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Should women aged 70-74 be invited to participate in screening mammography? A report on two Australian community juries

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5

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3 **Should women aged 70-74 be invited to participate in screening mammography? A**
4 **report on two Australian community juries**
5

6 **Abstract**
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8 **Objective:** To elicit informed views from Australian women aged 70-74 regarding acceptability
9 of ceasing to invite women their age to participate in government-funded mammography
10 screening (BreastScreen).
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12 **Design:** Two community juries held in 2017.
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14 **Setting:** Greater Sydney, a metropolis of 4.5 million people in NSW, Australia
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16 **Participants:** 34 women aged 70-74 with no personal history of breast cancer, recruited by
17 random digit dialling and previously randomly recruited list-based samples.
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19 **Main Outcomes and Measures:** Jury verdict and rationale in response to structured questions.
20 We transcribed audio-recorded jury proceedings and identified central reasons for the jury's
21 decision.
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23 **Results:** The women's average age was 71.5 years. Participants were of diverse sociocultural
24 backgrounds, with the sample designed to include women of lower levels of educational
25 attainment. Both juries concluded by majority verdict (16-to-2 and 10-to-6) that BreastScreen
26 should continue to send invitations and promote screening to their age group. Reasons given for
27 the majority position include: (i) invitations showed that society still cares about older women,
28 empowers them to access preventive health services, and recognises increasing and varied life
29 expectancy; (ii) screening provides women with information that enables choice; and (iii) if
30 experts cannot agree, the conservative approach is to maintain the status-quo until the evidence
31 is clear. Reasons for the minority position were the potential for harms through overdiagnosis,
32 and misallocation of scarce health resources.
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34 **Conclusions:** Preventive health programs such as mammography screening are likely to have
35 significant symbolic value once they are socially embedded. Arguments for program de-
36 implementation emphasising declining benefit because of limited life expectancy and the risks of
37 overdiagnosis seem unlikely to resonate with older women. In situations where there is no
38 consensus amongst experts on the value of established screening programs, people may strongly
39 prefer receiving information about their health and having the opportunity make their own
40 choices.
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Strengths and limitations of this study:

- First published study of community juries on the topic of whether women aged 70-74 should be invited to participate in mammography screening
- Provides in-depth analysis of the priorities and values of women aged 70-74 informed of the potential benefits and harms of early detection of breast cancer
- Demonstrates that epidemiological evidence an intervention potentially does more harm than good does not necessarily override other values that people may consider more important.
- The sample size was small but the results are clear and sustained therefore, it seems likely the findings are replicable.

For peer review only

Should women aged 70-74 be invited to participate in screening mammography? A report on two Australian community juries

Introduction

The appropriate age at which to cease mammography screening remains contested.^{1,2} Screening older women for breast cancer is intuitively attractive as the incidence of this condition increases with age. But detecting a breast cancer early is not always beneficial. Cancers detected in older women are more likely to be slow-growing,³ and breast cancer mortality as a proportion of all-cause mortality decreases with age.⁴ At the same time, the impacts and side effects of breast cancer treatments for older women are often exacerbated by concurrent disease burdens.⁵ Although breast screening may be beneficial for women aged 70 years and older who expect to live at least another 10 years, this must be weighed against the risk of harm due to false positives, overdiagnosis and the side effects of treatment in cases of breast cancer that were never going to cause clinical harm.² The scientific data relevant to mammography screening for women aged 70-74 is mixed and limited, and experts are divided as to the balance of benefit and harm of continuing to screen older age groups.⁶⁻⁸

The Australian breast cancer screening program (BreastScreen Australia) offers free biennial screening to women over age 40. Since 1991, women aged 50-69 years have been specifically targeted via individual letters of invitation. Until 2013, women older than 69 were able to access free screening services if they chose, but they did not receive biennial invitations and mammography screening was not actively promoted to them. In July 2013 BreastScreen Australia extended the target age group for breast screening by mammography from 50-69 years to 50-74 years. Supporting promotion and marketing campaigns were implemented to encourage women to participate.⁹ Participation by women aged over 70 in breast cancer screening has increased from just over 220,000 per annum to almost 270,000 as a consequence of these changes.¹⁰ There have been significant tensions in Australia over extending the target age for the BreastScreen program,¹¹⁻¹⁴ which have not been resolved by evidence of benefit and harm. It is often proposed that the solution is to give women the opportunity to make an informed choice about whether to undergo breast screening, supported by balanced, objective information,^{6,15} but the complexity and relative paucity of evidence on the effect of screening on this older age group makes this task difficult.

We report on two community juries convened to consider dilemmas raised by inviting women aged 70-74 to participate in mammography screening. Our aim was to elicit the informed views of Australian women aged 70-74 as to the acceptability and perceived legitimacy of continuing to invite women in this age group to the Australian mammography screening program. Community juries are an established, appropriate method to achieve this.¹⁶ Unlike surveys and focus groups, the process involves extensive provision of information, constructive, structured dialogue between publics and experts, and adequate time for consideration.¹⁷ The method assumes that people can think rationally and change their views should the evidence warrant it.¹⁸ The process is like a legal proceeding, but the outputs are not legally binding; instead they provide evidence to assist policymaking.^{16,19}

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3 We consulted with major stakeholders (consumer organisations, epidemiologists, women's health
4 physicians, and the Cancer Council of Australia) to determine the most appropriate questions for
5 the community juries to consider (Figure 1). All stakeholders agreed that the key issue to
6 consider was whether BreastScreen Australia should continue to invite women aged 70-74 to
7 participate in its program. Our study was approved by the Human Research Ethics Committee at
8 the University of Sydney. This work was supported by an award from the National Health and
9 Medical Research Council of Australia (CRE 1104136). The funding organization had no role in
10 the design, conduct, analyses or reporting of this study.
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14 **Methods**

15 *Design and Study Setting*

16 A community jury (similar to the proprietary method Citizens' Juries) is a group of citizens
17 brought together to receive detailed evidence about and deliberate on a specific issue.¹⁹
18 Community juries have been used in Australia and elsewhere to consider issues surrounding
19 cancer screening.²⁰⁻²² Community juries are a deliberative method, with these general
20 characteristics:
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- 23 1. A group of citizens is convened for 1-3 days;
- 24 2. They are asked to consider a specific issue;
- 25 3. They hear evidence from (often opposed) experts, and ask questions of those experts;
- 26 4. They are given time for deliberation, and to come to a conclusion, which is documented.
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30 There are two main approaches to community juries. In the first, participants work as a group to
31 draft open sets of recommendations on an issue; in the second, jury members vote on options
32 presented by researchers.²³ We used a combined approach (Figure 1). Both juries were held over
33 2 days in May 2017 at the University of Sydney.
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36 *Participants and Recruitment*

37 We contracted an independent professional research service to recruit two juries of women aged
38 70-74 living in Greater Sydney, Australia from randomly generated list-based samples and
39 random digit dialing. Potential participants with a personal history of breast cancer (themselves
40 or close family member) were excluded through a screening interview, as were health
41 professionals and those working in breast cancer advocacy. 34 women were selected based on
42 their eligibility, socio-demographic characteristics and availability. The juries were socially and
43 culturally diverse, sampling was skewed towards lower educational attainment than the average
44 for the Australian population (Table 1). All jurors received a modest honorarium in recognition
45 of their participation and contribution to jury processes and outcomes.
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49 Each jury commenced with an orientation session introducing the questions and the process,
50 where written consent was also obtained. Jury Day 1 focused on interrogating the evidence and
51 understanding the epidemiological, clinical and practical issues. Testimony from four experts
52 was pre-recorded and shown to jurors as video presentations. Experts were selected on the basis
53 of their institutional roles, experience and expertise, to provide balanced and factual information
54 and the best case "for" and "against" continuing to invite women their age. The expert
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3 presentations covered: (i) the varied nature and incidence of breast cancer, and common clinical
4 care pathways and treatment outcomes in Australia; (ii) the concept of overdiagnosis and the
5 difficulties of evaluating the value of mammography screening for individuals and populations;
6 and, (iii) opposing perspectives on the efficacy and potential impacts of including women their
7 age in mammography screening programs (Table 2). Each presentation ran for approximately 20
8 minutes. Pre-recording ensured the format of the evidence presented was standardized across
9 juries. Each expert's bio-sketch and the video presentations shown to the juries are available
10 online.²⁴
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13 Immediately after each expert's video was screened, we opened a conference call between that
14 expert and the jurors for questioning. Facilitated by a researcher, these question and answer
15 sessions allowed jurors to clarify or challenge the arguments presented and ask further questions.
16 Facilitation focused on promoting constructive dialogue and fair interaction amongst jurors.
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19 For the first hour and a half of Jury Day 2, jurors reflected on, discussed and debated the
20 evidence, aided by a researcher acting as facilitator. Juries then deliberated for an hour without
21 researchers present to come to a majority verdict on the questions posed and a set of
22 recommendations. The verdict, underpinning reasoning, and dissenting views were reported to
23 the research team in a final facilitated feedback session.
24
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26 *Data collection and analysis*

27 The unit of analysis in this study is the deliberative group (jury). All jury deliberations (facilitated
28 and un-facilitated) and expert question and answer sessions were audio-recorded and transcribed.
29 To track changes in the positions held by individual jurors, participants completed an
30 anonymous ballot at 3 time-points during jury proceedings (at the conclusion of day 1; at the
31 beginning of day 2; and, after the verdict at the end of day 2). During the final session of each
32 jury, the verdict and reasons were recorded by a researcher on a flipchart. Each point was
33 reviewed by the jury to ensure accuracy. Jury and interview transcripts were subsequently
34 reviewed to identify key reasons why jurors supported or rejected the presented options. In
35 analysis of all the data collected, the differences between lay and expert perspectives came into
36 sharp focus and showed the challenges of changing how screening services are targeted and
37 organized, and of communicating about screening risks, including overdiagnosis. For reasons of
38 space in this paper we will report only on the jurors' response to PART A (Figure 1). The
39 response of the jurors to PART B, and a more detailed analysis of the values and priorities
40 revealed during their deliberations and follow-up interviews, will be reported elsewhere. No
41 additional data is available for sharing.
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47 **Results**

48 Both juries reported a majority verdict that BreastScreen Australia should continue to invite
49 women 70-74 to participate in the government-funded breast screening program and promote
50 participation to this age group. Table 3 shows that this position was more strongly held by Jury 1
51 than Jury 2. Even though the balance of votes remained fairly stable during the course of both
52 juries, analysis of the 3 time-point ballots indicates that several participants changed their
53 positions during jury proceedings (3 in Jury 1 and 5 in Jury 2) – but most of these shifts
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3 cancelled each other out in the final tallies (Table 3). The reasons jurors gave for their decision
4 are as follows:
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6 *Reasons to continue inviting*

7 1. Being invited to be screened has symbolic importance

8 Many jurors said that extending the invitation to participate in screening to older women showed
9 that society still cared about them. The invitations demonstrated ongoing investment in
10 maintaining the health of older women. This relied on arguments that breast cancer remained
11 relevant in this group (older women could still get a fatal breast cancer), arguments about life
12 expectancy, and arguments about the function of an invitation.
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15 Health professionals cautious about screening in this age group argue that these women's life
16 expectancy is too short for them to benefit from screening. Women who said screening was
17 symbolically important rejected the life expectancy argument, for two reasons: 1) average life
18 expectancy was increasing; 2) some women lived much longer than average. Using average life
19 expectancy to limit resources for early breast cancer detection was therefore seen as unfairly
20 discriminatory. As a participant in Jury 1 noted:
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24 Today a 70-year-old still has a lot to contribute to a society and needs opportunity
25 to live a full and healthy life as any other citizen.
26

27 In the 'symbolic importance' view, invitations had a certain function: they signified a
28 respect/recognition that older women mattered, ensuring that women who wanted to continue
29 to participate in screening knew they were still eligible. The invitation allowed women to decide
30 for themselves if they still wanted information about their breast cancer status, and receive
31 reassurance that they remained cancer free.
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35 2. Screening is different from treatment

36 As indicated above, most participants held that receiving more knowledge about their health was
37 beneficial, and saw screening simply as a source of such knowledge, enabling choice. It was good
38 for a woman to know if she had breast cancer, even if the potential consequences were extremely
39 uncertain. The jury process was crafted to ensure jurors understood the extent and significance
40 of this uncertainty. Nonetheless, many jurors insisted that the problem was not the information
41 from screening, but the side effects of treatment that followed for a breast cancer that would not
42 have caused harm. Speaking on behalf of the majority position, a juror from Jury 2 said:
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45 ...over-diagnosis, it's the wrong expression. It skews the research in the wrong
46 direction... collecting knowledge is not harmful, it's what you do with it that can
47 cause harm.
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50 Jurors acknowledged that the potential for screening to cause unnecessary harms was a highly
51 significant issue, but were unconvinced this should restrict opportunities for individuals to
52 receive information and make choices. Instead, medical professionals should improve the
53 guidance they provided to women diagnosed through screening, and should tailor a woman's
54 treatment, if any, according to their preferences, profile of co-morbidities and specific
55 circumstances.
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3. There is too much uncertainty to arrive at a definitive answer

Finally, participants in both juries found arriving at a decision difficult because of the types and levels of uncertainty surrounding the evidence. Key concerns for jurors included:

- that there was no guarantee that an apparently indolent cancer would not become life-threatening at a later stage
- that the cut-off ages for screening target groups are based on out-of-date demographic data that do not reflect recent shifts towards longer life expectancy
- that environments are increasingly carcinogenic and therefore we cannot know what the future risk is for people living now
- that once defunded, it would be difficult to reinstate the program as the money would be allocated elsewhere

For these reasons, jurors argued that decision makers should be cautious about limiting opportunities for early detection. Invitations to women in this age group should cease only when the evidence of an adverse balance of harms to benefits is solid and not contested by experts.

Reasons to stop inviting

1. Iatrogenic harms

The key reason given for the minority position was the potential for unnecessary iatrogenic harms and in particular the risk of overtreatment. Participants who took this position in both juries gave great significance to evidence that pre-existing conditions (which may be unknown to the individual affected) can interact with and compound the harms of standard breast cancer treatments.

2. The shock of cancer heterogeneity

Almost all of the jurors were surprised to learn that not all breast cancers inevitably cause morbidity and mortality if left untreated. This is consistent with previous studies of public awareness around cancer overdiagnosis.^{25 26} For jurors who voted against continuing to invite women, the possibility that many cancers picked up by screening were harmless undermined the value of early detection, especially as modern treatments mean that those with more advanced disease are now able to be treated more effectively.

3. Opportunity costs

Some women thus argued that money spent on extending the organised program to older women would be better spent on breast cancer research. These women also tended to endorse Expert 4's proposal that clinical examination was a more trustworthy means of detection in older women.

Discussion

After 2 days of information and deliberation, the majority of both juries voted to continue to send invitations and promote participation in mammography screening to women aged 70-74. Neither jury was unanimous in their vote, consistent with previous studies indicating that women's responses to information about the relationship between mammography screening and overdiagnosis are diverse.^{27 28} Participants' responses reflected a central conceptual problem in reasoning about screening. Both the mortality benefit and the harm of overdiagnosis and

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3 overtreatment—at least in breast cancer—can only be seen at the level of populations, so there is
4 always uncertainty as to which individuals benefit from participation and which are harmed.
5 Nevertheless, the majority of participants in both juries maintained that an opportunity to detect
6 a potentially fatal breast cancer early was highly important. Even imperfect information could
7 assist women to make their own choices. Notably, however, this position was amenable to
8 change. Many jurors who voted to continue to invite women now said if the current UK age
9 extension trial found definitive evidence of significant harms from screening participation they
10 might alter their position.⁷
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14 A limitation to this study is that community juries are comprised of small groups of ‘engaged
15 citizens’ whose views may not represent those of the general public, or older women generally.
16 However as two juries came to similar conclusions, it seems likely our findings are replicable.
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19 Breast cancer is an emotive subject with a high public profile and most people have direct
20 experience of loved ones affected by the disease. Consistent with recent findings from the US
21 and UK, most jurors were enthusiastic about screening and rejected the use of average life
22 expectancy to decide screening program exit points.^{25 29 30} They did not find statements about
23 overdiagnosis to be persuasive or important to their decision-making about screening
24 participation.^{30 31} For many jurors, being invited to participate in screening programs validated
25 their continued worth to society; they deserved the same opportunities to maintain their health
26 as younger people. To remove services on the basis of projected life expectancy was seen as
27 being fundamentally ageist and entirely unjust.
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31 Importantly, the reasons given by jurors diverged from those often debated in clinical literature
32 on the pros and cons of breast cancer screening. Jurors were less concerned with consequences,
33 and utilitarian calculations of the balance between benefits and harms, or estimates of net
34 benefit. They focused more on other attributes of moral good, such as the protection of an
35 individual’s right to choose and recognition of the value of individual lives.³² Moreover, the
36 results of our research stand in contrast to a citizens’ jury held in New Zealand comprised of
37 women who had yet to commence screening, after the cut-off for program entry was lowered to
38 45 years.²¹ The jury of women aged 40-49 was asked: *Should the New Zealand government offer free*
39 *screening mammography to all women aged 40-49 years?* Participants were unanimously in favour before
40 the jury, but voted 10 to 1 against after. The balance of harms and benefits is different between
41 women 40-49 and 70-74. However, we speculate that the difference in outcome between the two
42 studies may arise in part from strong personal investment in the value of breast screening
43 because of past participation.^{27 31}
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48 Our study has significant implications for those advocating for extending or de-implementing
49 screening services to older target groups. The balance of benefits and harms from screening is
50 often finely balanced, when viewed from the perspective of guidelines committees (or
51 individuals) adopting an evidence-based approach to utility assessment. As our results show,
52 once a screening program becomes socially and culturally embedded it may develop significant
53 symbolic value. Consequently, any changes in the organisation of mammography screening—no
54 matter how well-founded in evidence—are likely to require greater-than-usual transparency and
55 engagement with other relevant community values.³³
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Conclusion

In the face of expert disagreement, members of the public may have a strong preference to continue to receive interventions that give them information about their health (however uncertain). Even older women who have been informed in detail of the potential benefits and harms of screening participation may highly value early detection of breast cancer, seeing the invitation to screening as an opportunity for choice and a demonstration that society continues to recognise and invest in them. Arguments for withdrawal of breast screening because of overdiagnosis harms and reduced life expectancy seem unlikely to resonate with older women. This study suggests that broader cultural values will need to be addressed if cancer screening is to be de-intensified or de-implemented because of epidemiological evidence of harm.

Statements

Contributors: CD designed the study, ran data collection and analysis processes, and led the drafting and revision of the manuscript. He is guarantor. AB designed the study, participated in data analyses and made significant contributions to the drafting and revision of the manuscript. SA and RB participated in data collection and contributed to and revised the drafted manuscript. JD, NH, JH and RS designed the study, participated in data collection and contributed to and revised the drafted manuscript. VE designed the study and contributed to and revised the drafted manuscript. SMC designed the study, ran data collection, contributed to data analysis, made significant contributions to the drafting and revision of the manuscript. We also acknowledge the contribution of the 34 women who took part in the community juries.

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Transparency declaration: The guarantor affirms that the manuscript is an honest, accurate, and transparent account of the study; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

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Figure 1: The Charge/Question for the Jury

PART A: Which of these options does the jury endorse? The program should:

1. Continue with the current program i.e. invite women and promote screening to women 70-74 to participate in the government-funded breast screening program without cost to participating women

OR

2. Revert to the previous screening program i.e. stop inviting women and stop promoting screening to women aged 70-74 to participate in the government-funded breast screening program.

PART B: During this jury process, you have heard a lot of information about breast screening in 70-74 year old women. Please consider the following questions, and provide reasons for your answers:

- Of the information you have heard, which is most essential to communicate to women 70-74 before they decide whether to participate in breast screening?
- When and how should these women be told about or given access to this information?
- What should we say to citizens and policymakers to convince them that your preferred option is the best option?

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	Jury 1 (n=18)	Jury 2 (n=16)
Age (years)		
Range	70-74	70-74
Median	71.64	71.24
Gender		
Female	18	16
Highest Educational Attainment		
High School	8	3
Trade / Diploma	7	9
University Degree	3	4
Cultural Background/Ethnicity#		
Australian / New Zealand	9	7
Southern/Eastern European	4	2
South-East Asian	1	1
North-East Asian	0	1
Southern/Central Asian	0	1
North-West European	4	4
Socio-Economic status of suburb*		
Low	1	1
Middle	4	3
High	13	12
# Based on Australian Standard Classification of Cultural and Ethnic Groups (ASCEG)		
* Based on Socio-economic Index for Area (SEIFA)		

Table 2: Expert testimony provided to the community juries

	Expertise	Expert area	Data provided
1	Public health and breast physician	Senior clinical consultant - Breast cancer screening and diagnostics (imaging).	(i) Review of breast cancer biology, epidemiology and mortality for women in Australia (ii) A detailed description of current approaches to breast cancer screening, common diagnostic and treatment pathways, and their outcomes for Australian women aged 70-74
2	Clinical Epidemiology and Family Medicine (General Practice)	Screening evaluation, clinical guidelines, and overdiagnosis	(i) Review of the benefits and harms of population screening (and how the balance between them changes with age) (ii) The nature of overdiagnosis, overtreatment and their relationship to population screening programs (iii) The importance and limitations of evidence in making decisions about screening
3	Cancer control and cancer service management	Healthcare administration, cancer primary prevention and palliative care	(i) Their expert opinion as to likely impacts and <u>implications of ceasing</u> to invite women aged 70-74 to participate in mammography screening (ii) The most compelling and important <u>reasons for continuing</u> to invite women aged 70-74 to participate in screening mammography
4	Medical epidemiology, clinical trial design, execution and analysis	Women's health epidemiology	(i) Their expert opinion as to likely impacts and <u>implications of continuing</u> to invite women aged 70-74 to participant in mammography screening (ii) The most compelling and important <u>reasons for ceasing</u> to invite women aged 70-74 to participate in screening mammography

Table 3: Final Jury Verdicts on Part A

Citizens' Jury 1:

- 16 voted to continue inviting
- 2 voted to stop inviting

Citizens' Jury 2:

- 10 voted to continue inviting
- 6 voted to stop inviting

Time-point	CJ1	CJ2
	For / Against continuing	For / Against continuing
Ballot after evidence	15 to 3	9 to 7
Ballot after overnight break	16 to 2	10 to 6
Ballot at end of process	16 to 2	10 to 6

BMJ Open

Should women aged 70-74 be invited to participate in screening mammography? A report on two Australian community juries

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3 **Should women aged 70-74 be invited to participate in screening mammography? A**
4 **report on two Australian community juries**
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3 **Should women aged 70-74 be invited to participate in screening mammography? A**
4 **report on two Australian community juries**
5

6 **Abstract**
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8 **Objective:** To elicit informed views from Australian women aged 70-74 regarding acceptability
9 of ceasing to invite women their age to participate in government-funded mammography
10 screening (BreastScreen).
11

12 **Design:** Two community juries held in 2017.
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14 **Setting:** Greater Sydney, a metropolis of 4.5 million people in NSW, Australia
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16 **Participants:** 34 women aged 70-74 with no personal history of breast cancer, recruited by
17 random digit dialling and previously randomly recruited list-based samples.
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19 **Main Outcomes and Measures:** Jury verdict and rationale in response to structured questions.
20 We transcribed audio-recorded jury proceedings and identified central reasons for the jury's
21 decision.
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23 **Results:** The women's average age was 71.5 years. Participants were of diverse sociocultural
24 backgrounds, with the sample designed to include women of lower levels of educational
25 attainment. Both juries concluded by majority verdict (16-to-2 and 10-to-6) that BreastScreen
26 should continue to send invitations and promote screening to their age group. Reasons given for
27 the majority position include: (i) sending the invitations shows that society still cares about older
28 women, empowers them to access preventive health services, and recognises increasing and
29 varied life expectancy; (ii) screening provides women with information that enables choice; and
30 (iii) if experts cannot agree, the conservative approach is to maintain the status-quo until the
31 evidence is clear. Reasons for the minority position were the potential for harms through
32 overdiagnosis, and misallocation of scarce health resources.
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34 **Conclusions:** Preventive programs such as mammography screening are likely to have
35 significant symbolic value once they are socially embedded. Arguments for program de-
36 implementation emphasising declining benefit because of limited life expectancy and the risks of
37 overdiagnosis seem unlikely to resonate with healthy older women. In situations where there is
38 no consensus amongst experts on the value of established screening programs, people may
39 strongly prefer receiving information about their health and having the opportunity make their
40 own choices.
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Strengths and limitations of this study:

- First published study of community juries on the topic of whether women aged 70-74 should be invited to participate in mammography screening
- Provides in-depth analysis of the priorities and values of women aged 70-74 informed of the potential benefits and harms of early detection of breast cancer
- Demonstrates that epidemiological evidence that an intervention potentially does more harm than good does not necessarily override other values that people may consider more important.
- The sample size was small but the results are clear and sustained therefore, it seems likely the findings are replicable.

For peer review only

Should women aged 70-74 be invited to participate in screening mammography? A report on two Australian community juries

Introduction

The appropriate age at which to cease mammography screening remains contested.^{1,2} Screening older women for breast cancer is intuitively attractive as the incidence of this condition increases with age. But detecting a breast cancer early is not always beneficial. Cancers detected in older women are more likely to be slow-growing,³ and breast cancer mortality as a proportion of all-cause mortality decreases with age.⁴ At the same time, the impacts and side effects of breast cancer treatments for older women are often exacerbated by concurrent disease burdens.⁵ Although breast screening may be beneficial for women aged 70 years and older who expect to live at least another 10 years, this must be weighed against the risk of harm due to false positives, overdiagnosis and the side effects of treatment in cases of breast cancer that were never going to cause clinical harm.² The scientific data relevant to mammography screening for women aged 70-74 is mixed and limited, and experts are divided as to the balance of benefit and harm of continuing to screen older age groups.⁶⁻⁸

The Australian breast cancer screening program (BreastScreen Australia) offers free biennial screening to women over age 40. Since 1991, women aged 50-69 years have been specifically targeted via individual letters of invitation. Until 2013, women older than 69 were able to access free screening services if they chose, but they did not receive biennial invitations and mammography screening was not actively promoted to them. In July 2013 BreastScreen Australia extended the target age group for breast screening by mammography from 50-69 years to 50-74 years. Supporting promotion and marketing campaigns were implemented to encourage women to participate.⁹ Participation by women aged over 70 in breast cancer screening has increased from just over 220,000 per annum to almost 270,000 as a consequence of these changes.¹⁰ There have been significant tensions in Australia over extending the target age for the BreastScreen program,¹¹⁻¹⁴ which have not been resolved by evidence of benefit and harm. It is often proposed that the solution is to give women the opportunity to make an informed choice about whether to undergo breast screening, supported by balanced, objective information,^{6,15} but the complexity and relative paucity of evidence on the effect of screening on this older age group makes this task difficult.

We report on two community juries convened to consider dilemmas raised by inviting women aged 70-74 to participate in mammography screening. Our aim was to elicit the informed views of Australian women aged 70-74 as to the acceptability and perceived legitimacy of continuing to invite women in this age group to the Australian mammography screening program. Community juries are an established, appropriate method to achieve this.¹⁶ Unlike surveys and focus groups, the process involves extensive provision of information, constructive, structured dialogue between publics and experts, and adequate time for consideration.¹⁷ The method assumes that people can think rationally and change their views should the evidence warrant it.¹⁸ The process is like a legal proceeding, but the outputs are not legally binding; instead they provide evidence of public values and the likely acceptability and perceived legitimacy of different policy alternatives to assist policymaking.^{16,19}

We consulted with major stakeholders (consumer organisations, epidemiologists, women's health physicians, and the Cancer Council of Australia) to determine the most appropriate questions for the community juries to consider (Figure 1). Because of continued uncertainty as to the balance of benefits and harms of breast cancer screening in older women, all stakeholders agreed that the key issue to consider was whether BreastScreen Australia should continue to invite women aged 70-74 to participate in its program. Even though a further change in policy is not currently being considered, the results of this study could be used to inform discussion and provision of information about overdiagnosis and overtreatment of screen detected breast cancer in older women and to inform future research on health communication. Additionally, the results may assist in developing policy in other jurisdictions where changes in the target age group for breast screening are being considered, such as the UK. Our study was approved by the Human Research Ethics Committee at the University of Sydney. This work was supported by an award from the National Health and Medical Research Council of Australia (CRE 1104136). The funding organization had no role in the design, conduct, analyses or reporting of this study.

Methods

Design and Study Setting

A community jury (similar to the proprietary method Citizens' Juries) is a group of citizens brought together to receive detailed evidence about and deliberate on a specific issue.¹⁹ Community juries have been used in Australia and elsewhere to consider issues surrounding cancer screening.²⁰⁻²² Community juries are a deliberative method, with these general characteristics:

1. A group of citizens is convened for 1-3 days;
2. They are asked to consider a specific issue;
3. They hear evidence from (often opposed) experts, and ask questions of those experts;
4. They are given time for deliberation, and to come to a conclusion, which is documented.

There are two main approaches to community juries. In the first, participants work as a group to draft open sets of recommendations on an issue; in the second, jury members vote on options presented by researchers.²³ We used a combined approach (Figure 1). Both juries were held over 2 days in May 2017 at the University of Sydney.

Participants and Recruitment

We contracted an independent professional research service to recruit two juries of women aged 70-74 living in Greater Sydney, Australia from randomly generated list-based samples and random digit dialing. We selected women based on their socio-demographic characteristics, as well as their eligibility and availability. Because women born in the late 1940s are likely to have had more limited educational opportunities than subsequent generations, and because many of them are long-term residents of recently gentrified suburbs, we chose to prioritise the stratification of participant education levels in our recruitment strategy. Potential participants with a personal history of breast cancer (themselves or close family member) were excluded through a screening interview, as were health professionals and those working in breast cancer advocacy. 34 women were recruited (Table 1). The juries were socially and culturally diverse,

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3 sampling was skewed towards higher levels of socioeconomic advantage and lower educational
4 attainment than the average for the Australian population (Table 1). All jurors received a
5 modest honorarium in recognition of their participation and contribution to jury processes and
6 outcomes.
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8 *Procedures*

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10 Each jury commenced with an orientation session introducing the questions and the process,
11 where written consent was also obtained. Jury Day 1 focused on interrogating the
12 epidemiological evidence and understanding basic cancer biology and common clinical and
13 practical issues (Table 2). Testimony from four experts was pre-recorded and shown to jurors as
14 video presentations. Experts were selected on the basis of their institutional roles, experience
15 and expertise, to provide balanced and factual information and the best case “for” and “against”
16 continuing to invite women their age. The expert presentations covered: (i) the varied nature and
17 incidence of breast cancer, and common clinical care pathways and treatment outcomes in
18 Australia; (ii) the concept of overdiagnosis and the difficulties of evaluating the value of
19 mammography screening for individuals and populations; and, (iii) opposing perspectives on the
20 efficacy and potential impacts of including women their age in mammography screening
21 programs (Table 2). Each presentation ran for approximately 20 minutes. Pre-recording ensured
22 the format of the evidence presented was standardized across juries. Each expert’s bio-sketch
23 and the video presentations shown to the juries are available online.²⁴
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29 After each expert’s video was screened, we opened a conference call between that expert and the
30 jurors for questioning. Facilitated by a researcher, these question and answer sessions allowed
31 jurors to clarify or challenge the arguments presented, ask further questions, and raise and
32 discuss practical and clinical issues that were important to them. Participants asked the experts
33 their individual questions directly via telephone, following a brief preparatory discussion among
34 the group. At the end of the interaction with each expert witness, jurors were asked whether
35 they were satisfied or had further questions. Because new issues can emerge and gain
36 importance to jurors during the course of a citizens’ jury, expert witnesses remained available via
37 email to answer any further questions that arose during subsequent proceedings. Facilitation
38 focused on promoting constructive dialogue and fair interaction amongst jurors.
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42 For the first hour and a half of Jury Day 2, jurors reflected on, discussed and debated the
43 evidence, aided by a researcher acting as facilitator. Juries then deliberated for an hour without
44 researchers present to come to a majority verdict on the questions posed and a set of
45 recommendations. The verdict, underpinning reasoning, and dissenting views were reported to
46 the research team in a final facilitated feedback session.
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49 *Data collection and analysis*

50 The unit of analysis in this study is the deliberative group (jury). All jury deliberations (facilitated
51 and un-facilitated) and expert question and answer sessions were audio-recorded and transcribed.
52 Previous research indicates that Australian women are generally enthusiastic about screening but
53 have minimal awareness about overdiagnosis.^{25,26} In our previously reported trial of a decision aid
54 about whether to continue or stop screening among women aged 70 years, 78% reported a
55 positive intention to continue screening at baseline.²⁷ To track changes in the positions held by
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3 individual jurors, participants completed an anonymous ballot at 3 time-points during jury
4 proceedings (after they had been presented all the evidence at the conclusion of day 1; after they
5 had had time to consider this evidence overnight at the beginning of day 2; and, after the
6 deliberation and delivery of the verdict at the end of day 2). Jurors also completed an Exit Survey
7 for the purposes of process evaluation at the very end of the final jury session. During the final
8 session of each jury, the verdict and reasons were recorded by a researcher on a flipchart. Each
9 point was reviewed by the jury to ensure accuracy. Jury transcripts were subsequently reviewed
10 to further explore and clarify the key reasons why jurors supported or rejected the presented
11 options. In what follows we have summarized jurors' own descriptions of the rationale and
12 reasoning that underpins their responses to the question asked of them. In analysis of all the
13 data collected, the differences between lay perspectives and those held by epidemiologists came
14 into sharp focus and showed the challenges of changing how screening services are targeted and
15 organized, and of communicating about screening risks, including overdiagnosis. For reasons of
16 space in this paper we will report only on the jurors' response to PART A (Figure 1). The
17 response of the jurors to PART B, and a more detailed analysis of the values and priorities
18 revealed during their deliberations will be reported elsewhere.

23 *Patient and Public Involvement*

24 Research question development was informed by our previous work with Australian women
25 exploring their attitudes to screening and understanding of the concept of overdiagnosis.²⁵⁻²⁷
26 Patients or members of the public were not involved in study design or recruitment. Study
27 results will be disseminated to participating member of the public through providing them with a
28 one-page summary and copies of published reports.

32 **Results**

33 Both juries reported a majority verdict that BreastScreen Australia should continue to invite
34 women 70-74 to participate in the government-funded breast screening program and promote
35 participation to this age group. Table 3 shows that this position was more strongly held by Jury 1
36 than Jury 2. Even though the overall balance of votes remained fairly stable during the course of
37 both juries, analysis of the 3 time-point ballots indicates that several participants changed their
38 positions during jury proceedings (3 in Jury 1 and 5 in Jury 2). Although some individuals
39 changed their position, the overall majority position of the groups did not change. This is
40 because individuals shifted in both directions – towards and away from supporting screening
41 (Table 3). The results of the Exit Surveys support our impression that all of the jurors were
42 confident in their interactions with each other and the experts. Transcripts of questions and
43 discussions during proceedings indicate that over the course of the jury proceedings the vast
44 majority of the jurors comprehended concepts being discussed and that all of them understood
45 the trade-offs implicit in the question we were asking them to address during their deliberations.
46 While we avoided formally 'testing' participants so as not to intimidate them, the Exit Surveys
47 for both juries show that all participants believed that the process was fair and that they had
48 sufficient understanding of the evidence presented to discuss the issues important to them and
49 come to a final decision. Table 4 illustrates the range of ways in which jurors justified their
50 positions. The key reasons jurors gave for their decision are as follows:

56 *Reasons to continue inviting*

1. Being invited to be screened has symbolic importance

Many jurors said that extending the invitation to participate in screening to older women showed that society still cared about them. The invitations demonstrated ongoing investment in maintaining the health of older women. This relied on arguments that breast cancer remained relevant in this group (older women could still get a fatal breast cancer), arguments about life expectancy, and arguments about the function of an invitation.

Health professionals cautious about screening in this age group argue that these women's life expectancy is too short for them to benefit from screening. Women who said screening was symbolically important rejected the life expectancy argument, for two reasons: 1) average life expectancy was increasing; 2) some women lived much longer than average. Using average life expectancy to limit resources for early breast cancer detection was therefore seen as unfairly discriminatory. As a participant in Jury 1 noted:

Today a 70-year-old still has a lot to contribute to a society and needs opportunity to live a full and healthy life as any other citizen.

In the 'symbolic importance' view, invitations had a certain function: they signified a respect/recognition that older women mattered, ensuring that women who wanted to continue to participate in screening knew they were still eligible. The invitation allowed women to decide for themselves if they still wanted information about their breast cancer status, and receive reassurance that they remained cancer free.

2. Screening is different from treatment

As indicated above, most participants held that receiving more knowledge about their health was beneficial, and saw screening simply as a source of such knowledge, enabling choice. It was good for a woman to know if she had breast cancer, even if the potential consequences were extremely uncertain. The jury process was crafted to ensure jurors understood the extent and significance of this uncertainty. Nonetheless, many jurors insisted that the problem was not the information from screening, but the side effects of treatment that followed for a breast cancer that would not have caused harm. Speaking on behalf of the majority position, a juror from Jury 2 said:

...over-diagnosis, it's the wrong expression. It skews the research in the wrong direction... collecting knowledge is not harmful, it's what you do with it that can cause harm.

Jurors acknowledged that the potential for screening to cause unnecessary harms was a highly significant issue, but were unconvinced this should restrict opportunities for individuals to receive information and make choices. Instead, medical professionals should improve the guidance they provided to women diagnosed through screening, and should tailor a woman's treatment, if any, according to their preferences, profile of co-morbidities and specific circumstances.

3. There is too much uncertainty to arrive at a definitive answer

Finally, participants in both juries found arriving at a decision difficult because of the types and levels of uncertainty surrounding the evidence. Key concerns for jurors included:

- that there was no guarantee that an apparently indolent cancer would not become life-threatening at a later stage
- that the cut-off ages for screening target groups are based on out-of-date demographic data that do not reflect recent shifts towards longer life expectancy
- that environments are increasingly carcinogenic and therefore we cannot know what the future risk is for people living now
- that once defunded, it would be difficult to reinstate the program as the money would be allocated elsewhere

For these reasons, jurors argued that decision makers should be cautious about limiting opportunities for early detection. This was because they ascribed a broader set of benefits to screening invitations and participation than those commonly recognised by epidemiologists. Invitations to women in this age group, they argued, should cease only when the evidence of an adverse balance of harms to benefits is solid and not contested by experts.

Reasons to stop inviting

1. Iatrogenic harms

The key reason given for the minority position was the potential for unnecessary iatrogenic harms and in particular the risk of overtreatment. Participants who took this position in both juries gave great significance to evidence that pre-existing conditions such as heart disease and pre-clinical cognitive disorders (which may be unknown to the individual affected) can interact with and compound the harms of standard breast cancer treatments.

2. The shock of cancer heterogeneity

Almost all of the jurors were surprised to learn that not all breast cancers inevitably cause morbidity and mortality if left untreated. This is consistent with previous studies of public awareness around cancer overdiagnosis.^{28 29} For jurors who voted against continuing to invite women, the possibility that many cancers picked up by screening were harmless undermined the value of early detection, especially as modern treatments mean that those with more advanced disease are now able to be treated more effectively.

3. Opportunity costs

Some women thus argued that money spent on offering organised screening to women aged 70-74 would be better spent on breast cancer research. These women also tended to endorse the proposal put forward by Expert 4 that clinical examination was a more trustworthy means of detection in older women.

Discussion

After 2 days of information and deliberation, the majority of both juries voted to continue to send invitations and promote participation in mammography screening to women aged 70-74. Neither jury was unanimous in their vote, consistent with previous studies indicating that women's responses to information about the relationship between mammography screening and overdiagnosis are diverse.^{25 30} Participants' responses reflected a central conceptual problem in reasoning about screening. Both the mortality benefit and the harm of overdiagnosis and overtreatment—at least in breast cancer—can only be seen at the level of populations, so there is

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3 always uncertainty as to which individuals benefit from participation and which are harmed.
4 Nevertheless, the majority of participants in both juries maintained that an opportunity to detect
5 a potentially fatal breast cancer early was highly important. In their deliberations several jurors
6 argued that even imperfect information could assist women to make their own choices. Notably,
7 however, during the reporting of the verdicts jurors also sought to emphasise that their support
8 for this position was amenable to change. Many jurors who voted to continue to invite women
9 now said if the current UK age extension trial found definitive evidence of significant harms
10 from screening participation they might alter their position.⁷
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14 Possible limitations to this study include 1) the small size of the groups; and 2) the relatively high
15 socio-economic status of the residential areas from which participants came. With respect to
16 group size, however, we note that this is an inevitable characteristic of jury research. Community
17 juries are comprised of small groups of 'engaged citizens'. Community juries are designed to
18 promote participant inclusivity and deliberative participation rather than achieve statistical
19 representation. Juries are typically comprised of a manageable number of people (12-15) to
20 ensure the quality of participation and deliberation: in larger groups it is difficult to ensure quality
21 of process. The constitution of these juries was in fact a strength. While most of the participants
22 lived in areas of relative socio-economic advantage, the rapid gentrification of some areas of
23 Sydney make this socio-demographic distinction difficult to interpret for older age groups. We
24 paid close attention, through participant screening, to obtaining a socially and culturally diverse
25 sample. Because two juries came to similar conclusions underpinned by similar reasoning, it
26 seems likely our findings are replicable.
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31 A possible limitation is the absence of expert testimony from breast cancer patients or survivors.
32 However, because all of the expert witnesses have previously occupied or continue to occupy
33 relevant clinical roles, they were able to reflect and comment upon the more personal aspects of
34 breast cancer diagnosis and care in response to jurors' questions and discussions. A strength of
35 this study was the quality and reputation of the experts who gave testimony, and the process by
36 which they moderated one another's presentations until all experts could accept that all views
37 presented could be argued from the evidence.
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41 Breast cancer is an emotive subject with a high public profile and most people have direct
42 experience of loved ones affected by the disease. Consistent with recent findings from the US
43 and UK, most jurors were and remained enthusiastic about screening and rejected the use of
44 average life expectancy to decide screening program exit points.^{28 31 32} They did not find
45 statements about overdiagnosis to be persuasive or important to their decision-making about
46 screening participation.^{32 33} For many jurors, being invited to participate in screening programs
47 validated their continued worth to society; they deserved the same opportunities to maintain
48 their health as younger people. To remove services on the basis of projected life expectancy was
49 seen as being fundamentally ageist and entirely unjust.
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53 Importantly, the reasons given by jurors diverged from those often debated in the
54 epidemiological and clinical literature on the pros and cons of breast cancer screening. Jurors
55 were less concerned with consequences, and utilitarian calculations of the balance between
56 benefits and harms, or estimates of net benefit. They focused more on other attributes of moral
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3 good, such as the protection of an individual's right to choose and recognition of the value of
4 individual lives.³⁴ Moreover, the results of our research stand in contrast to a citizens' jury held in
5 New Zealand comprised of women who had yet to commence screening, after the cut-off for
6 program entry was lowered to 45 years.²¹ The jury of women aged 40-49 was asked: *Should the*
7 *New Zealand government offer free screening mammography to all women aged 40-49 years?* Participants were
8 unanimously in favour before the jury, but voted 10 to 1 against after. The balance of harms and
9 benefits is different between women 40-49 and 70-74. However, we speculate that the difference
10 in outcome between the two studies may arise in part from strong personal investment in the
11 value of breast screening because of past participation.^{25 33}
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15 Our study has significant implications for those advocating for extending or de-implementing
16 screening services to older target groups. The balance of benefits and harms from screening is
17 often finely balanced, when viewed from the perspective of guidelines committees (or
18 individuals) adopting an evidence-based approach to utility assessment. As our results show,
19 once a screening program becomes socially and culturally embedded it may develop significant
20 symbolic value. Epidemiologically evidenced, population-based information about potential
21 benefits and harms of participation does not appear to resonate sufficiently with many women
22 so as to lead them to reassess the symbolic and personal values and meanings they ascribe to
23 screening.^{33 34} Consequently, any changes in the organisation of mammography screening need to
24 be strongly founded in evidence, but are also likely to require greater-than-usual transparency
25 and engagement with other relevant community values.³⁵
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29 **Conclusion**

30 In the face of expert disagreement, members of the public may have a strong preference to
31 continue to receive interventions that give them information about their health (however
32 uncertain). Older women, even those who have been informed in detail of the potential benefits
33 and harms of screening participation, may highly value early detection programs, seeing the
34 invitation to screening as an opportunity for choice and a demonstration that society continues
35 to recognise and invest in them. Current arguments for withdrawal of breast screening because
36 of harms associated with overdiagnosis in people with reduced life expectancy seem unlikely to
37 resonate with older women. This study suggests that broader cultural values will need to be
38 addressed if cancer screening is to be de-intensified or de-implemented because of
39 epidemiological evidence of harm.
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45 **Statements**

46 **Contributors:** CD designed the study, ran data collection and analysis processes, and led the
47 drafting and revision of the manuscript. He is guarantor. AB designed the study, participated in
48 data analyses and made significant contributions to the drafting and revision of the manuscript.
49 SA and RB participated in data collection and contributed to and revised the drafted manuscript.
50 JD, NH, JH and RS designed the study, participated in data collection and contributed to and
51 revised the drafted manuscript. VE designed the study and contributed to and revised the
52 drafted manuscript. SMC designed the study, ran data collection, contributed to data analysis,
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Captions for Figures

Figure 1: The Charge/Question for the Jury

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	Jury 1 (n=18)	Jury 2 (n=16)
Age (years)		
Range	70-74	70-74
Median	71.64	71.24
Gender		
Female	18	16
Highest Educational Attainment		
High School	8	3
Trade / Diploma	7	9
University Degree	3	4
Cultural Background/Ethnicity#		
Australian / New Zealand	9	7
Southern/Eastern European	4	2
South-East Asian	1	1
North-East Asian	0	1
Southern/Central Asian	0	1
North-West European	4	4
Socio-Economic status of suburb*		
Low	1	1
Middle	4	3
High	13	12
# Based on Australian Standard Classification of Cultural and Ethnic Groups (ASCEG)		
* Based on Socio-economic Index for Area (SEIFA)		

Table 2: Expert testimony provided to the community juries

	Expertise	Expert area	Data provided
1	Public health and breast physician	Senior clinical consultant - Breast cancer screening and diagnostics (imaging).	(i) Review of breast cancer biology, epidemiology and mortality for women in Australia (ii) A detailed description of current approaches to breast cancer screening, common diagnostic and treatment pathways, and their outcomes for Australian women aged 70-74
2	Clinical Epidemiology and Family Medicine (General Practice)	Screening evaluation, clinical guidelines, and overdiagnosis	(i) Review of the benefits and harms of population screening (and how the balance between them changes with age) (ii) The nature of overdiagnosis, overtreatment and their relationship to population screening programs (iii) The importance and limitations of evidence in making decisions about screening
3	Cancer control and cancer service management	Healthcare administration, cancer primary prevention and palliative care	(i) Their expert opinion as to likely impacts and <u>implications of ceasing</u> to invite women aged 70-74 to participate in mammography screening (ii) The most compelling and important <u>reasons for continuing</u> to invite women aged 70-74 to participate in screening mammography
4	Medical epidemiology, clinical trial design, execution and analysis	Women's health epidemiology	(i) Their expert opinion as to likely impacts and <u>implications of continuing</u> to invite women aged 70-74 to participant in mammography screening (ii) The most compelling and important <u>reasons for ceasing</u> to invite women aged 70-74 to participate in screening mammography

Table 3: Final Jury Verdicts on Part A

Citizens' Jury 1:

- 16 voted to continue inviting
- 2 voted to stop inviting

Citizens' Jury 2:

- 10 voted to continue inviting
- 6 voted to stop inviting

Time-point	CJ1	CJ2
	For / Against continuing	For / Against continuing
Ballot after evidence	15 to 3	9 to 7
Ballot after overnight break	16 to 2	10 to 6
Ballot at end of process	16 to 2	10 to 6

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Table 4: Examples of Reasons Participants Gave <u>For</u> and <u>Against</u> Proposed Actions	
Reasons to continue inviting	
1. Being invited has symbolic importance	
Jury 1	<ul style="list-style-type: none"> If I get a reminder it just gives me a little bit, um, more authority to go in and say, I've been invited, more confidence to go in and say - I know it's just emotional because I could just walk in and say, I want to be, you know, I want you to put me back on your roll, but it's just nice to know that I'm still there and I'm getting an invitation
Jury 2	<ul style="list-style-type: none"> if something which was offered for 20 years and suddenly it stops, it just has this connotation of I don't matter anymore. Invitation doesn't mean that it is mandatory.
2. Screening is different to treatment	
Jury 1	<ul style="list-style-type: none"> It's up to you then whether you want to go ahead with the treatment, and I'm not one to bury my head in the sand and say, "Oh, what I don't know doesn't hurt me." I would rather know and then it's my choice to have it treated or not treated.
Jury 2	<ul style="list-style-type: none"> It's not the screening .. it's the treatment what does the harm. And I think that the problem with the semantics here, right? How picking up more information which you really can do now because that screening is more effective, it's harmful, it's harmful what we do after.
3. There is too much uncertainty to arrive at a definitive answer	
Jury 1	<ul style="list-style-type: none"> I think it's a retrograde step because we haven't had enough Australian studies to justify going backwards yet. I would like to see more Australian studies to have a better argument for saying let's go back
Jury 2	<ul style="list-style-type: none"> I just feel like, wow, this is - I went home last night and I felt like, you know, I was going to avoid ..., it comes down to your interpretation of this. Some of the others might say that was very good, someone else would say negatively, well, you know, pretty ordinary. So it's hard to have a definitive answer to the question because the evidence is unclear.
Reasons to stop inviting	
1. Iatrogenic harms	
Jury 1	<ul style="list-style-type: none"> So we've got a range of reasons. We've got we might be making people anxious, such that it's not worth it. We've got that we might be harming people, um, and it might be more important to focus on quality of life rather than potentially harming them
Jury 2	<ul style="list-style-type: none"> I think that seems to me that over-diagnosis causes more trouble than no diagnosis at all, um, more harm is caused through over-treatment of cancer than – that are never going to cause any problems to people in the long-run anyway

2. The shock of cancer heterogeneity

Jury 1

- So it is not saving lives, which fascinates me. Because that's why I had mammograms, because I was wanting early detection. I wanted to have a longer life. But what you are all saying, except those who are voting to stop, um, is that you want to live longer and you want to have quality of life and you – you want to – to be valued and you want all that as, of course, I do, but screening is not going to make a difference to that

Jury 2

- ...the thing that really struck me yesterday was not all breast cancer is a death sentence and I don't think enough women know that. I still hear women say, oh well, I don't want to have a mammogram or, um, smear tests or anything because I don't want to find out if I have it, and I think if it were made clearer for women to know there are some cancers that are not a death sentence, you'll probably die of something else

3. Opportunity costs

Jury 1

- it is a fact that screening costs money and so we could allocate that money to screening, we could allocate it to something else. And I think this point against is actually screening is not a very good investment overall and we could get more value from investing that money in, say, breast cancer research.

Jury 2

- I would like to just bring up the fact about costs. I mean, some people might take it personally that, oh well, you know, we're a forgotten age, which in some ways I agree. But I'm also practical and there's only so much money in the health bucket. Now, you know, breast cancer gets a lots of publicity, it has a lot of charities, so to breast cancer, and I think because of that and all that publicity more women have had their screening, they've had, um, treatment for their breast cancers, but there are so many other different cancers and other terrible conditions where there's hardly any money, there's hardly any research being spent on that.

Figure 1: The Charge/Question for the Jury

PART A: Which of these options does the jury endorse? The program should:

1. Continue with the current program i.e. invite women and promote screening to women 70-74 to participate in the government-funded breast screening program without cost to participating women

OR

2. Revert to the previous screening program i.e. stop inviting women and stop promoting screening to women aged 70-74 to participate in the government-funded breast screening program.

PART B: During this jury process, you have heard a lot of information about breast screening in 70-74 year old women. Please consider the following questions, and provide reasons for your answers:

- Of the information you have heard, which is most essential to communicate to women 70-74 before they decide whether to participate in breast screening?
- When and how should these women be told about or given access to this information?
- What should we say to citizens and policymakers to convince them that your preferred option is the best option?

Figure 1: The Charge/Question for the Jury

330x236mm (300 x 300 DPI)

BMJ Open

Should women aged 70-74 be invited to participate in screening mammography? A report on two Australian community juries

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3 **Should women aged 70-74 be invited to participate in screening mammography? A**
4 **report on two Australian community juries**
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3 **Should women aged 70-74 be invited to participate in screening mammography? A**
4 **report on two Australian community juries**
5

6 **Abstract**
7

8 **Objective:** To elicit informed views from Australian women aged 70-74 regarding acceptability
9 of ceasing to invite women their age to participate in government-funded mammography
10 screening (BreastScreen).
11

12 **Design:** Two community juries held in 2017.
13

14 **Setting:** Greater Sydney, a metropolis of 4.5 million people in NSW, Australia
15

16 **Participants:** 34 women aged 70-74 with no personal history of breast cancer, recruited by
17 random digit dialling and previously randomly recruited list-based samples.
18

19 **Main Outcomes and Measures:** Jury verdict and rationale in response to structured questions.
20 We transcribed audio-recorded jury proceedings and identified central reasons for the jury's
21 decision.
22

23 **Results:** The women's average age was 71.5 years. Participants were of diverse sociocultural
24 backgrounds, with the sample designed to include women of lower levels of educational
25 attainment. Both juries concluded by majority verdict (16-to-2 and 10-to-6) that BreastScreen
26 should continue to send invitations and promote screening to their age group. Reasons given for
27 the majority position include: (i) sending the invitations shows that society still cares about older
28 women, empowers them to access preventive health services, and recognises increasing and
29 varied life expectancy; (ii) screening provides women with information that enables choice; and
30 (iii) if experts cannot agree, the conservative approach is to maintain the status-quo until the
31 evidence is clear. Reasons for the minority position were the potential for harms through
32 overdiagnosis, and misallocation of scarce health resources.
33

34 **Conclusions:** Preventive programs such as mammography screening are likely to have
35 significant symbolic value once they are socially embedded. Arguments for program de-
36 implementation emphasising declining benefit because of limited life expectancy and the risks of
37 overdiagnosis seem unlikely to resonate with healthy older women. In situations where there is
38 no consensus amongst experts on the value of established screening programs, people may
39 strongly prefer receiving information about their health and having the opportunity make their
40 own choices.
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Strengths and limitations of this study:

- Community juries are a deliberative method that involves a process of iterative two-way exchange of information between members of the public and experts. By providing extensive information from a range of experts, and ensuring conditions for reasonable and extended debate, community juries elicit more considered judgements than other social research methods such as surveys or focus groups.
- Women aged 70-74 were asked to deliberate on a well-defined question: whether they should be invited to participate in mammography screening.
- Consensus was encouraged but not required; the reasons jurors gave for their decision, and dissenting views and minority positions, were also recorded.
- The sample size was small, but this is an unavoidable characteristic of community jury methods and is necessary for high-quality deliberation.
- Results were clear and sustained across two juries, therefore it seems likely the findings are replicable in women this age who have participated in screening for several decades.

Should women aged 70-74 be invited to participate in screening mammography? A report on two Australian community juries

Introduction

The appropriate age at which to cease mammography screening remains contested.^{1 2} Screening older women for breast cancer is intuitively attractive as the incidence of this condition increases with age. But detecting a breast cancer early is not always beneficial. Cancers detected in older women are more likely to be slow-growing,³ and breast cancer mortality as a proportion of all-cause mortality decreases with age.⁴ At the same time, the impacts and side effects of breast cancer treatments for older women are often exacerbated by concurrent disease burdens.⁵ Although breast screening may be beneficial for women aged 70 years and older who expect to live at least another 10 years, this must be weighed against the risk of harm due to false positives, overdiagnosis and the side effects of treatment in cases of breast cancer that were never going to cause clinical harm.² The scientific data relevant to mammography screening for women aged 70-74 is mixed and limited, and experts are divided as to the balance of benefit and harm of continuing to screen older age groups.⁶⁻⁸

The Australian breast cancer screening program (BreastScreen Australia) offers free biennial screening to women over age 40. Since 1991, women aged 50-69 years have been specifically targeted via individual letters of invitation. Until 2013, women older than 69 were able to access free screening services if they chose, but they did not receive biennial invitations and mammography screening was not actively promoted to them. In July 2013 BreastScreen Australia extended the target age group for breast screening by mammography from 50-69 years to 50-74 years. Supporting promotion and marketing campaigns were implemented to encourage women to participate.⁹ Participation by women aged over 70 in breast cancer screening has increased from just over 220,000 per annum to almost 270,000 as a consequence of these changes.¹⁰ There have been significant tensions in Australia over extending the target age for the BreastScreen program,¹¹⁻¹⁴ which have not been resolved by evidence of benefit and harm. It is often proposed that the solution is to give women the opportunity to make an informed choice about whether to undergo breast screening, supported by balanced, objective information,^{6 15} but the complexity and relative paucity of evidence on the effect of screening on this older age group makes this task difficult.

We report on two community juries convened to consider dilemmas raised by inviting women aged 70-74 to participate in mammography screening. Our aim was to elicit the informed views of Australian women aged 70-74 as to the acceptability and perceived legitimacy of continuing to invite women in this age group to the Australian mammography screening program. Community juries are an established, appropriate method to achieve this.¹⁶ Unlike surveys and focus groups, the process involves extensive provision of information, constructive, structured dialogue between publics and experts, and adequate time for consideration.¹⁷ The method assumes that people can think rationally and change their views should the evidence warrant it.¹⁸ The process is like a legal proceeding, but the outputs are not legally binding; instead they provide evidence of public values and the likely acceptability and perceived legitimacy of different policy alternatives to assist policymaking.^{16 19}

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4 We consulted with major stakeholders (consumer organisations, epidemiologists, women's health
5 physicians, and the Cancer Council of Australia) to determine the most appropriate questions for
6 the community juries to consider (Figure 1). Because of continued uncertainty as to the balance
7 of benefits and harms of breast cancer screening in older women, all stakeholders agreed that the
8 key issue to consider was whether BreastScreen Australia should continue to invite women aged
9 70-74 to participate in its program. Even though a further change in policy is not currently being
10 considered, the results of this study could be used to inform discussion and provision of
11 information about overdiagnosis and overtreatment of screen detected breast cancer in older
12 women and to inform future research on health communication. Additionally, the results may
13 assist in developing policy in other jurisdictions where changes in the target age group for breast
14 screening are being considered, such as the UK. Our study was approved by the Human
15 Research Ethics Committee at the University of Sydney. This work was supported by an award
16 from the National Health and Medical Research Council of Australia (CRE 1104136). The
17 funding organization had no role in the design, conduct, analyses or reporting of this study.
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23 **Methods**

24 *Design and Study Setting*

25 A community jury (similar to the proprietary method Citizens' Juries) is a group of citizens
26 brought together to receive detailed evidence about and deliberate on a specific issue.¹⁹
27 Community juries have been used in Australia and elsewhere to consider issues surrounding
28 cancer screening.²⁰⁻²² Community juries are a deliberative method, with these general
29 characteristics:
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- 32 1. A group of citizens is convened for 1-3 days;
- 33 2. They are asked to consider a specific issue;
- 34 3. They hear evidence from (often opposed) experts, and ask questions of those experts;
- 35 4. They are given time for deliberation, and to come to a conclusion, which is documented.
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39 There are two main approaches to community juries. In the first, participants work as a group to
40 draft open sets of recommendations on an issue; in the second, jury members vote on options
41 presented by researchers.²³ We used a combined approach (Figure 1). Both juries were held over
42 2 days in May 2017 at the University of Sydney.
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45 *Participants and Recruitment*

46 We contracted an independent professional research service to recruit two juries of women aged
47 70-74 living in Greater Sydney, Australia from randomly generated list-based samples and
48 random digit dialing. We selected women based on their socio-demographic characteristics, as
49 well as their eligibility and availability. Because women born in the late 1940s are likely to have
50 had more limited educational opportunities than subsequent generations, and because many of
51 them are long-term residents of recently gentrified suburbs, we chose to prioritise the
52 stratification of participant education levels in our recruitment strategy. Potential participants
53 with a personal history of breast cancer (themselves or close family member) were excluded
54 through a screening interview, as were health professionals and those working in breast cancer
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3 advocacy. 34 women were recruited (Table 1). The juries were socially and culturally diverse,
4 sampling was skewed towards higher levels of socioeconomic advantage and lower educational
5 attainment than the average for the Australian population (Table 1). All jurors received a
6 modest honorarium in recognition of their participation and contribution to jury processes and
7 outcomes.
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9 10 *Procedures*

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12 Each jury commenced with an orientation session introducing the questions and the process,
13 where written consent was also obtained. Jury Day 1 focused on interrogating the
14 epidemiological evidence and understanding basic cancer biology and common clinical and
15 practical issues (Table 2). Testimony from four experts was pre-recorded and shown to jurors as
16 video presentations. Experts were selected on the basis of their institutional roles, experience
17 and expertise, to provide balanced and factual information and the best case “for” and “against”
18 continuing to invite women their age. The expert presentations covered: (i) the varied nature and
19 incidence of breast cancer, and common clinical care pathways and treatment outcomes in
20 Australia; (ii) the concept of overdiagnosis and the difficulties of evaluating the value of
21 mammography screening for individuals and populations; and, (iii) opposing perspectives on the
22 efficacy and potential impacts of including women their age in mammography screening
23 programs (Table 2). Each presentation ran for approximately 20 minutes. Pre-recording ensured
24 the format of the evidence presented was standardized across juries. Each expert’s bio-sketch
25 and the video presentations shown to the juries are available online.²⁴
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30 After each expert’s video was screened, we opened a conference call between that expert and the
31 jurors for questioning. Facilitated by a researcher, these question and answer sessions allowed
32 jurors to clarify or challenge the arguments presented, ask further questions, and raise and
33 discuss practical and clinical issues that were important to them. Participants asked the experts
34 their individual questions directly via telephone, following a brief preparatory discussion among
35 the group. At the end of the interaction with each expert witness, jurors were asked whether
36 they were satisfied or had further questions. Because new issues can emerge and gain
37 importance to jurors during the course of a citizens’ jury, expert witnesses remained available via
38 email to answer any further questions that arose during subsequent proceedings. Facilitation
39 focused on promoting constructive dialogue and fair interaction amongst jurors.
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43 For the first hour and a half of Jury Day 2, jurors reflected on, discussed and debated the
44 evidence, aided by a researcher acting as facilitator. Juries then deliberated for an hour without
45 researchers present to come to a majority verdict on the questions posed and a set of
46 recommendations. The verdict, underpinning reasoning, and dissenting views were reported to
47 the research team in a final facilitated feedback session.
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50 *Data collection and analysis*

51 The unit of analysis in this study is the deliberative group (jury). All jury deliberations (facilitated
52 and un-facilitated) and expert question and answer sessions were audio-recorded and transcribed.
53 Previous research indicates that Australian women are generally enthusiastic about screening but
54 have minimal awareness about overdiagnosis.^{25,26} In our previously reported trial of a decision aid
55 about whether to continue or stop screening among women aged 70 years, 78% reported a
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3 positive intention to continue screening at baseline.²⁷ To track changes in the positions held by
4 individual jurors, participants completed an anonymous ballot at 3 time-points during jury
5 proceedings (after they had been presented all the evidence at the conclusion of day 1; after they
6 had had time to consider this evidence overnight at the beginning of day 2; and, after the
7 deliberation and delivery of the verdict at the end of day 2). Jurors also completed an Exit Survey
8 for the purposes of process evaluation at the very end of the final jury session. During the final
9 session of each jury, the verdict and reasons were recorded by a researcher on a flipchart. Each
10 point was reviewed by the jury to ensure accuracy. Jury transcripts were subsequently reviewed
11 to further explore and clarify the key reasons why jurors supported or rejected the presented
12 options. In what follows we have summarized jurors' own descriptions of the rationale and
13 reasoning that underpins their responses to the question asked of them. In analysis of all the
14 data collected, the differences between lay perspectives and those held by epidemiologists came
15 into sharp focus and showed the challenges of changing how screening services are targeted and
16 organized, and of communicating about screening risks, including overdiagnosis. For reasons of
17 space in this paper we will report only on the jurors' response to PART A (Figure 1). The
18 response of the jurors to PART B, and a more detailed analysis of the values and priorities
19 revealed during their deliberations will be reported elsewhere.

24 *Patient and Public Involvement*

25 Research question development was informed by our previous work with Australian women
26 exploring their attitudes to screening and understanding of the concept of overdiagnosis.²⁵⁻²⁷
27 Patients or members of the public were not involved in study design or recruitment. Study
28 results will be disseminated to participating member of the public through providing them with a
29 one-page summary and copies of published reports.
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33 **Results**

34 Both juries reported a majority verdict that BreastScreen Australia should continue to invite
35 women 70-74 to participate in the government-funded breast screening program and promote
36 participation to this age group. Table 3 shows that this position was more strongly held by Jury 1
37 than Jury 2. Even though the overall balance of votes remained fairly stable during the course of
38 both juries, analysis of the 3 time-point ballots indicates that several participants changed their
39 positions during jury proceedings (3 in Jury 1 and 5 in Jury 2). Although some individuals
40 changed their position, the overall majority position of the groups did not change. This is
41 because individuals shifted in both directions – towards and away from supporting screening
42 (Table 3). The results of the Exit Surveys support our impression that all of the jurors were
43 confident in their interactions with each other and the experts. Transcripts of questions and
44 discussions during proceedings indicate that over the course of the jury proceedings the vast
45 majority of the jurors comprehended concepts being discussed and that all of them understood
46 the trade-offs implicit in the question we were asking them to address during their deliberations.
47 While we avoided formally 'testing' participants so as not to intimidate them, the Exit Surveys
48 for both juries show that all participants believed that the process was fair and that they had
49 sufficient understanding of the evidence presented to discuss the issues important to them and
50 come to a final decision. Table 4 illustrates the range of ways in which jurors justified their
51 positions. The key reasons jurors gave for their decision are as follows:
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Reasons to continue inviting

1. Being invited to be screened has symbolic importance

Many jurors said that extending the invitation to participate in screening to older women showed that society still cared about them. The invitations demonstrated ongoing investment in maintaining the health of older women. This relied on arguments that breast cancer remained relevant in this group (older women could still get a fatal breast cancer), arguments about life expectancy, and arguments about the function of an invitation.

Health professionals cautious about screening in this age group argue that these women's life expectancy is too short for them to benefit from screening. Women who said screening was symbolically important rejected the life expectancy argument, for two reasons: 1) average life expectancy was increasing; 2) some women lived much longer than average. Using average life expectancy to limit resources for early breast cancer detection was therefore seen as unfairly discriminatory. As a participant in Jury 1 noted:

Today a 70-year-old still has a lot to contribute to a society and needs opportunity to live a full and healthy life as any other citizen.

In the 'symbolic importance' view, invitations had a certain function: they signified a respect/recognition that older women mattered, ensuring that women who wanted to continue to participate in screening knew they were still eligible. The invitation allowed women to decide for themselves if they still wanted information about their breast cancer status, and receive reassurance that they remained cancer free.

2. Screening is different from treatment

As indicated above, most participants held that receiving more knowledge about their health was beneficial, and saw screening simply as a source of such knowledge, enabling choice. It was good for a woman to know if she had breast cancer, even if the potential consequences were extremely uncertain. The jury process was crafted to ensure jurors understood the extent and significance of this uncertainty. Nonetheless, many jurors insisted that the problem was not the information from screening, but the side effects of treatment that followed for a breast cancer that would not have caused harm. Speaking on behalf of the majority position, a juror from Jury 2 said:

...over-diagnosis, it's the wrong expression. It skews the research in the wrong direction... collecting knowledge is not harmful, it's what you do with it that can cause harm.

Jurors acknowledged that the potential for screening to cause unnecessary harms was a highly significant issue, but were unconvinced this should restrict opportunities for individuals to receive information and make choices. Instead, medical professionals should improve the guidance they provided to women diagnosed through screening, and should tailor a woman's treatment, if any, according to their preferences, profile of co-morbidities and specific circumstances.

3. There is too much uncertainty to arrive at a definitive answer

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3 Finally, participants in both juries found arriving at a decision difficult because of the types and
4 levels of uncertainty surrounding the evidence. Key concerns for jurors included:

- 5 – that there was no guarantee that an apparently indolent cancer would not become life-
6 threatening at a later stage
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- 8 – that the cut-off ages for screening target groups are based on out-of-date demographic
9 data that do not reflect recent shifts towards longer life expectancy
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- 11 – that environments are increasingly carcinogenic and therefore we cannot know what the
12 future risk is for people living now
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- 14 – that once defunded, it would be difficult to reinstate the program as the money would be
15 allocated elsewhere

16 For these reasons, jurors argued that decision makers should be cautious about limiting
17 opportunities for early detection. This was because they ascribed a broader set of benefits to
18 screening invitations and participation than those commonly recognised by epidemiologists.
19 Invitations to women in this age group, they argued, should cease only when the evidence of an
20 adverse balance of harms to benefits is solid and not contested by experts.
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23 *Reasons to stop inviting*

24 1. Iatrogenic harms

25 The key reason given for the minority position was the potential for unnecessary iatrogenic
26 harms and in particular the risk of overtreatment. Participants who took this position in both
27 juries gave great significance to evidence that pre-existing conditions such as heart disease and
28 pre-clinical cognitive disorders (which may be unknown to the individual affected) can interact
29 with and compound the harms of standard breast cancer treatments.
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32 2. The shock of cancer heterogeneity

33 Almost all of the jurors were surprised to learn that not all breast cancers inevitably cause
34 morbidity and mortality if left untreated. This is consistent with previous studies of public
35 awareness around cancer overdiagnosis.^{28 29} For jurors who voted against continuing to invite
36 women, the possibility that many cancers picked up by screening were harmless undermined the
37 value of early detection, especially as modern treatments mean that those with more advanced
38 disease are now able to be treated more effectively.
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43 3. Opportunity costs

44 Some women thus argued that money spent on offering organised screening to women aged 70-
45 74 would be better spent on breast cancer research. These women also tended to endorse the
46 proposal put forward by Expert 4 that clinical examination was a more trustworthy means of
47 detection in older women.
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50 **Discussion**

51 After 2 days of information and deliberation, the majority of both juries voted to continue to
52 send invitations and promote participation in mammography screening to women aged 70-74.
53 Neither jury was unanimous in their vote, consistent with previous studies indicating that
54 women's responses to information about the relationship between mammography screening and
55 overdiagnosis are diverse.^{25 30} Participants' responses reflected a central conceptual problem in
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3 reasoning about screening. Both the mortality benefit and the harm of overdiagnosis and
4 overtreatment—at least in breast cancer—can only be seen at the level of populations, so there is
5 always uncertainty as to which individuals benefit from participation and which are harmed.
6 Nevertheless, the majority of participants in both juries maintained that an opportunity to detect
7 a potentially fatal breast cancer early was highly important. In their deliberations several jurors
8 argued that even imperfect information could assist women to make their own choices. Notably,
9 however, during the reporting of the verdicts jurors also sought to emphasise that their support
10 for this position was amenable to change. Many jurors who voted to continue to invite women
11 now said if the current UK age extension trial found definitive evidence of significant harms
12 from screening participation they might alter their position.⁷
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16 Possible limitations to this study include 1) the small size of the groups; and 2) the relatively high
17 socio-economic status of the residential areas from which participants came. With respect to
18 group size, however, we note that this is an inevitable characteristic of jury research. Community
19 juries are comprised of small groups of ‘engaged citizens’. Community juries are designed to
20 promote participant inclusivity and deliberative participation rather than achieve statistical
21 representation. Juries are typically comprised of a manageable number of people (12-15) to
22 ensure the quality of participation and deliberation: in larger groups it is difficult to ensure quality
23 of process. The constitution of these juries was in fact a strength. While most of the participants
24 lived in areas of relative socio-economic advantage, the rapid gentrification of some areas of
25 Sydney make this socio-demographic distinction difficult to interpret for older age groups. We
26 paid close attention, through participant screening, to obtaining a socially and culturally diverse
27 sample. Because two juries came to similar conclusions underpinned by similar reasoning, it
28 seems likely our findings are replicable.
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33 A possible limitation is the absence of expert testimony from breast cancer patients or survivors.
34 However, because all of the expert witnesses have previously occupied or continue to occupy
35 relevant clinical roles, they were able to reflect and comment upon the more personal aspects of
36 breast cancer diagnosis and care in response to jurors’ questions and discussions. A strength of
37 this study was the quality and reputation of the experts who gave testimony, and the process by
38 which they moderated one another’s presentations until all experts could accept that all views
39 presented could be argued from the evidence.
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43 Breast cancer is an emotive subject with a high public profile and most people have direct
44 experience of loved ones affected by the disease. Consistent with recent findings from the US
45 and UK, most jurors were and remained enthusiastic about screening and rejected the use of
46 average life expectancy to decide screening program exit points.^{28 31 32} They did not find
47 statements about overdiagnosis to be persuasive or important to their decision-making about
48 screening participation.^{32 33} For many jurors, being invited to participate in screening programs
49 validated their continued worth to society; they deserved the same opportunities to maintain
50 their health as younger people. To remove services on the basis of projected life expectancy was
51 seen as being fundamentally ageist and entirely unjust.
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55 Importantly, the reasons given by jurors diverged from those often debated in the
56 epidemiological and clinical literature on the pros and cons of breast cancer screening. Jurors
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3 were less concerned with consequences, and utilitarian calculations of the balance between
4 benefits and harms, or estimates of net benefit. They focused more on other attributes of moral
5 good, such as the protection of an individual's right to choose and recognition of the value of
6 individual lives.³⁴ Moreover, the results of our research stand in contrast to a citizens' jury held in
7 New Zealand comprised of women who had yet to commence screening, after the cut-off for
8 program entry was lowered to 45 years.²¹ The jury of women aged 40-49 was asked: *Should the*
9 *New Zealand government offer free screening mammography to all women aged 40-49 years?* Participants were
10 unanimously in favour before the jury, but voted 10 to 1 against after. The balance of harms and
11 benefits is different between women 40-49 and 70-74. However, we speculate that the difference
12 in outcome between the two studies may arise in part from strong personal investment in the
13 value of breast screening because of past participation.^{25 33}
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17 Our study has significant implications for those advocating for extending or de-implementing
18 screening services to older target groups. The balance of benefits and harms from screening is
19 often finely balanced, when viewed from the perspective of guidelines committees (or
20 individuals) adopting an evidence-based approach to utility assessment. As our results show,
21 once a screening program becomes socially and culturally embedded it may develop significant
22 symbolic value. Epidemiologically evidenced, population-based information about potential
23 benefits and harms of participation does not appear to resonate sufficiently with many women
24 so as to lead them to reassess the symbolic and personal values and meanings they ascribe to
25 screening.^{33 34} Consequently, any changes in the organisation of mammography screening need to
26 be strongly founded in evidence, but are also likely to require greater-than-usual transparency
27 and engagement with other relevant community values.³⁵
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31 **Conclusion**

32 In the face of expert disagreement, members of the public may have a strong preference to
33 continue to receive interventions that give them information about their health (however
34 uncertain). Older women, even those who have been informed in detail of the potential benefits
35 and harms of screening participation, may highly value early detection programs, seeing the
36 invitation to screening as an opportunity for choice and a demonstration that society continues
37 to recognise and invest in them. Current arguments for withdrawal of breast screening because
38 of harms associated with overdiagnosis in people with reduced life expectancy seem unlikely to
39 resonate with older women. This study suggests that broader cultural values will need to be
40 addressed if cancer screening is to be de-intensified or de-implemented because of
41 epidemiological evidence of harm.
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47 **Statements**

48 **Contributors:** CD designed the study, ran data collection and analysis processes, and led the
49 drafting and revision of the manuscript. He is guarantor. AB designed the study, participated in
50 data analyses and made significant contributions to the drafting and revision of the manuscript.
51 SA and RB participated in data collection and contributed to and revised the drafted manuscript.
52 JD, NH, JH and RS designed the study, participated in data collection and contributed to and
53 revised the drafted manuscript. VE designed the study and contributed to and revised the
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3 drafted manuscript. SMC designed the study, ran data collection, contributed to data analysis,
4 made significant contributions to the drafting and revision of the manuscript.
5

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9

10
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12 form at http://www.icmje.org/coi_disclosure.pdf and declare: no support from any organisation
13 for the submitted work; no financial relationships with any organisations that might have an
14 interest in the submitted work in the previous three years, no other relationships or activities that
15 could appear to have influenced the submitted work.
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31 **Transparency declaration:** The guarantor affirms that the manuscript is an honest, accurate,
32 and transparent account of the study; that no important aspects of the study have been omitted;
33 and that any discrepancies from the study as planned have been explained.
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35

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38
39

40 **Ethics approval:** The research project was approved by the University of Sydney Human Ethics
41 Research Committee (2016/967)
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44 **Data sharing statement:** No additional data is available for sharing.
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47 Captions for Figures

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49 Figure 1: The Charge/Question for the Jury
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	Jury 1 (n=18)	Jury 2 (n=16)
Age		
(years)		
Range	70-74	70-74
Median	71.64	71.24
Gender		
Female	18	16
Highest Educational Attainment		
High School	8	3
Trade / Diploma	7	9
University Degree	3	4
Cultural Background/Ethnicity#		
Australian / New Zealand	9	7
Southern/Eastern European	4	2
South-East Asian	1	1
North-East Asian	0	1
Southern/Central Asian	0	1
North-West European	4	4
Socio-Economic status of suburb*		
Low	1	1
Middle	4	3
High	13	12
# Based on Australian Standard Classification of Cultural and Ethnic Groups (ASCEG)		
* Based on Socio-economic Index for Area (SEIFA)		

Table 2: Expert testimony provided to the community juries

	Expertise	Expert area	Data provided
1	Public health and breast physican	Senior clinical consultant - Breast cancer screening and diagnostics (imaging).	(i) Review of breast cancer biology, epidemiology and mortality for women in Australia (ii) A detailed description of current approaches to breast cancer screening, common diagnostic and treatment pathways, and their outcomes for Australian women aged 70-74
2	Clinical Epidemiology and Family Medicine (General Practice)	Screening evaluation, clinical guidelines, and overdiagnosis	(i) Review of the benefits and harms of population screening (and how the balance between them changes with age) (ii) The nature of overdiagnosis, overtreatment and their relationship to population screening programs (iii) The importance and limitations of evidence in making decisions about screening
3	Cancer control and cancer service management	Healthcare administration, cancer primary prevention and palliative care	(i) Their expert opinion as to likely impacts and <u>implications of ceasing</u> to invite women aged 70-74 to participate in mammography screening (ii) The most compelling and important <u>reasons for continuing</u> to invite women aged 70-74 to participate in screening mammography
4	Medical epidemiology, clinical trial design, execution and analysis	Women's health epidemiology	(i) Their expert opinion as to likely impacts and <u>implications of continuing</u> to invite women aged 70-74 to participant in mammography screening (ii) The most compelling and important <u>reasons for ceasing</u> to invite women aged 70-74 to participate in screening mammography

Table 3: Final Jury Verdicts on Part A

Citizens' Jury 1:

- 16 voted to continue inviting
- 2 voted to stop inviting

Citizens' Jury 2:

- 10 voted to continue inviting
- 6 voted to stop inviting

Time-point	CJ1	CJ2
	For / Against continuing	For / Against continuing
Ballot after evidence	15 to 3	9 to 7
Ballot after overnight break	16 to 2	10 to 6
Ballot at end of process	16 to 2	10 to 6

Table 4: Examples of Reasons Participants Gave <u>For</u> and <u>Against</u> Proposed Actions	
Reasons to continue inviting	
1. Being invited has symbolic importance	
Jury 1	<ul style="list-style-type: none"> If I get a reminder it just gives me a little bit, um, more authority to go in and say, I've been invited, more confidence to go in and say - I know it's just emotional because I could just walk in and say, I want to be, you know, I want you to put me back on your roll, but it's just nice to know that I'm still there and I'm getting an invitation
Jury 2	<ul style="list-style-type: none"> if something which was offered for 20 years and suddenly it stops, it just has this connotation of I don't matter anymore. Invitation doesn't mean that it is mandatory.
2. Screening is different to treatment	
Jury 1	<ul style="list-style-type: none"> It's up to you then whether you want to go ahead with the treatment, and I'm not one to bury my head in the sand and say, "Oh, what I don't know doesn't hurt me." I would rather know and then it's my choice to have it treated or not treated.
Jury 2	<ul style="list-style-type: none"> It's not the screening .. it's the treatment what does the harm. And I think that the problem with the semantics here, right? How picking up more information which you really can do now because that screening is more effective, it's harmful, it's harmful what we do after.
3. There is too much uncertainty to arrive at a definitive answer	
Jury 1	<ul style="list-style-type: none"> I think it's a retrograde step because we haven't had enough Australian studies to justify going backwards yet. I would like to see more Australian studies to have a better argument for saying let's go back
Jury 2	<ul style="list-style-type: none"> I just feel like, wow, this is - I went home last night and I felt like, you know, I was going to avoid ..., it comes down to your interpretation of this. Some of the others might say that was very good, someone else would say negatively, well, you know, pretty ordinary. So it's hard to have a definitive answer to the question because the evidence is unclear.
Reasons to stop inviting	
1. Iatrogenic harms	
Jury 1	<ul style="list-style-type: none"> So we've got a range of reasons. We've got we might be making people anxious, such that it's not worth it. We've got that we might be harming people, um, and it might be more important to focus on quality of life rather than potentially harming them
Jury 2	<ul style="list-style-type: none"> I think that seems to me that over-diagnosis causes more trouble than no diagnosis at all, um, more harm is caused through over-treatment of cancer than – that are never going to cause any problems to people in the long-run anyway

2. The shock of cancer heterogeneity

Jury 1

- So it is not saving lives, which fascinates me. Because that's why I had mammograms, because I was wanting early detection. I wanted to have a longer life. But what you are all saying, except those who are voting to stop, um, is that you want to live longer and you want to have quality of life and you – you want to – to be valued and you want all that as, of course, I do, but screening is not going to make a difference to that

Jury 2

- ...the thing that really struck me yesterday was not all breast cancer is a death sentence and I don't think enough women know that. I still hear women say, oh well, I don't want to have a mammogram or, um, smear tests or anything because I don't want to find out if I have it, and I think if it were made clearer for women to know there are some cancers that are not a death sentence, you'll probably die of something else

3. Opportunity costs

Jury 1

- it is a fact that screening costs money and so we could allocate that money to screening, we could allocate it to something else. And I think this point against is actually screening is not a very good investment overall and we could get more value from investing that money in, say, breast cancer research.

Jury 2

- I would like to just bring up the fact about costs. I mean, some people might take it personally that, oh well, you know, we're a forgotten age, which in some ways I agree. But I'm also practical and there's only so much money in the health bucket. Now, you know, breast cancer gets a lots of publicity, it has a lot of charities, so to breast cancer, and I think because of that and all that publicity more women have had their screening, they've had, um, treatment for their breast cancers, but there are so many other different cancers and other terrible conditions where there's hardly any money, there's hardly any research being spent on that.

Figure 1: The Charge/Question for the Jury

PART A: Which of these options does the jury endorse? The program should:

1. Continue with the current program i.e. invite women and promote screening to women 70-74 to participate in the government-funded breast screening program without cost to participating women

OR

2. Revert to the previous screening program i.e. stop inviting women and stop promoting screening to women aged 70-74 to participate in the government-funded breast screening program.

PART B: During this jury process, you have heard a lot of information about breast screening in 70-74 year old women. Please consider the following questions, and provide reasons for your answers:

- Of the information you have heard, which is most essential to communicate to women 70-74 before they decide whether to participate in breast screening?
- When and how should these women be told about or given access to this information?
- What should we say to citizens and policymakers to convince them that your preferred option is the best option?

Figure 1: The Charge/Question for the Jury

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