include an activity log and records of all meetings, recorded panel discussions and recorded individual interviews with all members of the research team at key time points (12 and 24 months after establishment of the panel). Data will be transcribed, managed in NVivo and analysed using an inductive approach to thematic analysis. Dissemination of research findings will be facilitated by the research partnership team of academics and older adults.

Discussion: This study will identify learning about the process of

Open Peer Review

Reviewer Status  

	Invited Reviewers	
	1	2
version 1 14 Jan 2020	 report	 report

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establishing a PPI panel guided by a partnership-focused framework and will qualitatively evaluate the impact of participation in a PPI panel for all members of the research team.

Keywords

Older adults, public and patient involvement, research participation, collaboration, engagement.



This article is included in the [Ageing Populations](#) collection.

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Author roles: **Conneely M:** Conceptualization, Methodology, Project Administration, Writing – Original Draft Preparation, Writing – Review & Editing; **Boland P:** Methodology, Writing – Review & Editing; **O'Neill A:** Writing – Review & Editing; **Byrne D:** Writing – Review & Editing; **Cronin S:** Writing – Review & Editing; **Quinn D:** Writing – Review & Editing; **Trépel D:** Supervision, Writing – Review & Editing; **Leahy S:** Supervision, Writing – Review & Editing; **Salsberg J:** Conceptualization, Methodology, Writing – Review & Editing; **Galvin R:** Conceptualization, Funding Acquisition, Methodology, Supervision, Writing – Review & Editing; **Robinson K:** Conceptualization, Methodology, Project Administration, Supervision, Writing – Original Draft Preparation, Writing – Review & Editing

Competing interests: No competing interests were disclosed.

Grant information: This work was supported by the Health Research Board (HRB) of Ireland through the HRB Collaborative Doctoral Awards under Grant CDA-2018-005 (Right Care Programme).

The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

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How to cite this article: Conneely M, Boland P, O'Neill A *et al.* **A protocol for the establishment and evaluation of an older adult stakeholder panel for health services research [version 1; peer review: 1 approved, 1 approved with reservations]** HRB Open Research 2020, 3:1 <https://doi.org/10.12688/hrbopenres.12979.1>

First published: 14 Jan 2020, 3:1 <https://doi.org/10.12688/hrbopenres.12979.1>

Introduction

Ireland, like many other countries has seen a steady increase in life expectancy and has an ageing population. By 2031, it is forecasted that there will be more than one million older adults (aged 65 years and older) in Ireland, representing an increase from 13% (2015) to 20% of our overall population¹. Nationally, the Health Services Executive (HSE) Planning for Health Report (2017) predicts a significant increase in healthcare service use over the next decade¹. As older adults bear the greatest burden of disease, they account for the greatest proportion of healthcare use.

It is widely acknowledged that patients and the public should be involved as research partners to identify meaningful research priorities and to enhance the design and implementation of health services that are responsive to the changing needs and preferences of service users². The term “Public and Patient Involvement” (PPI) is described by the United Kingdom’s National Institute for Health Research body INVOLVE as “an active partnership between patients and the public and researchers³. The research is “being carried out ‘with’ or ‘by’ members of the public”, not just ‘to’, ‘about’ or ‘for them’³. There are many terms used in the literature to describe “involvement” of lay users of health services⁴⁻⁶. These terms include community members, stakeholders, public, citizens, consumers of health-care services, patient and service users⁷⁻⁹. In this paper our preferred term is “PPI panel of older adults”.

In recent years, there has been an increased drive to involve patients and the public in health research including moral, practical and pragmatic arguments¹⁰⁻¹². Morally, patient involvement is recommended on the grounds that people affected by a condition have a right in the decision process about research that may affect them. From a practical perspective, involving patients in research is intended to increase the relevance¹⁰, accountability and transparency of research¹³. Patient involvement brings a lived-experience perspective to research, with the potential to extend the range of people represented in research and improve dissemination of key findings beyond academic audiences¹²⁻¹⁵. From a research funding perspective, the British National Institute of Health recognised that public and patients can shape important aspects of health care research and established the INVOLVE organisation in 1996. Similarly, the Canadian Institutes for Health Research developed a Strategy for Patient Outcome Research; and the Patient-Centred Outcomes Research Unit was established in the United States in 2010¹². The Health Research Board (HRB), an Irish state agency that supports research to improve health and transform patient care, recognised the importance of PPI in its 2016–2020 strategy¹⁶. Inclusion of PPI is now a standard feature of most HRB funding calls and the HRB PPI Ignite Awards 2017 focused on promoting institutional-wide PPI within Irish universities¹⁷.

Though most researchers, funders and patient advocacy groups agree on the merit and importance of PPI, the impact of PPI is not readily measurable. A Cochrane review, exploring the effects of patient involvement in developing healthcare research,

concluded that engaging patients in the research process may lead to an output that is more readable and understandable by other patients¹⁸. The authors reported that engagement with patients was feasible in most of the randomised controlled trials included in the review. A further review including 66 studies examining the impact of PPI in health and social care research reported that PPI enhanced the quality of research, ensuring relevance and appropriateness⁸. The authors reported that PPI may have a more positive impact when PPI is embedded throughout the study and when patients and the public are involved as partners in the research team. Many studies within this systematic review reported positive impacts in the initial stages of research, with users developing user-friendly information, user-focused research objectives and more appropriate recruitment strategies. The results of this review also reported that user involvement may achieve better dissemination of research findings due to the influence of research-users in the communities for whom the findings are intended.

There are many documented challenges to embedding PPI in the research cycle^{12,19}. Challenges to PPI are reported where public and patients are involved sporadically in the study with no clear defined role⁶. There has also been concern that involvement was tokenistic²⁰. Other challenges reported in the literature include patient frustration with the research process which involved training, attendance at meetings and power issues between researcher and PPI contributors¹⁰. Poor quality of reporting of PPI has been cited as one of the barriers to understanding the impact of PPI in research¹⁴.

Evidence for evaluating the involvement and impact of older people in health research is sparse. A systematic review in 2007 analysed 30 studies which involved older adults in commissioning, prioritising, designing or disseminating research. Involvement varied from completing questionnaires or taking part in an interview⁷. The review found only four studies which formally evaluated involving older people in the research studies using different evaluation methods ranging from questionnaire to an ethnographic approach. A recent systematic review evaluated the impacts of involving older adults in health and social care research on older co-researchers, academic researchers and research processes²¹. The review analysed nine articles using a qualitative methodology evaluating older adults’ involvement in research. The authors reported that all nine articles described beneficial impacts for older co-researchers in terms of social benefits, new learning, being valued, developing relationships with academics and shared workloads. Five studies in the review reported beneficial impacts for academic researchers which included learning from the experiences of the co-researchers during recruitment, data collection and dissemination. The challenges reported for older co-researchers were reported in seven articles detailing issues with a demanding workload and dissatisfaction with the level of involvement. Whilst challenges were reported with all studies reporting a lengthy participatory process, the authors concluded that the benefits outweighed the challenges.

Patient engagement in healthcare research is feasible and adaptable to many contexts and settings^{12,22}. The study aims to:

- Describe the process of establishing a PPI panel of older adults, family carers and ageing research academics to meaningfully engage as partners in a research team guided by a partnership-focused framework
- Evaluate the impact of this research partnership on all members of the PPI panel.

Study context

The study will be carried out in collaboration with the Ageing Research Centre (ARC) at the University of Limerick, Ireland. The ARC comprises of an interdisciplinary group of researchers that aim to:

- Conduct excellent research that leads to improvement in the health, well-being and social inclusion of older people.
- Work across disciplinary boundaries to address research priorities that reflect the day to day realities of older people's lives.
- Develop capacity in ageing research at UL and build collaborations with researchers, clinicians, industry partners, older people and their representative organisations.

The ARC membership includes academic researchers, postdoctoral researchers and PhD students. Four PhD students affiliated with the ARC are completing their doctoral studies on the "Right Care" programme of research funded by the Health Research Board (HRB) in Ireland. The aim of the four aligned PhD projects is to advance the evidence base on appropriate, safe and cost-effective "Right Care" for older adults.

Methods

The study will employ a qualitative participatory approach^{12,23} to data collection. To ensure rigour of the investigation, the consolidated criteria for reporting qualitative research (COREQ)²⁴ will be employed to guide data collection and analysis. Furthermore, the Guidance for Reporting Involvement of Patients and the Public (GRIPP2)²⁵ standardised reporting guidelines will be adopted. The GRIPP2 checklist was developed to improve the quality, consistency and reporting of patient and public engagement in research, in publications.

Framework

A partnership-focused framework will guide the establishment of an older adult health services research stakeholder panel¹¹. This framework embeds INVOLVE principles and values²⁶. The authors (MC, KR, JS and RG) identified the participant "mix" that was required to set up this PPI group via discussion and consensus that older adults and family carers with health service utilisation experience were the most appropriate group to recruit.

Recruitment

Identifying public contributors can be challenging²⁷; therefore, a broad and flexible recruitment strategy is planned. Recruitment

will follow the principles of purposeful and snowball sampling^{12,28}, drawing on existing contacts between the team, and collaborators and relevant agencies (Age Action Ireland, Family Carers Ireland). The first author (MC) will consult with older adults on the steering groups of Age Action Ireland and Family Carers Ireland to refine the recruitment strategy and recruitment flyer. We will use the following strategies for completing the PPI panel:

1. Public advertising in community locations, in community publications and community radio.
2. Advertising through patient organization/community group/active retirement groups/Men's sheds and family carer organisations as advised by the relevant agency steering groups (Age Action Ireland).
3. Established relationships and networks of ARC members will be explored to identify gatekeepers or community leaders in relevant organisations (NGO's public and community organisations) who could identify prospective participants.

After prospective participants express interest in joining the PPI panel, a researcher will schedule a meeting to discuss the information sheet and any queries the participant may have. The researcher will also assure participants that they will not, at any stage, be required to disclose any personal details of their own medical history or any other personal information. The researcher will refer to the INVOLVE guidelines on the knowledge, skills and experience required to participate in PPI when addressing participant queries²⁹. For example, participants should feel able to be reflective; confident and able to speak up in a group; be respectful of others in the group and have the confidence to question information and explanations supplied by others, who may be experts in their field, and have the ability to take an objective view, seeing issues from all perspectives. We plan to recruit 8–10 older adults, 4–6 family carers and 15 ARC members³⁰, acknowledging that not all ARC members will participate in all workshops/meetings.

Panel involvement

The guidelines for involving older adults in research will be followed throughout the course of the study³¹ in conjunction with INVOLVE principles for partnership frameworks. The following guidelines for involving older adults in research will be adhered to:

- Acknowledge research as a iterative process (the PPI panel of older adults will have input throughout various research projects at different stages of the research process)
- Provide training if required in order for older adults to participate in the research studies⁷
- Clarify roles and determine levels of involvement to manage expectations
- Communicate effectively and be respectful of language difficulties

- Appreciate different expectations between academics, PPI panel of older adults and CDA students
- Acknowledge the concept of equal but different research partners²⁰.

We will consider specific issues identified in the literature on how to engage/collaborate with older people including:

- In any setting, family caregivers (defined to include family, friends, and other social support systems) play an important role in engaging and empowering older adults within the community
- Engagement opportunities need to be flexible (e.g., location, time, type)
- Incentivising engagement for researchers, patients and the public (financial and otherwise) may be necessary
- The education and training of citizens, health and social care providers, and researchers on engagement practices
- Patient-centered care approaches should consider the specific needs of individuals living with frailty including end-of-life care and advanced care planning
- Influencing policy can occur in many ways including participating at institutional, regional, provincial or national committees that relate to health and social care.
- Ensure representativeness and diversity while acknowledging that there is no single blueprint for involvement, as research involves working with a diversity of perspectives³².

Workshops/Meetings

A series of workshops involving the PPI panel of academic researchers from the ARC, older adults and family carers will be scheduled four times per year commencing in February 2020. The workshops will be approximately of 2 hours duration. The PPI group of older adults will have an active role at all stages of the research process for the 'Right Care' programme, ensuring that stakeholders are meaningfully engaged at all relevant stages of the research process, particularly in identifying knowledge and action priorities for each of the 'Right Care' doctoral projects, and interpreting and disseminating findings.

An initial meeting will consist of building a rapport with the members²⁸ and will be chaired by the authors (MC, KR, JS). The facilitators will set the context to the event by describing the aim of the meeting and providing a clear description of the Right Care programme. The principles of a World Café²⁹ and ground rules for participation will be discussed. Participants will be invited to discuss a number of issues relating to the Right Care programme. During the four meetings over the course of a year, participants will take part in a variety of activities over a period of time to support the Right Care CDA students. Participants may be asked for their expertise for a number of

projects including developing consent forms for recruitment in a trial; the development of lay summaries of the projects; assistance with the feasibility of the content of a pilot trial and the most appropriate method of dissemination of key research findings.

A number of interim reflexive meetings will be conducted throughout the year and records of interim reflective meetings will be collected. All correspondence, minutes of the meetings and other documents used during consultation activities will be logged.

A sample of a proposed participatory approach to engaging our PPI group as research partners, the World Café approach, is outlined below. The methodology is based upon the World Café's seven integrated principles³³.

The World Café Approach

The World Café principles and guidelines emphasise the importance of creating a hospitable environment (i.e. a café-style ambience) where individual and collective knowledge and ideas can be shared. There is no pressure to reach consensus, as diverse perspectives are encouraged and valued.

Process: Participants will be invited to discuss aspects of the proposed intervention. Tables will be covered with white paper 'tablecloths' and participants will be provided with pens and markers, facilitating participants to take notes on the paper tablecloth if they wish. At the end of the 'table' discussion, participants will rotate to another table as a group to discuss a different aspect of the proposed intervention. Participants will self-facilitate their own discussions, reinforcing the view that there is no hierarchy in the group. Self-recording will be used to allow less confident participants to draw or write their contribution. Facilitators at each table will ensure the write-up of notes resulting from each group discussion.

Co-analysis: After all groups have rotated around all tables, knowledge from all the discussions will be shared with the full participant group. The café facilitators will facilitate the summary and co-analysis of the responses. Participants will then be provided with sticky, coloured paper dots and each participant will have the opportunity to vote, e.g. for their top three responses to each question.

One-to-one interviews

All PPI panel members will be invited to complete a one-to-one semi-structured interview either over the phone or in person 12 and 24 months after the panel is formed. The panel members will be questioned as to their experiences of the research partnership. Specific research questions regarding each Right Care PhD project will allow combining PPI with qualitative research²⁸. The interview will explore similar topics as investigated in the World Café groups with the addition of prompts and follow up questions. Interviews are anticipated to last between 40 and 60 minutes, will be audio-recorded electronically (with the written consent of the participant) and transcribed in full.

Data analysis

Data transcription, analysis, interpretation and write-up will be carried out by the first author (MC) and the lead author (KR). Efforts will be made to ensure that both authors do not use leading language during data collection or shared personal experiences while maintaining a compassionate and positive attitude. The authors will strive to maintain a neutral and unbiased perspective during the analysis and interpretation of the data.

Transcribed 1:1 interview recordings and transcribed World Café group notes will be entered into the qualitative data analysis software NVivo 12 Pro. A descriptive thematic approach to data analysis will be employed to provide a rich and detailed account of the data. An inductive approach to analysis will be undertaken linked to the research project aims. The six stage guide to thematic analysis described by Braun and Clark³⁴ will be adhered to: 1) familiarization with the data through repeated reading; 2) identification of initial codes; 3) sorting of codes into potential themes; 4) review and discussion of themes by the two researchers to ensure internal homogeneity and external heterogeneity; 5) naming and definition of themes; 6) final analysis and generation of underlying story linking the themes. Additionally, there will be have a member checking stage where the codes and themes will be discussed with representatives from the PPI panel of older adults.

Ethical approval

PPI does not, in and of itself, require ethical approval. If, however, the PPI process is evaluated and the participants transcend their roles as co-researchers to become sources of data, then ethical approval is necessary³⁵. Our participatory research approach is at the interface between PPI and qualitative research and the principles do not account for ethical approvals which might be required when there is such overlap. Therefore, we considered it necessary to obtain approval from a Research

Ethics Committee to ensure that our approach is consistent with the Helsinki declaration and not over-burdening service users³⁶. The University of Limerick, Education and Health Sciences (EHS) Research Ethics Committee (2019_10_12_EHS) approved the study (10th October 2019). This study is funded by the Health Research Board (HRB) and the Health Research Institute (HRI), University of Limerick (UL) and will be conducted between November 2019 and October 2022.

Discussion

Population ageing is an international priority with a urgent need for high quality multidisciplinary research to inform ageing policy³¹. PPI is increasingly recognised as an integral part of the research process²¹ with numerous positive impacts throughout the research process^{6,8}. To ensure the relevance of research outcomes, it is essential that the views and experiences of older people are taken into account when designing research³⁷. The available scant literature on PPI involving older people indicates that there are many benefits and challenges of engaging older people in the research process, but challenges can be overcome. Insufficient published examples of how to conduct effective PPI with older people exist. This paper describes the methodological approach adopted to recruit and establish a PPI panel of older adults, family carers and academic researchers and our plans for describing the process and evaluating its impact on the research panel.

Data availability

No data are associated with this article

Acknowledgements

The authors wish to thank Edel Murphy, Programme Manager at PPI Ignite @ NUI Galway for her help with initial discussions regarding the formation of a PPI panel.

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Open Peer Review

Current Peer Review Status:



Version 1

Reviewer Report 27 March 2020

<https://doi.org/10.21956/hrbopenres.14065.r27201>

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Summary

The study protocol by Conneely *et al.* (2020), proposes to establish a public and patient involvement (PPI) panel consisting of older adults, family carers, and ageing research academics to address the need to include the perspective of older adults in applied health research. The aim of the study is to describe setting up a PPI panel and to evaluate the impact of membership on all members. The PPI panel meetings will be conducted in the “world café” style and the authors will conduct semi structured interviews after 12 and 24 months. Thereafter, an inductive thematic analysis will be conducted on all available data including workshop and individual interview data.

General comment

Although the study is about evaluating PPI impact and the authors describe the gold standard for involvement as having PPI onboard from the get-go, there is no PPI involvement in the current proposed evaluation study. It would be beneficial to include the authors’ considerations and justifications for this in the paper. This would fit in either the methods or discussion, depending on how the authors wish to present it.

Introduction

There appears to be a need in the research community to on one side evaluate the contribution public and patients make to research although they clearly are stakeholders, while on the other there is no such need as this is not done for other stakeholders such as the research fellow or statistician. It would be good if the authors could mention this duality somewhere in the paper. It could be early in the rationale for doing the study, or the Discussion in recognition of the different views.

Given the increase in the healthy ageing population and the increasing number of older adults identifying as regular health service-users, it has become important to involve the older generation and provide them with an opportunity to shape decisions which may ultimately affect the healthcare that they receive. For this reason, the authors should be commended for this timely intervention. However, it may be more

appropriate to highlight the need to involve older adults in a more positive light at the beginning of the article: rather than describing older adults as a burden for the healthcare system, it is an opportunity to increase representation of the ageing population. This would harmonise with the content outlined at the beginning of the discussion session, where the authors describe population ageing as an international priority and an older PPI panel as an integral part of the research process.

Methods

The authors should be clearer on exactly *how* they will consider specific issues identified in the literature on engaging older adults. While it is suggested that they will attempt to address these issues, it would have been helpful to highlight how each issue will be addressed with the study design/methods outlined. For example, when conducting one-to-one interviews, the authors should indicate whether they will be flexible to adapting the location of the interviews to meet the older adults' needs. It would also be helpful to highlight a justification for the timepoints of conducting these interviews (12 and 24 months). It may be worth considering an early 6 month data collection period to establish first impressions of the formation of the PPI. This would allow researchers to compare early vs. late attitudes, and subsequently identify any barriers and facilitators that may change overtime.

The World Café Approach is an interesting method of collecting data. The authors should consider recording individual group tables to capture valuable data which may be discussed but not written on the white paper tablecloths.

Please provide either a justification or the considerations of the team when deciding on the number of people from different groups to be recruited for the panel. Although not all ageing researchers will attend every meeting there might be drop-outs etc in the older adult group or family carer group which might make balancing membership tricky. This information will also be of great help to researchers looking to this protocol for guidance on setting up a similar PPI panel.

There is no record of any practical considerations for involvement of older adults e.g. if panel members withdraw or consideration of how to make involvement 'easier' for this population e.g. by providing documents in larger font, having meetings in a space where background noise will not be an issue (or even provide an audio induction loop). Any such provision is likely to help 'recruitment' and continued panel membership. The easiest way to address this would be to check with interested prospective panel members what their needs are. This might be a matter of course for the authors in which case a mention will be helpful to other researchers looking for guidance. In case of withdrawals – will members be replaced or how many members need to withdraw before replacements will be considered?

It is a complex study and it would be good if the authors would help the reader more so they are better able to distinguish between the PPI panel evaluation study and the PPI panel activities while making clear that all PPI panel outputs contribute to the evaluation study. Particularly the section on 'One-to-one interviews' is currently difficult to follow and we think it would be helpful to give more descriptive details of the approach. The authors should also consider describing the approach used, just a short description, earlier in the methods, to help prepare readers.

The authors use the terms 'involvement', 'engagement' and 'participation' seemingly interchangeably which can be confusing when the study is specifically about involvement. It would be good if the authors would review the use of the other terms (engagement and participation) for this reason. For example page 5, first paragraph – reference is made to 'engagement' throughout the points.

Data analysis

On page 6, in the section on 'Data analysis' the authors state:

"The authors will strive to maintain a neutral and unbiased perspective during the analysis and interpretation of the data." This is ambitious and strictly speaking not possible. Some possible biases will have to be acknowledged e.g. research colleagues are panel members. One way of dealing with this would be to have someone independent of the study do the analysis or to have two people look at the data independently and then come to an agreement if there are discrepancies between them. There are likely to be other additional options which the authors might prefer.

Data availability

In the section on data availability it would be good if the authors could clarify whether there is a plan for the data from the study to be made available for secondary analysis and how requests will be dealt with.

Other small observations:

- Page 4, paragraph on 'Panel Involvement', there is a space too much at the end of the following sentence:
"The guidelines for involving older adults in research will be followed..."
- Page 5, first bullet point, the abbreviation "CDA" has not been defined previously.
- Page 6, 2nd paragraph, the following sentence does not make sense:
"Additionally, **there will be have** a member checking stage where the codes and themes will be discussed with representatives from the PPI panel of older adults."
- Page 6, Discussion paragraph, the following sentence is confusing:
"Insufficient published examples of how to conduct effective PPI with older people exist."

Is the rationale for, and objectives of, the study clearly described?

Yes

Is the study design appropriate for the research question?

Partly

Are sufficient details of the methods provided to allow replication by others?

Partly

Are the datasets clearly presented in a useable and accessible format?

Not applicable

Competing Interests: No competing interests were disclosed.

We confirm that we have read this submission and believe that we have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 30 January 2020

<https://doi.org/10.21956/hrbopenres.14065.r27084>

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? **Éidín Ní Shé** 

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This is a well written and very welcome protocol outlining an evaluation proposal to capture learnings of the establishment of a PPI panel involving older people and family carers.

My only reservation is to request clarity from the team on the following:

- What involvement has occurred with older people and family carers on the establishment of the panel and the proposed evaluation as outlined?
- What will the team do if members recruited do not agree with the evaluation as proposed?
- Who holds the power in understanding and interpreting the data? How will members of the PPI panel be supported if they want to be involved in analysis?
- What strategies have the team devised if members of the PPI panel object to having their sessions recorded?
- How will the knowledge created be shared with PPI panel members?

Minor comment:

First paragraph: Overall this opening paragraph from my readings seems to place blame on our older population for being a burden on the health services: "As older adults bear the greatest burden of disease, they account for the greatest proportion of healthcare use" - where is the evidence for this?

Our ageing population it can be argued is the result of advances in our health system a point that should be celebrated. This shift points to the need to rethink the reconfiguration of our services and enabling older peoples involvement in what they want should be at the core of this shift. I would suggest a reframing of this opening paragraph.

Is the rationale for, and objectives of, the study clearly described?

Yes

Is the study design appropriate for the research question?

Partly

Are sufficient details of the methods provided to allow replication by others?

Partly

Are the datasets clearly presented in a useable and accessible format?

Yes

Competing Interests: I am part of the UCD PPI ignite program that receives funding from the health research board: Health Research Board Ireland [PPI-2017-004], HRB PPI Ignite Award.

Reviewer Expertise: Health Systems, Co-Design, Public and Patient Involvement.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.
