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IMPAACT: IMproving the PARTICipation of older people in policy decision-making on common health ConDiTions:A study protocol

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Note from the Editors: Instructions for reviewers of study protocols

Since launching in 2011, BMJ Open has published study protocols for planned or ongoing research studies. If data collection is complete, we will not consider the manuscript.

Publishing study protocols enables researchers and funding bodies to stay up to date in their fields by providing exposure to research activity that may not otherwise be widely publicised. This can help prevent unnecessary duplication of work and will hopefully enable collaboration. Publishing protocols in full also makes available more information than is currently required by trial registries and increases transparency, making it easier for others (editors, reviewers and readers) to see and understand any deviations from the protocol that occur during the conduct of the study.

The scientific integrity and the credibility of the study data depend substantially on the study design and methodology, which is why the study protocol requires a thorough peer-review.

BMJ Open will consider for publication protocols for any study design, including observational studies and systematic reviews.

Some things to keep in mind when reviewing the study protocol:

- Protocol papers should report planned or ongoing studies. The dates of the study should be included in the manuscript.
- Unfortunately we are unable to customize the reviewer report form for study protocols. As such, some of the items (i.e., those pertaining to results) on the form should be scored as Not Applicable (N/A).
- While some baseline data can be presented, there should be no results or conclusions present in the study protocol.
- For studies that are ongoing, it is generally the case that very few changes can be made to the methodology. As such, requests for revisions are generally clarifications for the rationale or details relating to the methods. If there is a major flaw in the study that would prevent a sound interpretation of the data, we would expect the study protocol to be rejected.

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**IMPAACT: IMproving the ParticipAtion of older people
in policy decision-making on common health ConDiTions:
A study protocol**

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Abstract

Introduction

Rapid population ageing is a demographic trend being experienced and documented worldwide—including Australia—leading to a rising number of people living with common health conditions. While increased health screening and assessment may help mitigate the burden of illness in older people, issues including misdiagnosis and pervasive ageism may affect access to preventative interventions, including screening. This study aims to elicit the values and preferences of evidence-informed older people living in the community on early screening and proactive diagnosis of common health conditions (cardiovascular disease (CVD), diabetes, dementia, and frailty).

Methods and analysis

This study will be conducted in three phases – 1) Citizens' Juries, 2) Policy Roundtables and 3) Production of Knowledge Translation resources. Firstly, older people aged 50+ (n= 80), including those from traditionally hard-to-reach and diverse groups, will be purposively recruited to four Citizen Juries. Secondly, representatives from health and ageing practice and policy settings (n=40) will be purposively recruited for two Policy Roundtables. Finally, two researchers and six purposively recruited consumers will co-design Knowledge Translation resources. Data collected will include the findings from the Citizens' Juries and Policy Roundtable deliberations recordings and researcher notes. Qualitative data analysis (thematic analysis) will be performed on documentation and transcripts.

Ethics and dissemination

Ethical approval has been obtained through the Torrens University HREC. Participants will give written informed consent. Findings will be disseminated through development of a policy brief and lay summary, peer-reviewed publications, conference presentations and seminars.

Strengths and Limitations

- The use of deliberative methods to involve older people (particularly those from diverse, hard to reach groups) and service providers/policymakers in resolving questions around the use of screening among older people.
- The Citizens Juries will emphasise the purposive recruitment of older people of diverse backgrounds and experiences, thereby addressing a common shortcoming of this method of data collection.
- A limitation - the separation of each common health condition into distinct individual juries (rather than considering them together) - was based on the need for clarity and simplicity when presenting the evidence base to jurors.

Introduction

Across the globe, societies are experiencing a period of rapid and unprecedented population ageing (1). Consequently, there has been a growing focus on increased access to primary health care for older people, including preventative screening and assessment. Misdiagnosis of diseases and conditions is common among older people, with serious consequences for them and the health systems they access (2). A systematic review by Skinner and colleagues revealed rates of over- and/or under-diagnosis of at least 5-10% among persons aged 65+ years, for various common health conditions, including cardiovascular disease (CVD) (heart failure, stroke, acute myocardial infarction), dementia and diabetes (2). Over-diagnosis too is problematic for older people. A range of over-diagnosis-related harms have previously been identified in the literature, including self-stigma due to incorrectly diagnosed mild cognitive impairment in dementia prevention (3). Statistics of this nature indicate a critical and urgent need to strike the right balance between over- and under-diagnosis of various common health conditions, highlighting the importance of appropriate and timely screening.

Clearly, if older people are to receive appropriate, acceptable and timely preventative advice on screening and assessment for common health conditions, then critical attention needs to be given to engaging providers, older people and policymakers in evidence-informed discussions about screening and treatment. Deliberative methods (i.e., approaches that bring together a diverse group of community members to engage with evidence on a topic of public concern) provide an opportunity for effective community engagement in evidence-informed policy dialogues on screening. Health and care policymakers are increasingly turning to deliberative and inclusive methodologies to address public policy questions such as whom to screen, and when. A key advantage of deliberative methods is that they allow members of the public to participate directly in key decisions and policies that will impact their daily lives, answering a need that has received growing acknowledgement from policymakers, scientists, and consumers alike (4).

A deliberative method that has been widely applied in health policy development is citizens' juries (5). Citizens' juries are groups inclusive of members of the public, purposively selected to represent their community, and who are tasked with deliberating on a jury charge (research question) on a matter of public interest (6). Jurors are usually provided with access to supporting evidence-based resources and expert witness testimonies to support their deliberations and asked to deliver a verdict or make recommendations at the jury end (6). However, few citizens' juries have addressed the views of older people on screening for common health conditions to date. Of studies we identified that have canvassed older people's views on screening, most have focused on cancer screening (7-13), with none on diabetes, CVD, or frailty, and a small number on dementia (14-16), highlighting a critical knowledge gap. Additionally, only one-third of all studies identified used a formal Citizens' Jury format to arrive at their findings (only one of these focusing on dementia), with the remainder using a variety of other less rigorous deliberative methods. A number of studies acknowledged a lack of diversity among participants as a limitation (7,10,11). Lastly, only three of the studies were conducted within Australia (8,10,14). Our study aims to address this critical gap, by canvassing the evidence-informed views of older people on screening for several key common health conditions within the community.

Aims and objectives

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3 The aim of the ‘IMproving the PARTicipAtion of older Australians in policy decision-
4 making on common health CondiTions’ (IMPAACT) project is to elicit the values and
5 preferences of evidence-informed older people, including those within under-
6 represented groups, on early screening and diagnosis of several common health
7 conditions (CVD, diabetes, frailty, dementia) within the community. These conditions
8 were chosen as they represent common health conditions experienced by older people,
9 but which have been under-examined through a Citizens’ Jury methodology.
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12 Project objectives include:

- 13 1. To generate recommendations from diverse groups of older people on screening for
14 selected common health conditions within the community via a citizens’ jury
15 process;
- 16 2. To obtain feedback from a diverse range of professional groups, older people, and
17 industry representatives on the jury findings; and
- 18 3. To co-design (together with a diverse group of older people) Knowledge Translation
19 resources to facilitate the implementation of key recommendations and feedback on
20 screening for common health conditions into research, policy, and practice.
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23 **Methods and Analysis**

24 ***Participants and study setting***

25 We have elected to set an age limit (50 years and over) for the older population included
26 within our study because this is the population affected by screening for the conditions
27 in question within General Practice. We will seek to recruit participants into the study
28 across a wide range of age groups within this category. We will also purposively recruit
29 participants to reflect diversity with respect to gender, socio-economic status/income,
30 location, Culturally and Linguistically Diverse (CALD), Gender and Sexually Diverse
31 (GSD), functional ability and frailty level.
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34 Australia has a population of 25 million people, of whom an estimated 9.0 million (35%
35 of the total population) are aged 50 years and over (17,18). The Australian health care
36 system is a federated system with responsibility for funding and provision split between
37 the National and State level governments. A universal health care scheme (Medicare)
38 provides the main source of funding for hospital services, General Practice and
39 medicines (19).
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42 Our study is set within the state of South Australia. South Australia offers particular
43 advantages for a study seeking to reflect diversity among its participants, as it is a state
44 characterised by significant heterogeneity with respect to population density,
45 accessibility/remoteness, and health service distribution (20).
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50 ***Study design***

51 We will apply a participatory design conducted in three phases, which are aligned with
52 the study objectives stated above:
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- 54 • Phase 1: Conduct Citizens’ Juries on screening for common health conditions
55 within the community,
- 56 • Phase 2: Conduct Policy Roundtables on screening for common health conditions
57 within the community, and
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- Phase 3: Co-design Knowledge Translation (KT) resources for input into research, policy and practice.

The study will be carried out between November 2022 and January 2025.

Phase 1: Citizens' Juries on screening for common health conditions within the community

We will conduct four Citizens' Juries with older people aged 50 years and above, each one specific to a different common health condition (i.e., CVD, diabetes, frailty, or dementia). The sample size for the juries will be based on prior research, suggesting approximately 20 participants in each group (21). All participants will provide fully informed consent.

The jury charge (research question) is shown in Table 1 and has been developed with reference to other Citizens' Juries conducted within Australia (5,22). Jury charges will be adapted to reflect the nominated condition for each respective jury and will be refined in consultation with the Project Advisory Group before commencement of the juries. A depiction of the Phase 1 Citizens' Jury process is shown in Figure 1.

Recruitment of jurors

Recruitment into the study will be via a two-step process. In the first step, 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 invited to the second step. Ineligible participants will be informed by email or post. A Participant Information and Consent forms will be mailed or emailed to the participant's specified mailing address as part of the second step in the recruitment process. Participants will be given two weeks to consider participation, after which time they will followed up with a phone call. Those willing will provide written informed consent for participation in Phase 1.

Citizens' Jury process

We will ask jurors to attend a two-day workshop. In the week prior to attending the workshops, jurors will receive an information pack containing logistical details for the workshop, guidance as to what to expect regarding the jury process, guidelines for participation, agenda and objectives of the workshop, introductory background materials to support the expert witness testimonies, questions for consideration by participants, and an evaluation sheet (5). They will also be asked to complete a short survey with demographic details. An independent facilitator will facilitate all juries.

The Citizens' Juries will follow standard procedures for this method (22). Expert and consumer witnesses (consumers with lived experience of the condition and/or their proxies) will be identified and recruited by the Project Management team prior to the commencement of Phase 1 (22).

On the first day, jurors will hear live expert witness evidence, which will be followed by an interactive session with the witness panel to allow jurors to ask questions. On the second day, the jury will have allocated time to discuss the jury charge, formulate recommendations, and conduct discussions within their jury group. During the closing session of the jury, jurors will be asked to vote on the recommendations generated by

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3 the group. Voting will be conducted in an open manner and juror votes will be known to
4 the rest of the group.
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6 At the conclusion of each jury, participants will participate in a short debriefing session
7 and complete a project-specific evaluation form (5). The form will include Likert-scale
8 ratings (1-7 scale) relating to juror satisfaction with the jury process, including elements
9 such as degree of satisfaction with background material provided, expert witness
10 testimony and time commitment required, along with a small number of open-ended
11 questions to allow jurors to make explanatory comments or suggestions. The evaluation
12 data will be used iteratively to improve the implementation of the juries as they
13 progress, and for overall assessment of the feasibility of our approach at project close.
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16 ***Phase 2: Policy Roundtables on screening for common health conditions*** 17 ***within the community***

18 Following the Citizen's Jury process, two Policy Roundtables will be convened (23) on
19 the theme of '*Screening for common health conditions in the community*'. Roundtables
20 are an engagement tool designed to bring together a range of stakeholders to converse
21 on a topic of interest, the outcome of which should be improved representation of the
22 viewpoints of those who have stakes in the issue under consideration (24). The
23 roundtables will each run over two days. The aim of the roundtables will be twofold: 1)
24 encourage evidence-informed dialogue between researchers, older people and policy-
25 makers on the subject of screening for common health conditions; and 2) support the
26 translation of findings from the Citizen's Jury process into research, policy and practice.
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30 *Recruitment of participants*

31 We will recruit approximately 20 stakeholders to attend each roundtable (2
32 representatives from each profession and stakeholder group), to be held in person (or
33 online if COVID-related restrictions are in force). One of the key considerations in
34 identifying participants is the question of who would potentially benefit from or be
35 harmed by the implementation of screening. Aside from older people and their carers, it
36 is also important to recognise the commercial interests behind some of the moves
37 towards earlier screening. Consequently, the professional stakeholders identified as a
38 component of this study will include representation from health and aged care
39 policymakers, general practitioners, practice nurses, geriatricians, allied health
40 practitioners, pharmaceutical companies, private health insurers, and community and
41 aged care providers. We will recruit the desired number of participants purposively via
42 direct approach and/or snowball sampling.
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46 *Policy Roundtable process*

47 Roundtable participants will be sent an information pack two weeks before the event,
48 inclusive of a short survey including demographic information. Each roundtable will be
49 jointly co-chaired by a representative from the research team and a consumer
50 representative (23), while an experienced external facilitator will facilitate group
51 discussions. An invited external speaker will present an overview of the issue of
52 misdiagnosis of common health conditions among older people within Australia. Day 1
53 sessions will include a contextual overview of each of the four conditions analysed in
54 Phase 1, along with presenting key findings from the condition-specific citizens' juries.
55 Day 2 will focus on deliberative group discussions to consider the findings and generate
56 feedback. A representative from each group will provide detailed feedback to the main
57 group. Each day will conclude with a summary of the main discussion points. At the end
58 of Day 2, participants will be given a short evaluation form to complete.
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Phase 3: Consumer co-design of Knowledge Translation resources: policy brief and lay summary

The aim of the consumer co-design process will be to develop two Knowledge Translation resources: 1) a policy brief that synthesises the recommendations from the Citizens' Juries and feedback from Policy Roundtables, and 2) an accompanying lay summary targeted at older people and their families. Where consumer and/or professional feedback obtained as a result of the jury and roundtable process differs from existing clinical guidelines, these differences will be retained and highlighted within the resources as areas requiring further research and consultation. The co-design team will comprise of two researchers and 6 consumer co-researchers (purposively selected with respect to age, gender, income level, and ethnicity). Recruitment of participants will be conducted by approaching participants who indicated willingness to take part in further research from the earlier phases and who meet the needs of this phase as determined by the research team. The team will be responsible for defining the target audience/s for the recommendations, identifying key messages for translation, designing appropriate knowledge translation resources (final format/s to be decided by the co-design team) and developing action and communication plans for dissemination.

We will provide co-design team participants with background material on the aims of the co-design process, methodology, and study findings two weeks before Phase 3 commencement. Participants will attend three meetings of two hours' duration, an approach which proved feasible in our previous consumer co-design work (25,26). The meetings will be held face-to-face within Adelaide (virtual attendance to be offered if required). An external facilitator will facilitate all co-design meetings. At the initial meeting, the co-design team will be presented with the summary of findings from Phases 1 and 2. At the second and third meetings, the co-design team will be shown interim drafts of the emergent knowledge translation resources and asked to provide comment. A small group of stakeholders will review the draft/s before finalisation and provide any further feedback required. The final meeting will also include a reflection on the co-design process among participants and discussion of future correspondence.

Patient and public involvement statement

Our study will be grounded in participatory action research and co-design principles (27), with the intent to meaningfully engage older people at all stages, beginning from project conceptualisation (with the appointment of an older person with extensive experience of co-design processes, as a co-researcher on our project team), through to the design, delivery, and ultimately, dissemination of results. Recruitment of participants from diverse backgrounds will be aided by researcher networks and the involvement of a number of aged care and community professionals and services.

Data collection and analysis

A Hansard reporter will transcribe all juries (Phase 1) and roundtables (Phase 2), with backup audio recording using a password-protected late model iPhone. Research team members will also take field notes during the sessions and include these within the analysis, together with participant feedback and evaluations. Documentation used within the workshops will also be analysed. Data will be uploaded and analysed within the latest versions of the Excel and NVivo software packages.

We will adopt a qualitative descriptive approach to analyse data (28), with the aim of understanding the key justifications for the recommendations put forward by jurors and

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3 participants. Two independent analysts will first familiarise themselves with the
4 transcripts through repeated readings. The unit of analysis will be at the individual
5 jury/roundtable level. We will code the transcripts and additional documentation
6 inductively according to thematic analysis principles, cross-verifying codes to ensure
7 rigour. We will organise codes into categories, sub-categories and candidate themes,
8 refining these in discussion with a third analyst (29).
9

10 **Ethics and Dissemination**

11 *Ethical and safety considerations*

12 We will support all participants throughout the project to give informed consent, either
13 in written form or verbally (video-recorded), dependent on context. Participants will be
14 anonymous in all reporting of the different phases of the study unless they wish to be
15 identified, for example as co-designers of the resources in Phase 3. Consumer
16 participants in any Phase of the research will be paid a research honorarium for their
17 time.
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19 The Torrens University Human Research Ethics Committee (HREC) (approvals 0206,
20 0238 and 0253) has approved the ethical aspects of this research project.
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22 *Dissemination*

23 Dissemination of the research findings will consist of multiple strategies within an
24 integrated knowledge translation (KT) strategy (30). National and international
25 platforms and websites, newsletters for both professionals and older people, journal
26 publication, conferences and a cross-national seminar series will be employed as
27 channels for dissemination.
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32 **Contributors**

33 All authors contributed to the conception and design of the study. CH and RA drafted
34 the manuscript. All authors critically reviewed the manuscript. All authors had final
35 responsibility for the decision to submit for publication.
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50 **Patient consent for publication:** Not required

51 **Provenance and peer review:** Not commissioned; externally peer reviewed
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Table 1: Jury Charge

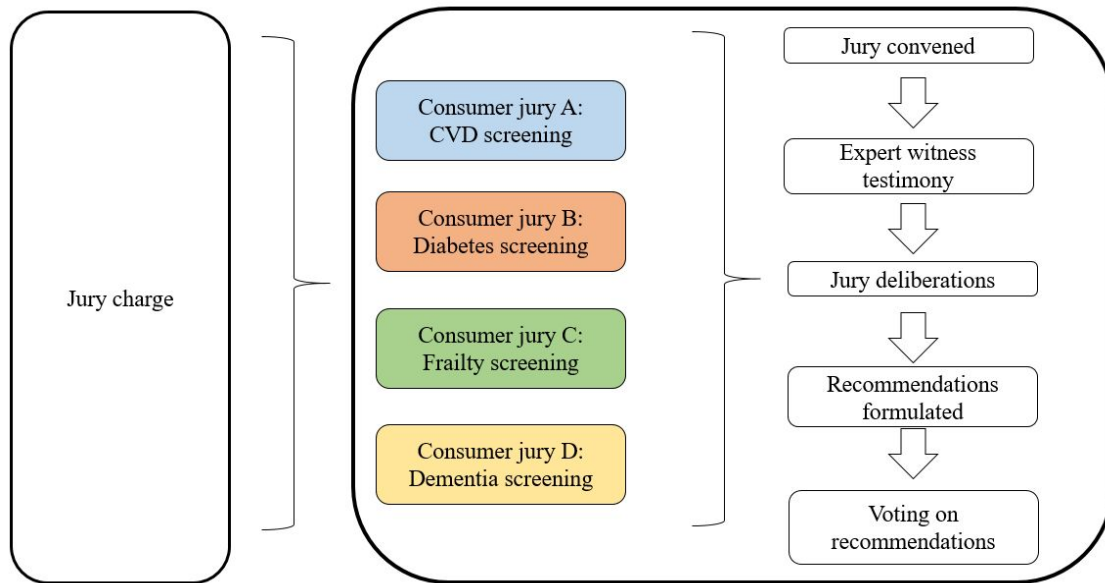
The jury charge (i.e. the research question the jury will be asked to consider) will be adapted for each of four juries, each focusing on a different age-related condition (cardiovascular, diabetes, frailty, dementia). The jury charge is:

- Under what circumstances should screening be provided for this condition within general practice?

Further questions for the jury to consider over the course of the two day program and which may guide the development of recommendations include:

- What benefits and harms might arise from screening?
- How could harms be addressed?
- Should there be age limits on screening?/When should screening be provided?
- Who should provide screening?
- Where should screening be provided?

Figure 1: Overview of Citizens' Jury process



Source: Adapted from Crotty et al 2020¹⁹

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IMPAACT: IMproving the PARTICipation of older people in policy decision-making on common health ConDiTions:A study protocol

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**IMPAACT: IMproving the PARTICipATION of older people
in policy decision-making on common health ConDiTions:
A study protocol**

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Abstract

Introduction

Rapid population ageing is a demographic trend being experienced and documented worldwide. While increased health screening and assessment may help mitigate the burden of illness in older people, issues such as misdiagnosis may affect access to interventions. This study aims to elicit the values and preferences of evidence-informed older people living in the community on early screening for common health conditions (cardiovascular disease (CVD), diabetes, dementia, and frailty). The study will proceed in three Phases: 1) generating recommendations of older people through a series of citizens' juries; 2) obtaining feedback from a diverse range of stakeholder groups on the jury findings; and 3) co-designing a set of knowledge translation resources to facilitate implementation into research, policy, and practice. Conditions were chosen to reflect common health conditions characterised by increasing prevalence with age, but which have been under-examined through a Citizens' Jury methodology.

Methods and analysis

This study will be conducted in three phases – 1) Citizens' Juries, 2) Policy Roundtables and 3) Production of Knowledge Translation resources. Firstly, older people aged 50+ (n= 80), including those from traditionally hard-to-reach and diverse groups, will be purposively recruited to four Citizen Juries. Secondly, representatives from a range of key stakeholder groups, including consumers and carers, health and aged care policymakers, general practitioners, practice nurses, geriatricians, allied health practitioners, pharmaceutical companies, private health insurers, and community and aged care providers (n=40) will be purposively recruited for two Policy Roundtables. Finally, two researchers and six purposively recruited consumers will co-design Knowledge Translation resources. Thematic analysis will be performed on documentation and transcripts.

Ethics and dissemination

Ethical approval has been obtained through the Torrens University HREC. Participants will give written informed consent. Findings will be disseminated through development of a policy brief and lay summary, peer-reviewed publications, conference presentations and seminars.

Strengths and Limitations

- The use of deliberative methods to involve older people (particularly those from diverse, hard to reach groups) and service providers/policymakers in resolving questions around the use of screening among older people.
- The Citizens Juries will purposively recruit older people of diverse backgrounds and experiences, thereby addressing a common shortcoming of this method of data collection.
- A limitation - the separation of each common health condition into distinct individual juries (rather than considering them together) - was based on the need for clarity and simplicity when presenting the evidence base to jurors.

Introduction

Across the globe, societies are experiencing a period of rapid and unprecedented population ageing (1). Consequently, there has been a growing focus on increased access to primary health care for older people, including preventative screening and assessment, with screening here intended to refer to the object of identifying those who have a disease among those who have no symptoms of that disease (2). Misdiagnosis of diseases and conditions is common among older people, with serious consequences for them and the health systems they access (3). A systematic review by Skinner and colleagues revealed rates of over- and/or under-diagnosis of at least 5-10% among persons aged 65+ years, for various common health conditions, including cardiovascular disease (CVD) (heart failure, stroke, acute myocardial infarction), dementia and diabetes (3). Over-diagnosis too is problematic for older people. A range of over-diagnosis-related harms have previously been identified in the literature, including self-stigma due to incorrectly diagnosed mild cognitive impairment in dementia prevention (4). Statistics of this nature indicate a critical and urgent need to strike the right balance between over- and under-diagnosis of various common health conditions, highlighting the importance of appropriate and timely screening.

Clearly, if older people are to receive appropriate, acceptable and timely preventative advice on screening and assessment for common health conditions, then critical attention needs to be given to engaging providers, older people and policymakers in evidence-informed discussions about screening and treatment. Deliberative methods (i.e., approaches that bring together a diverse group of community members to engage with evidence on a topic of public concern) provide an opportunity for effective community engagement in evidence-informed policy dialogues on screening. Health and care policymakers are increasingly turning to deliberative and inclusive methodologies to address public policy questions such as whom to screen, and when. A key advantage of deliberative methods is that they allow members of the public to participate directly in key decisions and policies that will impact their daily lives, answering a need that has received growing acknowledgement from policymakers, scientists, and consumers alike (5).

A deliberative method that has been widely applied in health policy development is citizens' juries (6). Citizens' juries are groups inclusive of members of the public, purposively selected to represent their community, and who are tasked with deliberating on a jury charge (research question) on a matter of public interest (7). Jurors are usually provided with access to supporting evidence-based resources and expert witness testimonies to support their deliberations and asked to deliver a verdict or make recommendations at the jury end (7). However, few citizens' juries have addressed the views of older people on screening for common health conditions to date. Of studies we identified that have canvassed older people's views on screening, most have focused on cancer screening (8-14), with none on diabetes, CVD, or frailty, and a small number on dementia (15-17), highlighting a critical knowledge gap. Additionally, only one-third of all studies identified used a formal Citizens' Jury format to arrive at their findings (only one of these focusing on dementia), with the remainder using a variety of other less rigorous deliberative methods. A number of studies acknowledged a lack of diversity among participants as a limitation (8,11,12). Lastly, only three of the studies were conducted within Australia (9,11,15). Our study aims to address this critical gap, by canvassing the evidence-informed views of older people on screening for several key common health conditions within the community.

Aims and objectives

The aim of the 'IMproving the PARTicipAtion of older Australians in policy decision-making on common health CondiTions' (IMPAACT) project is to elicit the values and preferences of evidence-informed older people, including those within under-represented groups, on early screening and diagnosis of several common health conditions (CVD, diabetes, frailty, dementia) within the community. 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.

Project objectives include:

1. To generate recommendations from diverse groups of older people on screening for selected common health conditions within the community via a citizens' jury process;
2. To obtain feedback from a diverse range of professional groups, older people, and industry representatives on the jury findings; and
3. To co-design (together with a diverse group of older people) Knowledge Translation resources to facilitate the implementation of key recommendations and feedback on screening for common health conditions into research, policy, and practice.

Methods and Analysis

Participants and study setting

We have elected to set an age limit (50 years and over) for the older population included within our study because this is the population affected by screening for the conditions in question within General Practice. We will seek to recruit participants into the study across a wide range of age groups within this category. We will also purposively recruit participants to reflect diversity with respect to gender, socio-economic status/income, location, Culturally and Linguistically Diverse (CALD), Gender and Sexually Diverse (GSD), functional ability and frailty level.

Australia has a population of 25 million people, of whom an estimated 9.0 million (35% of the total population) are aged 50 years and over (18,19). The Australian health care system is a federated system with responsibility for funding and provision split between the National and State level governments. A universal health care scheme (Medicare) provides the main source of funding for hospital services, General Practice and medicines (20).

Our study is set within the state of South Australia. South Australia offers particular advantages for a study seeking to reflect diversity among its participants, as it is a state characterised by significant heterogeneity with respect to population density, accessibility/remoteness, and health service distribution (21).

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).

Study design

We will apply a participatory design conducted in three phases, which are aligned with the study objectives stated above:

- Phase 1: Conduct Citizens' Juries on screening for common health conditions within the community,
- Phase 2: Conduct Policy Roundtables on screening for common health conditions within the community, and
- Phase 3: Co-design Knowledge Translation (KT) resources for input into research, policy and practice.

The study will be carried out between November 2022 and January 2025.

Phase 1: Citizens' Juries on screening for common health conditions within the community

We will conduct four Citizens' Juries with older people aged 50 years and above, each one specific to a different common health condition (i.e., CVD, diabetes, frailty, or dementia). The sample size for the juries will be based on prior research, suggesting approximately 20 participants in each group (22). All participants will provide fully informed consent.

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.

The jury charge (research question) is shown in Box 1 and has been developed with reference to other Citizens' Juries conducted within Australia (6,23). Jury charges will be adapted to reflect the nominated condition for each respective jury and will be refined in consultation with the Project Advisory Group before commencement of the juries. 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). A depiction of the Phase 1 Citizens' Jury process is shown in Figure 1.

Recruitment of jurors

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 (Supplementary File 1), 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/mailed a Participant Information and Consent form. Ineligible participants will be informed by email or post. Participants will be given two weeks to consider participation, after which time they will be followed up with a phone call. Those willing will provide written informed consent for participation in Phase 1.

Citizens' Jury process

We will ask jurors to attend a two-day workshop. In the week prior to attending the workshops, jurors will receive an information pack containing logistical details for the workshop, guidance as to what to expect regarding the jury process, guidelines for participation, agenda and objectives of the workshop, introductory background materials to support the expert witness testimonies, questions for consideration by participants, and an evaluation sheet (6). They will also be asked to complete a short survey with demographic details. An independent facilitator will facilitate all juries.

The Citizens' Juries will follow standard procedures for this method (23). 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 (23).

On the first day, jurors will hear live expert witness evidence, which will be followed by an interactive session with the witness panel to allow jurors to ask questions. On the second day, the jury will have allocated time to discuss the jury charge, formulate recommendations, and conduct discussions within their jury group. During the closing session of the jury, jurors will be asked to vote on the recommendations generated by the group. Voting will be conducted in an open manner and juror votes will be known to the rest of the group.

At the conclusion of each jury, participants will participate in a short debriefing session and complete a project-specific evaluation form (6). The form will include Likert-scale ratings (1-7 scale) relating to juror satisfaction with the jury process, including elements such as degree of satisfaction with background material provided, expert witness testimony and time commitment required, along with a small number of open-ended questions to allow jurors to make explanatory comments or suggestions. The evaluation data will be used iteratively to improve the implementation of the juries as they progress, and for overall assessment of the feasibility of our approach at project close.

Phase 2: Policy Roundtables on screening for common health conditions within the community

Following the Citizen's Jury process, two Policy Roundtables will be convened (24) on the theme of '*Screening for common health conditions in the community*'. Roundtables are an engagement tool designed to bring together a range of stakeholders to converse on a topic of interest, the outcome of which should be improved representation of the viewpoints of those who have stakes in the issue under consideration (25). The roundtables will each run over two days. The aim of the roundtables will be twofold: 1) encourage evidence-informed dialogue between researchers, older people and policy-makers on the subject of screening for common health conditions; and 2) support the translation of findings from the Citizen's Jury process into research, policy and practice. Roundtables will focus on all the recommendations collectively emerging from the juries in relation to the four identified health conditions.

Recruitment of participants

We will recruit approximately 20 stakeholders to attend each roundtable, to be held in person (or online if COVID-related restrictions are in force). One of the key considerations in identifying participants is the question of who would potentially benefit from or be harmed by the implementation of screening. Aside from older people

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3 and their carers, it is also important to recognise the commercial interests behind some
4 of the moves towards earlier screening. Consequently, the professional stakeholders
5 identified as a component of this study will include representation from consumers and
6 carers, health and aged care policymakers (State and Federal), general practitioners,
7 practice nurses, geriatricians, allied health practitioners, pharmaceutical companies,
8 private health insurers, and community and aged care providers. We will recruit the
9 desired number of participants purposively via direct approach and/or snowball
10 sampling.
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13 *Policy Roundtable process*

14 Roundtable participants will be sent an information pack two weeks before the event,
15 inclusive of a short survey including demographic information. Each roundtable will be
16 jointly co-chaired by a representative from the research team and a consumer
17 representative (24), while an experienced external facilitator will facilitate group
18 discussions. An invited external speaker will present an overview of the issue of
19 misdiagnosis of common health conditions among older people within Australia. Day 1
20 sessions will include a contextual overview of each of the four conditions analysed in
21 Phase 1, along with presenting key findings from the condition-specific citizens' juries.
22 Day 2 will focus on deliberative group discussions to consider the findings and generate
23 feedback. A representative from each group will provide detailed feedback to the main
24 group. Each day will conclude with a summary of the main discussion points. At the end
25 of Day 2, participants will be given a short evaluation form to complete. Members of the
26 research team will also be in attendance to observe proceedings and collect observations
27 against a pre-determined template.
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30 ***Phase 3: Consumer co-design of Knowledge Translation resources: policy 31 brief and lay summary***

32 The aim of the consumer co-design process will be to develop two Knowledge
33 Translation resources: 1) a policy brief that synthesises the recommendations from the
34 Citizens' Juries and feedback from Policy Roundtables, and 2) an accompanying lay
35 summary targeted at older people and their families. Within the context of this study,
36 knowledge translation is defined to mean the process of closing the gap from knowledge
37 production (e.g. through research) to policy and practice (26). Where consumer and/or
38 professional feedback obtained as a result of the jury and roundtable process differs
39 from existing clinical guidelines, these differences will be retained and highlighted
40 within the resources as areas requiring further research and consultation. With respect
41 to co-design, we refer to the process by which end-users of research are meaningfully
42 engaged throughout all stages of research design and implementation (27). The co-
43 design team will comprise of two researchers and 6 consumer co-researchers
44 (purposively selected with respect to age, gender, income level, and ethnicity).
45 Recruitment of participants will be conducted by approaching participants who
46 indicated willingness to take part in further research from the earlier phases and who
47 meet the needs of this phase as determined by the research team. The team will be
48 responsible for defining the target audience/s for the recommendations, identifying key
49 messages for translation, designing appropriate knowledge translation resources (final
50 format/s to be decided by the co-design team) and developing action and
51 communication plans for dissemination.
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57 We will provide co-design team participants with background material on the aims of
58 the co-design process, methodology, and study findings two weeks before Phase 3
59 commencement. Participants will attend three meetings of two hours' duration, an
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3 approach which proved feasible in our previous consumer co-design work (28,29). The
4 meetings will be held face-to-face within Adelaide (virtual attendance to be offered if
5 required). An external facilitator will facilitate all co-design meetings. At the initial
6 meeting, the co-design team will be presented with the summary of findings from
7 Phases 1 and 2. At the second and third meetings, the co-design team will be shown
8 interim drafts of the emergent knowledge translation resources and asked to provide
9 comment. A small group of stakeholders will review the draft/s before finalisation and
10 provide any further feedback required. The final meeting will also include a reflection
11 on the co-design process among participants and discussion of future correspondence.
12
13

14 **Patient and public involvement statement**

15 Our study will be grounded in participatory action research and co-design principles
16 (30), with the intent to meaningfully engage older people at all stages, beginning from
17 project conceptualisation (with the appointment of an older person with extensive
18 experience of co-design processes, as a co-researcher on our project team), through to
19 the design, delivery, and ultimately, dissemination of results. Recruitment of
20 participants from diverse backgrounds will be aided by researcher networks and the
21 involvement of a number of aged care and community professionals and services.
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26 **Data collection and analysis**

27 A Hansard reporter will transcribe all juries (Phase 1) and roundtables (Phase 2), with
28 backup audio recording using a password-protected late model iPhone. Research team
29 members will also take field notes during the sessions and include these within the
30 analysis, together with participant feedback and evaluations. Documentation used
31 within the workshops will also be analysed. Data will be uploaded and analysed within
32 the latest versions of the Excel and NVivo software packages.
33
34

35 We will adopt a qualitative descriptive approach to analyse data (31), with the aim of
36 understanding the key justifications for the recommendations put forward by jurors and
37 participants. Two independent analysts will first familiarise themselves with the
38 transcripts through repeated readings. The unit of analysis will be at the individual
39 jury/roundtable level. We will code the transcripts and additional documentation
40 inductively according to thematic analysis principles, cross-verifying codes to ensure
41 rigour. We will organise codes into categories, sub-categories and candidate themes,
42 refining these in discussion with a third analyst (32).
43
44

45 **Ethics and Dissemination**

46 *Ethical and safety considerations*

47 We will support all participants throughout the project to give informed consent, either
48 in written form or verbally (video-recorded), dependent on context. Participants will be
49 anonymous in all reporting of the different phases of the study unless they wish to be
50 identified, for example as co-designers of the resources in Phase 3. Consumer
51 participants in any Phase of the research will be paid a research honorarium for their
52 time.
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55 The Torrens University Human Research Ethics Committee (HREC) (approvals 0206,
56 0238 and 0253) has approved the ethical aspects of this research project.
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59 *Dissemination and Implementation Strategies*

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Dissemination of the research findings will consist of multiple strategies within an integrated knowledge translation (KT) strategy (33). National and international platforms and websites, newsletters for both professionals and older people, journal publication, conferences and a cross-national seminar series will be employed as channels for dissemination. Beyond dissemination, we will also explore and co-develop potential implementation strategies with stakeholders throughout all stages of the project.

Limitations

We acknowledge a number of limitations of the study. Firstly, due to the complexity of the conditions included, we have elected to address them on an individual basis within Phase 1 (the citizens' juries). However, we will aim to synthesise the key findings across each condition in Phase 2, highlighting areas of commonality and difference. A second limitation is the high degree of dependence between the sequential Phases of the project, with the outcomes for each Phase highly dependent on the Phase before it. However, we have endeavoured to mitigate this potential risk by ensuring that Phase 1 is designed to a high standard of quality with reference to established practice for the conduct for citizens' juries, thereby maximising the likelihood that subsequent Phases will eventuate in meaningful outcomes for the project. Further, the project is underpinned by strong governance structures with a comprehensive risk management plan in place to minimise unintended consequences. Lastly, while we have made efforts to enhance diversity amongst the participant group, it is not possible to represent all aspects of diversity within the participant base.

Contributors

RA is the Principal Investigator for the project and was responsible for the initial conception of the study, and for coordination of study design and manuscript development. CH contributed to study design, drafted the initial version of the manuscript and contributed to drafting and critical revision of the manuscript. MLawless, ABM, RV, JB, SS, VC, MLeach, DT, MQT and ED are Chief Investigators on the project and made substantive contributions to development of the study design and to the drafting and critical revision of the manuscript. LW, MA, HMOR, KW and AC are Associate Investigators on the project and made substantive contributions to development of the study design and to the drafting and critical revision of the manuscript. All authors approved the final manuscript.

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Box 1: Jury Charge

The jury charge (i.e. the research question the jury will be asked to consider) will be adapted for each of four juries, each focusing on a different age-related condition (cardiovascular, diabetes, frailty, dementia). The jury charge is:

- Under what circumstances should screening be provided for this condition within general practice?

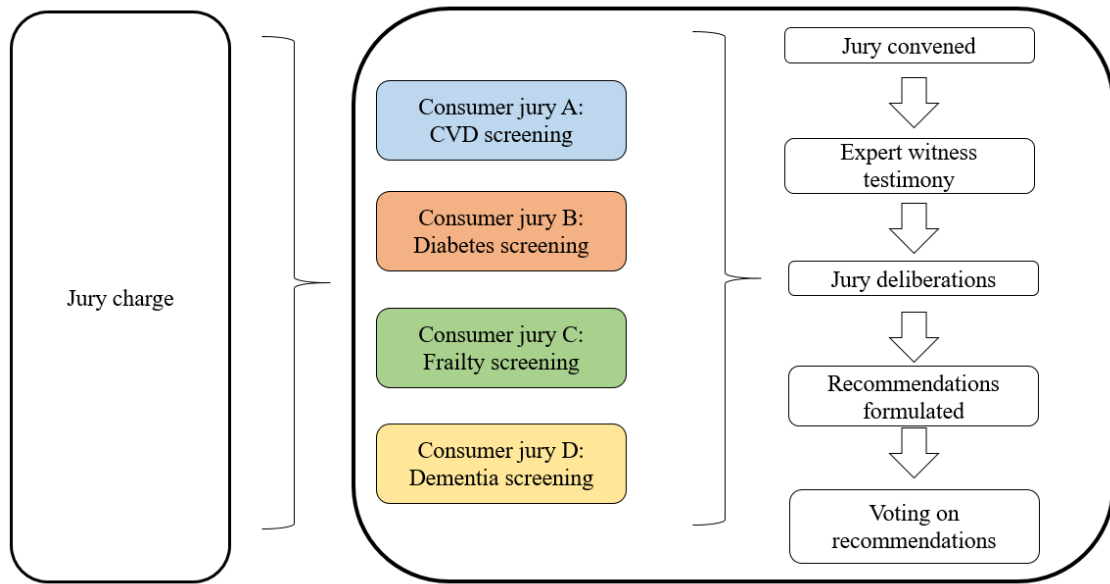
Further questions for the jury to consider over the course of the two day program and which may guide the development of recommendations include:

- What benefits and harms might arise from screening?
- How could harms be addressed?
- Should there be age limits on screening?/When should screening be provided?
- Who should provide screening?
- Where should screening be provided?

Figure 1: Overview of Citizens' Jury process

For peer review only

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Source: Adapted from Crotty et al 2020

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Screening Questions

1. What is your age group?

- Under 50
 - 50 to 64
 - 65 to 74
 - 75 to 84
 - 85+
-

IF Over 50, GO TO Q2

IF Under 50 Or Prefer Not to Answer, say 'Unfortunately you are outside the eligible age range for the study.' Then

GO TO STEP 3A (Exit script).

2. Have you ever worked as a GP or Practice Nurse in general practice?

- Yes
 - No
-

IF No, GO TO Q3

IF Yes, say 'Unfortunately you are ineligible for the study.' Then

GO TO STEP 3A (Exit script).

3. What is the main language spoken in your home?

4. What is your country of birth?

4a. What is your gender?

- Male
- Female
- Non-binary
- Other (please specify)
- Prefer not to answer

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9 4b. What suburb and postcode do you live in?
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13 5. What is your household tenure type?
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- 15 * Owns home outright
 - 16 * Paying a mortgage
 - 17 * Paying rent
 - 18 * Living in someone else's household e.g. with son/daughter
 - 19 * Other (specify)
- 20
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26 6. What is your estimated yearly household income (in dollars) after tax?
27

- 28 • Under \$20,000
 - 29 • \$20,001 – \$40,000
 - 30 • \$40,001 – \$60,000
 - 31 • \$60,001 – \$80,000
 - 32 • \$80,001 – \$100,000
 - 33 • \$100,001 or over
 - 34 • Prefer not to answer
- 35
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38
39 7. Have you been told by a doctor that you have any of the following conditions (identify which):

- 40 • Cardiac disease
 - 41 • Stroke
 - 42 • Obesity
 - 43 • Chronic lung disease
 - 44 • Arthritis
 - 45 • Osteoporosis/osteopaenia
 - 46 • Kidney disease
 - 47 • Cancer
 - 48 • Dementia or mild cognitive impairment
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52 none
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6 8a. What best describes your current employment status? Please tick one box only.

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- Full time employed
 - Part-time employed
 - Unemployed
 - Home duties
 - Student/Training
 - Retired
 - Unable to work (e.g. Disability/WorkCover)
 - I prefer not to answer

17
18 8b. Do you identify as frail?

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- Yes
 - No
 - Unsure
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27 9. What is your sexual orientation?

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- Heterosexual or straight
 - Gay
 - Lesbian
 - Bisexual
 - Pansexual
 - Other (please specify)
 - Prefer not to answer
-

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41 We have completed the telephone screening portion of our call.

- 42
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- Do you have any questions?
 - Do you think you would still like to take part in this research?

46 IF NO, GO TO STEP 3A

47 IF YES, GO TO STEP 5

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7 We will now need to review your eligibility to participate in the study. This may take some time.
8 We will call you within one week from today to let you know if you qualify to participate. At
9 this time, if you are still interested in participating, we will send you a Participant Information
10 sheet and Consent Form in the mail to fill out and send back to us. Participation is voluntary and
11 participants may withdraw at any time.
12

13
14 If you have further questions about the study, please feel free to get in touch with our research
15 team on this number or via the email address you have previously been given – do you need that
16 again?
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18 Thank-you for your time today. (End Call.)
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