PEER REVIEW HISTORY

ARTICLE DETAILS

TITLE (PROVISIONAL)	IMPAACT: IMproving the PArticipAtion of older people in policy decision-making on common health CondiTions:A study protocol
AUTHORS	Ambagtsheer, Rachel; Hurley, Catherine; Lawless, Michael; Braunack-Mayer, Annette; Visvanathan, Renuka; Beilby, Justin; Stewart, Simon; Cornell, Victoria; Leach, Matthew; Taylor, Danielle; Thompson, Mark; Dent, Elsa; Whiteway, Lyn; Archibald, Mandy; O'Rourke, Hannah; Williams, Kathy; Chudecka, Agnieszka

VERSION 1 – REVIEW

REVIEWER	Stapleton, Tadhg Trinity College Dublin
REVIEW RETURNED	06-Jun-2023

GENERAL COMMENTS	This is an interesting topic and methodological approach. With regard to the methods section I think you could give greater detail on the proposed recruitment process: Phase 1 Citizens Juries. The initial steps of the recruitment to the citizens juries are not outlined. How, and via what mechanisms, are the potential jury members notified of the project before they can express an interest in participating? The inclusion criteria for the juries is not outlined? Recruitment is not fully clear, are there two potential groups of participants – jurors and witnesses? It appears this may be the case, 'witnesses' with lived experience of the conditions (CVD, Diabetes, frailty, dementia) or their proxies will be recruited by the project management team – but this process for recruitment of witnesses is not outlined? Phase 2 Roundtables. Appears there will be two roundtables, both will be held over 2 days on the topic of 'screening for common health conditions in the community'. It is not fully clear if these round tables will only focus on the 4 areas outlined in phase 1 (CVD, Diabetes, frailty, dementia), and will all 4 conditions (that would presumably require different screening processes and procedures) be covered in each of the two roundtable sessions? Recruitment of participants to the roundtables is not clearly outlined, how will they be recruited, where will they be recruited from etc? mentions that they will be recruited purposively via a direct approach – does this mean that only people known to the researchers will be approached? Phase 3 Co design phase.

	Will include six consumer co-researchers who will be selected from participants in the earlier phases (but as per earlier comments, this initial recruitment is not fully clear). Analysis An overall qualitative descriptive approach is proposed to analyse the collective findings. Unsure if there is any quantitative element to the data gathered in the three phases, for example rankings, ratings, voting etc for any sort of consensus formation that would lend itself to some quantitative analysis?

REVIEWER	Huijsman, Robbert Erasmus University Rotterdam, Health Policy and Management
REVIEW RETURNED	28-Jun-2023

GENERAL COMMENTS	This is a protocol paper, so some items above are not applicable (N/A). Although the study has already been started in November 2022, I would suggest to give some more detailed clarifications of the Methods, and the concrete results or products of each of the three phases. First, the main methods of citizen's juries, deliberative methods, different forms and steps of coding and analysing qualitative data, co-research with consumers and production of knowledge translation might not be familiar to a broader audience; so please explain a bit more, also with more recent references. Second, the recruitment and selection process and methods (for jurors on p. 5, lines 25-36; for phase two on p. 6, lines 30-43) are not very concise, especially about the very first step of invitations (how to you acquire a gross lists of possible candidates, which canals do you use to “express potential interest” and send invitations, directly or indirectly via other organisations), the methods and arguments about diversity, what are the exact in- and ex-clusion criteria? What efforts do you really make to reacht and involve the hard-to-reach groups (note: consistently use hyphens)? May participants drop-out, how (and will first answers before dropout be deleted or pertained in the analyses) and how do you prevent it? Do the participants in phase 2 also include patient organisations, informal care givers? And how do you sketch the field of policy makers and care provider organisations to select representatives? I would suggest to add observer-researches with standardized to observations lists to strengthen the qualitative methods. Third, it is very nice and fruitful to make consumers co-researchers (p. 7, lines 13- 18). But how do you train them and how concrete is their involvement, also in decision making (what will you do if the 6 co-researcher hold a different position then the two researchers). And are they really in the co-driver’s seat (for instance, which author in the list of 14 authors is the co-researcher?). Finally, it would strengthen the end of your protocol paper if you explicitly add a paragraph about limitations, risks and possible counter measures to secure a high quality research all along the way of the whole project, with its three phases and possible dependencies between them. I’m also wondering what you will do when the outcomes of your study contradict the official guidelines and care standards. Making that a bit broader, perhaps think not only about rather classis methods of “dissemination” (one way direction of sending your results) but about “implementation strategies” (making it a two ways endeavor to landing of your results).

	I wish you the best with the project itself and especially the way your participatory action and co-design research methods will create high involvement of consumers in the four disease groups.

REVIEWER	Villalobos Dintrans, Pablo Universidad de Santiago de Chile Facultad de Ciencias Medicas, Programa Centro Salud Pública
REVIEW RETURNED	29-Jun-2023

GENERAL COMMENTS	This is an interesting proposal to address several issues concerning older people's health: improving screening for NCDs, ageism, and participation. My main concern is how the authors will balance the participation/ diversity criteria of the juries' composition with the fact they need people that can be able to interpret scientific evidence (presented by the experts witnesses) to make deliberations. I think that could be solved by expanding the discussion on the criteria for selecting the jury. - The reviewer provided a marked copy with additional comments. Please contact the publisher for full details.

REVIEWER	Colombo, Cinzia Ist Ric Farmacol Mario Negri, Public Health
REVIEW RETURNED	04-Jul-2023

GENERAL COMMENTS	The protocol by Ambagtsheer et al. describes a project on a citizens' jury, a deliberative methodology aimed to involve citizens in decisions on areas of collective interest. The project is developed in three phases including other methodologies and stakeholders, such as policy roundtables and co-design in producing knowledge translation resources. Some major revisions are needed to better clarify the project's articulation, rational and planned methods. The required revisions are reported below point by point. -The meaning of the term screening that the authors refer to should be clarified in the introduction. -The protocol refers to a screening for cardiovascular diseases, diabetes, frailty and dementia. What is the rational to propose the screening of these conditions to the jury? The authors should address this point in the Introduction and provide references of the rational of these screenings. -The research questions should be described more specifically in the context of the diseases of interest. For example, which are the screening tests proposed to the jury for each of this screening? -A revision of the abstract is needed to clarify the protocol to the reader: -the introduction should focus on the rationale for addressing the conditions described in the protocol and describe the objective by including all the phases of the project (not just the citizens' jury). - the methods section refers to representatives from health and ageing practice and policy settings: a more specific description might help the reader to better understand which stakeholders will be involved.

	-more specific information on the selection criteria would be also useful for the reader. -methods to reach citizens and other stakeholders should be reported. -The second bullet point in the Strengths and limitations sections is not clear to me. How citizen juries will emphasise the purposive recruitment of older people of diverse backgrounds? -In the protocol, in the methods section, the authors should clarify the methods for reaching citizens and other stakeholders, and their selection criteria, along the different phases. --In the protocol, in the methods section, the questions included in the survey to select eligible participants should be reported. -Finally, the authors should describe the criteria to select experts and the sources of the information pack for participants. I suggest that this protocol be considered for publication, after careful review.

VERSION 1 – AUTHOR RESPONSE

Feedback & reviewer	Response
Reviewer 1, point 1: The initial steps of the recruitment to the citizens juries are not outlined. How, and via what mechanisms, are the potential jury members notified of the project before they can express an interest in participating? (reviewer 1)	We thank the reviewer for bring this clarification to our attention. We have now added/edited the following text to the Protocol under the Methods and Analysis/Study Design/Phase 1 sub-section: “Recruitment into the study will be via self-selection. The opportunity to participate in the study will be promoted to selected community and consumer organisations via electronic newsletters, print flyers and social media posts targeting subscribers/members aged 50+ years in South Australia. Community groups will be selected to target culturally diverse, gender diverse and rural populations. Those participants expressing potential interest in the project will be verbally consented for participation with an initial screening survey, to be administered via telephone. Responses to this survey will be assessed against the inclusion criteria and project requirements and those deemed eligible will be mailed/emailed a Participant Information and Consent form.“

Feedback & reviewer	Response
Reviewer 1, point 2: The inclusion criteria for the juries is not outlined? (reviewer 1)	Apologies for this omission. We have now added a section (same sub-section as the previous edit), which reads as follows: "Inclusion criteria for the Citizens' Juries will be residents of South Australian aged 50 years or over; able to effectively conduct a conversation in English; able to provide fully informed consent. Exclusion criteria for the Citizens' Juries will be: previously or currently employed as a doctor or nurse in general practice; are a close contact of the research team. For individual juries, participants will be excluded if they are a close contact/relation of another participant attending the same jury; and/or diagnosed with the specified condition that is the subject of that jury."
Reviewer 1, point 3: Recruitment is not fully clear, are there two potential groups of participants – jurors and witnesses? It appears this may be the case, 'witnesses' with lived experience of the conditions (CVD, Diabetes, frailty, dementia) or their proxies will be recruited by the project management team – but this process for recruitment of witnesses is not outlined? (reviewer 1)	To clarify, witnesses are not participants, but rather should be viewed as an extension of the research team. To address the Reviewer's comments, we have edited the following text (same sub-section as the previous edit): "Expert and consumer witnesses (consumers with lived experience of the condition and/or their proxies) will be identified directly through the professional networks of the researchers and secured by the Project Management team prior to the commencement of Phase 1 (22)."
Reviewer 1, point 4: Appears there will be two roundtables, both will be held over 2 days on the topic of 'screening for common health conditions in the community'. It is not fully clear if these round tables will only focus on the 4 areas outlined in phase 1 (CVD, Diabetes, frailty, dementia), and will all 4 conditions (that would presumably require different screening processes and procedures) be covered in each of the two roundtable sessions?	Thank-you – we have now added the following clarification under the Methods and Analysis/Study Design/Phase 2 sub-section: Roundtables will focus on all the recommendations collectively emerging from the juries in relation to the four identified health conditions.

Feedback & reviewer	Response
Reviewer 1, point 5: Recruitment of participants to the roundtables is not clearly outlined, how will they be recruited, where will they be recruited from etc? mentions that they will be recruited purposively via a direct approach – does this mean that only people known to the researchers will be approached?	As we have stated in the protocol (see below), we will apply a combination of direct and snowball sampling through our networks and through peak body associations. As the approach implies, this signifies that recruitment will involve a combination of participants both known and unknown to the research team. "We will purposively recruit the desired number of participants via direct approach and/or snowball sampling through the extended networks of the project team, inclusive of letters/emails sent to potential participants and flyers posted in newsletters of peak body associations."
Reviewer 1, point 6: Phase 3 Co design phase. Will include six consumer co-researchers who will be selected from participants in the earlier phases (but as per earlier comments, this initial recruitment is not fully clear).	We thank the Reviewer for their query. This issue has now been addressed in a previous comment.
Reviewer 1, point 7: An overall qualitative descriptive approach is proposed to analyse the collective findings. Unsure if there is any quantitative element to the data gathered in the three phases, for example rankings, ratings, voting etc for any sort of consensus formation that would lend itself to some quantitative analysis?	We thank the Reviewer for their query. As is standard practice for the analysis of citizens' juries, we will be limiting our quantitative analysis to reporting on the number of participants voting for/against each recommendation.
Reviewer 2, point 1: First, the main methods of citizen's juries, deliberative methods, different forms and steps of coding and analysing qualitative data, co-research with consumers and production of knowledge translation might not be familiar to a broader audience; so please explain a bit more, also with more recent references.	In response to the Reviewer's concerns, we have now added a number of supporting references where co-design and knowledge translation are mentioned. We also draw the Reviewer's attention to the Introduction, where we have explained the concept of citizens' juries in depth.

Feedback & reviewer	Response
Reviewer 2, point 2: the recruitment and selection process and methods (for jurors on p. 5, lines 25-36; for phase two on p. 6, lines 30-43) are not very concise, especially about the very first step of invitations (how to you acquire a gross lists of possible candidates, which canals do you use to "express potential interest" and send invitations, directly or indirectly via other organisations), the methods and arguments about diversity, what are the exact in- and ex-clusion criteria.	Please refer to our response to Reviewer 1, points 1 & 2, which directly addresses this question.
Reviewer 2, point 3: What efforts do you really make to reach and involve the hard-to-reach groups (note: consistently use hyphens)?	We have added additional clarifying statements within the protocol relating to this point in response to a question from Reviewer 1. We have specifically targeted community organisations that cater to hard-to-reach-groups (e.g. for example, organisations representing specific ethnic groups) in order to invite their members to express interest in the study.
Reviewer 2, point 4: May participants drop-out, how (and will first answers before dropout be deleted or pertained in the analyses) and how do you prevent it?	We thank the Reviewer for their query. In response, we have now added the following statement under the Methods and Analysis/Participants and study setting sub-section. We would also like to acknowledge that, as much as we can put strategies in place to avoid attrition (e.g. by ensuring that participants are given appropriate recompense for their time), it is not possible to prevent it entirely. Participants will be free to withdraw at any time during the research project without providing an explanation. Participants can ask the researchers to return or dispose of any data collected from them at any time (unless it is not possible to disaggregate their data from the rest of the data, e.g. where a participant has contributed to discussions such as jury deliberations or roundtable proceedings).

Feedback & reviewer	Response
Reviewer 2, point 5: Do the participants in phase 2 also include patient organisations, informal care givers? And how do you sketch the field of policy makers and care provider organisations to select representatives? I would suggest to add observer-researches with standardized to observations lists to strengthen the qualitative methods.	We have now added clarification to this section to respond to the Reviewer comments… as per below. The key policy-makers in this space are drawn from State and Federal government agencies so we have now specified this explicitly. "Consequently, the professional stakeholders identified as a component of this study will include representation from consumers and carers, health and aged care policymakers (State and Federal), general practitioners, practice nurses, geriatricians, allied health practitioners, pharmaceutical companies, private health insurers, and community and aged care providers." We also appreciate the Reviewer's suggestion to add observers and have included this within the section below: "Members of the research team will also be in attendance to observe proceedings and collect observations against a pre-determined template."
Reviewer 2, point 6: it is very nice and fruitful to make consumers co-researchers (p. 7, lines 13- 18). But how do you train them and how concrete is their involvement, also in decision making (what will you do if the 6 co-researcher hold a different position then the two researchers). And are they really in the co-driver's seat (for instance, which author in the list of 14 authors is the co-researcher?).	In response to the Reviewer's concerns, the consumers we engage with will be equal partners in the decision making process – as with all members of the research team, key decisions will be made on a consensus basis. Additionally, an external facilitator with significant experience in co-design processes, who will be cognizant of the need to ensure that consumer viewpoints are heard and respected throughout the process, will facilitate all Phases of the project. Lastly, our consumer co-researcher on the Protocol is Co-researcher Whiteway (13th author). The ordering of the authors on the Protocol reflects the original ordering of the IMPAACT grant submission; as such, Ms. Whiteway, who holds an Associate rather than Chief Investigator role due to her non-academic status under the requirements of the grant, is the first of the Associate Investigators within the co-author list. She has been extensively involved through all phases of grant submission and research design.

Feedback & reviewer	Response
Reviewer 2, point 8: It would strengthen the end of your protocol paper if you explicitly add a paragraph about limitations, risks and possible counter measures to secure a high quality research all along the way of the whole project, with its three phases and possible dependencies between them. I'm also wondering what you will do when the outcomes of your study contradict the official guidelines and care standards. Making that a bit broader, perhaps think not only about rather classis methods of "dissemination" (one way direction of sending your results) but about "implementation strategies" (making it a two ways endeavor to landing of your results).	We acknowledge the Reviewer's point and have now added a Limitations Section to the manuscript. We have also reframed the Dissemination Section to become 'Dissemination and Implementation Strategies', adding some methods here to enable knowledge translation to be more of a two-way process.
REVIEWER 3 My main concern is how the authors will balance the participation/ diversity criteria of the juries' composition with the fact they need people that can be able to interpret scientific evidence (presented by the experts witnesses) to make deliberations. I think that could be solved by expanding the discussion on the criteria for selecting the jury.	To clarify, we do not select the jury based on their ability to interpret scientific evidence (other than a basic ability to communicate in written and spoken English). Rather, it is the joint responsibility of the expert witnesses to ensure that they present evidence in a manner that is accessible to lay people, and of the facilitator to determine if key concepts have been understood or if more time should be allocated to revise key concepts.
Reviewer 4, point 1: The meaning of the term screening that the authors refer to should be clarified in the introduction.	We draw the Reviewer's attention to the following justification provided within the Introduction: "These conditions were chosen as they represent common health conditions experienced by older people, but which have been under-examined through a Citizens' Jury methodology."

Feedback & reviewer	Response
Reviewer 4, point 2: The protocol refers to a screening for cardiovascular diseases, diabetes, frailty and dementia. What is the rational to propose the screening of these conditions to the jury? The authors should address this point in the Introduction and provide references of the rational of these screenings.	To address the Reviewer's comments, we have now added the following statement to the Introduction: "Conditions were selected on the basis of 1) increased prevalence rate with age 2) expert knowledge and specialities of the research team."
Reviewer 4, point 3: The research questions should be described more specifically in the context of the diseases of interest. For example, which are the screening tests proposed to the jury for each of this screening? (	We thank the Reviewer for their question. To clarify, the jury charge focuses on 'screening' as a general concept rather than screening using a specific tool/measure. However, one component of the evidence usually presented to juries is discussion of the screening tests most commonly used to screen for each condition in Australian general practice. To identify the tools that are most appropriate to be presented to jurors, we rely on official clinical guideline/advice published by the peak body for general practice, the Royal Australian College of General Practitioners, as well as advice from our expert witnesses.

Feedback & reviewer	Response
Reviewer 4, point 4: A revision of the abstract is needed to clarify the protocol to the reader: -the introduction should focus on the rationale for addressing the conditions described in the protocol and describe the objective by including all the phases of the project (not just the citizens' jury). - the methods section refers to representatives from health and ageing practice and policy settings: a more specific description might help the reader to better understand which stakeholders will be involved. -more specific information on the selection criteria would be also useful for the reader. -methods to reach citizens and other stakeholders should be reported.	The abstract has now been revised in line with these suggestions. Please note that space limitations do not permit us to provide detailed selection criteria across all Phases of the Project within the Abstract, however this is provided in the main body of the document.
Reviewer 4, point 5: -The second bullet point in the Strengths and limitations sections is not clear to me. How citizen juries will emphasise the purposive recruitment of older people of diverse backgrounds?	We have now reworded the dot point to improve clarity, as shown below: The Citizens Juries will purposively recruit older people of diverse backgrounds and experiences, thereby addressing a common shortcoming of this method of data collection.
Reviewer 4, point 6: In the protocol, in the methods section, the authors should clarify the methods for reaching citizens and other stakeholders, and their selection criteria, along the different phases.	This point has now been clarified in additional text added to the manuscript in response to previous comments raised by the other Reviewers.
Reviewer 4, point 7: In the protocol, in the methods section, the questions included in the survey to select eligible participants should be reported.	We thank the Reviewer for this suggestion. Due to the length of the survey, it is not possible to include the screening questions within the body of the manuscript, however they have been added as a a Supplementary file.

Feedback & reviewer	Response
Reviewer 4, point 8: Finally, the authors should describe the criteria to select experts and the sources of the information pack for participants.	We thank the Reviewer for bringing this point of clarification to our attention, and have added the following text under sub-section Methods and Analysis/Study design/Phase 1 to clarify. "Expert witnesses will be identified through the extended networks of the research team, and will be nationally/internationally recognised experts in their field (with the exception of lived experience witnesses, who will be defined as consumers aged 50 years and over with lived experience of the condition)."

VERSION 2 – REVIEW

REVIEWER	Stapleton, Tadhg Trinity College Dublin
REVIEW RETURNED	13-Dec-2023

GENERAL COMMENTS	IMPAACT: IMproving the PArticipation of older adults in policy decision-making on common health CondiTions: A study protocol. I have reviewed the revised protocol and am satisfied that my previous comments have been addressed sufficiently. Inclusion criteria and recruitment to citizens juries has been clarified. Clarification has been provided that the focus of each of the initial phase 1 juries will be exclusive to each of the 4 conditions (CVD, Diabetes, Frailty, Dementia), and that the subsequent phases 2 & 3 will focus on the collective recommendation emerging from the phase 1 juries. The addition of a Limitations section is very useful and demonstrates awareness and acknowledgement the difficulties associated with this undertaking.