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1-1-2019

## **Citizens' juries can bring public voices on overdiagnosis into policy making**

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### Abstract

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### Disciplines

Education | Social and Behavioral Sciences

### Publication Details

Degeling, C., Thomas, R. & Rychetnik, L. (2019). Citizens' juries can bring public voices on overdiagnosis into policy making. *BMJ (Online)*, 364 l351-1-l351-6.



## ANALYSIS

# Citizens' juries can bring public voices on overdiagnosis into policy making

As practitioners and policy makers struggle to manage the risks and harms of overdiagnosis, **Chris Degeling and colleagues** contend that citizens' juries offer a way forward

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## Key messages

Overdiagnosis challenges the social contract that underpins healthcare, and community voices are often missing from the relevant policy discussions

Citizens' juries elicit the voices, values, and preferences of informed citizens who are presented with evidence based expert views

Jurors deliberate the evidence among themselves before formulating their opinions and recommendations

Citizens' juries can elucidate public values that can then be used to inform policies and practices to manage the risks of overdiagnosis

The findings can contribute to guideline development and proposed changes to disease thresholds

The process of citizens' juries align with the basic tenets of evidence based medicine and can broaden and improve the dialogue around medical uncertainty

Unnecessary and harmful interventions from overdiagnosis challenge the social and ethical contract that underpins healthcare.<sup>1,2</sup> Strategies to tackle overdiagnosis from population screening should engage with the public and consider its values and concerns.<sup>3</sup> Most high income countries develop evidence based policies to guide population screening using stringent criteria that are applied by expert panels to review the available technical evidence. Similarly, if perhaps not so systematically, expert panels collect and analyse pathophysiological and clinical evidence to determine disease thresholds and definitions.<sup>4</sup> But in both cases the final judgments on the acceptability and legitimacy of different screening policies and disease definitions are informed by the values of the decision makers, because the relative balance of harms and benefits of making changes are also subjectively weighed and valued.<sup>5-7</sup> For the deliberation sponsors (researchers, government, or other agencies), putting matters to the public can promote greater social and political engagement, public accountability, and confidence in the decision ultimately made.

Public engagement occurs on a spectrum of participation in events that aim to consult the public (consumer forums or patient groups) to more formal deliberative methods such as citizens or community juries that seek to bring lay people into structured deliberation to tackle key complex problems (box 1).<sup>8</sup> In this paper, we explore some of the advantages and limitations of

using citizens' juries to inform policy making in the complex policy areas of overdiagnosis.<sup>9</sup>

## Box 1: The characteristics of citizens' juries

First developed by the Jefferson Centre in 1970s, citizens' juries have been used to tackle issues such as reproductive technology, xenotransplantation, biobanking,<sup>8,13,25</sup> and overdiagnosis.<sup>10,11,14,20</sup> Several approaches exist, but at a minimum a group of 12-15 people are selected to meet over 2-4 days to consider and respond to a specific question. A topic, rather than an individual, is "on trial."<sup>33</sup> All citizens' juries have two phases: the first focuses on educating participants, the second on deliberation. In the first phase jurors are provided with balanced factual information from expert witnesses (of whom they can ask questions and seek clarification), such that a diverse range of potentially conflicting perspectives are considered.<sup>25,34</sup> In the second phase the group work together in facilitated session to produce a verdict or set of recommendations. Citizens' juries create the conditions for people to move beyond superficial arguments and suspicion of vested interests to understand the complexity of medical decision making and then to reflect on their own values and what is important to their communities. Consensus is encouraged but not essential; dissenting views and minority positions are included in the final report.

What distinguishes deliberative methods from other forms of public engagement is a process of iterative two way exchange between representatives of the public and the deliberation sponsor. Like all engagement methods, however, citizens' juries have been criticised.<sup>35-38</sup> The most common concerns are about the selected group being representative of the citizenry and whether a group of lay people can overcome deficits in expertise to make judgments that truly reflect their values and informed preferences.<sup>17</sup> Juries of 12-24 people cannot possibly represent a statistically characterised sample of the general public or the prevalence of views. Rather, they offer insights into how and why informed citizens prioritise concerns about complex issues like overdiagnosis and provide explanations for divergence in opinions. Participants should be recruited to capture diversity of experiences and backgrounds in a community, and the deliberation processes organised so as to redress power imbalances as much as is feasible.<sup>39</sup> When conducted in this way, citizens' juries can reveal and capture key community concerns and arguments about current or proposed policy directions and enhance accountability in decision making.

## Citizens' juries to consider screening and overdiagnosis

They are appropriate when the evidence is uncertain, and experts or stakeholder groups (or both) disagree on its implications. In relation to overdiagnosis, citizens' juries have been convened primarily by health researchers to provide research evidence for policy making that articulates values and explains the reasoning and preferences of an informed public. Juries can help those who develop screening guidelines to understand why patients go against expert advice and can inform them of the

factors that need to be explained and explicitly considered to retain public trust.

Citizens' juries are designed to allow participants to first be informed, and then to discuss, reflect, and clarify their own views about a topic rather than recording people's top-of-mind or intuitive reactions to contentious problems (like focus groups or mass surveys). In response to the question: "Should the government offer free mammography screening to all women aged 40-49?" surveys would likely capture the prevailing public mood as to the importance of helping women access preventive health services rather than a nuanced view on the implications of lowering the age related entry point for the national mammography screening programme. A citizens' jury comprising women who had never participated in screening convened in Otago, New Zealand, to answer this question. Almost all of the women had been in favour of mammography screening for women aged 40-49 at the start of the jury. By the end of its deliberations, however, the jury voted 10 to 1 against the proposal to lower the entry age because of the potential for harms and the lack of evidence of lives saved in that age group (table 1).<sup>10</sup>

Citizen juries emphasise public values and social concerns that are not part of the evidence base but could be of great importance to policy implementation. Two juries composed of Australian women aged 70-74 voted to retain invitations to mammography screening for their age group, explicitly placing a low priority on the potential for overdiagnosis in their decision making (table 1).<sup>11</sup> The reasons the jurors provided show that, once established, organised preventive health services have great symbolic value, and epidemiological evidence of an unfavourable balance of benefit to harm may not be enough to convince people of the need to stop.

Although independent evidence based expert advice on population screening is essential, good policy also relies on public trust. Through their exposure to evidence and expert opinion, the participants in these juries about mammography understood that for population screening services to be effective there must be tolerance for some degree of overdiagnosis. The women's tolerance threshold, however, seemed to be higher than that of the clinical research experts who were advising against screening. The benefits of screening, as well as the harms of screening related overdiagnosis, are experienced by otherwise healthy people. For reasons of transparency and accountability, the values and priorities of potential service users should be considered and included in guideline development and programme implementation.

## Choosing jurors, types of evidence, and framing jury questions

The policy relevance of a citizens' jury convened to tackle an important issue such as overdiagnosis will depend on three important factors: how the topic or question is posed; who sits on the jury and how they are recruited; and the engagement of policy decision makers.

### Framing question for the jurors

In the juries that we have conducted on screening and overdiagnosis the question, expert witnesses, and the evidence presented to jurors were determined by a steering committee comprising neutral experts and representatives of stakeholders from each side of the existing debates. The committee, organisers, and expert witnesses worked together to ensure that the question put to the jury was framed as "neutrally" as possible

so that the verdict was less likely to be subsequently dismissed. The quality and reputation of the experts who provided the testimony and the structured process through which they reviewed and moderated each other's presentations helped to ensure that all views presented to jurors were relevant and could be argued from the evidence.

Not every issue is suitable for deliberation. Broadly speaking, citizens' juries on screening and overdiagnosis have answered two somewhat different but overlapping policy questions: those that explicitly focus on resource allocation and those about which policy options are most justifiable and perceived to be legitimate (table 1).<sup>12</sup> Juries are most useful for public engagement when the policy options require a deep consideration of both values and evidence.<sup>13</sup>

## Juror characteristics and the type of evidence produced

Citizens' juries construct a form of "mini-public," such that composition of participants will determine how representatives the outcome is. Three juries held in Sydney, Australia, on PSA testing and overdiagnosis risks show the difference between those composed of "targeted" or "general" public (table 1).<sup>14</sup>

One of the juries comprised men of screening age (potential PSA test users) and two were composed of participants of mixed genders and ages. All juries prioritised allocating resources to support GPs to adopt an active role in supporting individual men to make decisions about PSA. But the two mixed juries wanted all the information on potential harms and benefits of PSA testing to be provided to men before they took the PSA test, whereas the all male jury did not want men burdened with uncertain and detailed information about risks associated with diagnosis and treatment until they had an adverse test result. This example shows how a jury composed of service users can provide a different perspective and insights into a different recommendation from that of one composed of members of the public who may not be directly affected by the outcome.

The findings of juries of service users provide insights into what changes to the status quo are likely to be acceptable to those affected. Juries comprising a broader range of citizens tend to reveal broader considerations, including the range of issues that may be important for weighing the fairness of resource re-allocation against a background of competing priorities.<sup>8</sup>

## Involvement by policy decision makers

Policy makers do not convene citizens' juries but tend to commission independent researchers. The explicit and public nature of the jury process and its reporting are important. It is hard to find anyone who is free from bias, and policy makers are no more likely to be neutral than researchers. Indeed, policy makers are more likely to be less skilled at setting up an objective or independent steering committee when subject to political or budgetary pressures. The juries described in table 1 were initiated by researchers, but all had clinical and policy stakeholders as expert witnesses or members of the steering committee. Public deliberation aimed at informing policy decisions around overdiagnosis should ideally involve the decision makers in the design or implementation. If the jury is organised as an independent research project then a subsequent process of "translation" or knowledge mobilisation may be required to inform decision makers of the content and significance of the verdict.<sup>15</sup> We don't mean to suggest that decision makers who engage with citizens' juries should be bound by the jury verdict or that citizens' juries cannot be legitimately done purely as research. But they are more likely

to inform policy decisions if those involved recognise the value, role, and limitations of the jury outcomes in larger political processes.<sup>16</sup> Individual clinicians and healthcare managers may find value in juries performed as research as a way to synthesise the diverse values that patients may consider when weighing up screening decisions.

## Informing policy around overdiagnosis

Where expert opinion and public opinion diverge, citizens' juries are valuable for understanding why and potentially informing future decisions about public communication and service delivery requirements to deal with patient concerns. The provision of facts, exposure to well reasoned and sometimes opposing expert opinions, and commitment to working through persistent disagreements (rather than dismissing them as deficits in understanding) can help to rebalance information gaps about overdiagnosis and the discrepancy of power between experts, decision makers, and the community affected.<sup>18 19</sup>

Between us, we have conducted more than 15 citizens' juries, several of which have considered overdiagnosis.<sup>11 14 20-22</sup> A consistent observation has been that members of the public report great surprise at the level of uncertainty embedded in medical practice. And particularly how new technologies and medical tests can create more uncertainties, rather than resolve concerns. Most people in high income countries like Australia are encultured to trust medical tests and their doctors.<sup>23</sup> They believe that doctors know the "right" thing to do.<sup>24</sup> Trust in doctors is inevitably the resource that people draw on when decisions need to be made in the face of conflicting or uncertain evidence. Citizens' juries enable them to pull back the curtain on medical evidence and engage more meaningfully in screening policy debates. In our experience, in deliberations people first looked for the embedded interests that could drive apparent differences in expert opinion. But ultimately most jurors came to both understand and feel sympathy for GPs and other care providers who must manage medical uncertainty on a day-to-day basis.

## Conclusions

If done well, citizens' juries are an effective means to conduct research that informs guideline development for population screening and disease threshold determination.<sup>12 25</sup> Much could be achieved to tackle the social and ethical dimensions of overdiagnosis if those charged with organising and regulating these processes made a commitment to formally consider the values and preferences of well informed members of the public and to understand the complex trade-offs entailed. Procedurally, citizens' juries are explicit about the limits of medicine and the pervasiveness of medical uncertainty. This fits with the basic tenets of evidence based medicine<sup>26 27</sup> and offers an authentic means to tackle issues related to overdiagnosis.<sup>28</sup>

In addition, citizens' juries have the potential to uncover other ways that health services provide value to the public, which need to be explicitly mentioned and accounted for in the implementation of policy.<sup>29</sup> Bringing the public into deliberation about overdiagnosis can broaden and improve the dialogue and make the reasons for decisions about resource allocation and potential withdrawal of services more clear and transparent, thus promoting public trust and partnerships at a time when trust in science and medical expertise seems to be in decline.<sup>30-32</sup>

Contributors: All authors contributed to the conceptualisation of the paper. CD led the drafting of the paper, with substantial contributions from RT and LR. All authors

commented and contributed to the revision of the final submitted version. CD is the guarantor.

Funding: This work was supported by NHMRC CRE 1104136 and NHMRC programme grant 1106452. The funder had no role in the conceptualisation and drafting of this paper or the decision to submit for publication.

Competing interests: All authors have completed the Unified Competing Interest form (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work

Transparency declaration: The lead author affirms that the manuscript is an honest, accurate, and transparent account of the studies being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

Data sharing: These are no further data available for sharing.

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## Table

**Table 1 | Key questions pertinent to overdiagnosis that have been tackled by citizens' juries in Australasia**

Question	Sponsors of and reasons for the jury	Specific question and jury characteristics	Verdict	Novel insights
Should governments fund cancer screening services for populations at higher risk of overdiagnosis?	Convened by health researchers in New Zealand to explore the use of citizens' juries to inform the development of population screening policy	1 jury of 11 women aged 40-49 with no previous diagnosis of breast cancer was asked: "Should the government offer free mammography screening to all women aged 40-49?" <sup>10</sup>	The jury voted (10-1) against government provision of mammography screening to this age group	Conducted in 2008, this jury established the viability of the citizens' jury method to engage members of the public in deliberations about how to manage overdiagnosis. Women who were almost all initially in favour of screening for women aged 40-49 changed their minds because of the potential for harms and the lack of evidence of lives saved in this age group. The findings showed how women weighed the benefits and harms and how withdrawing an existing service is more challenging than not offering it in the first place
What are the values and priorities that should guide decision making around the promotion of participation in screening services?	Convened by health researchers in Australia and funded by the NHMRC to examine informed men's views about the benefits and harms of PSA testing. Also established to further examine the value of citizens' juries for informing screening policy	1 jury of 11 men aged 50-70 with no previous diagnosis of prostate cancer was asked: "Should government campaigns be provided (on PSA screening) and if so, what information should be included in those campaigns?" <sup>20 22</sup>	The jury voted unanimously against government information campaigns, and against an invitation programme for PSA testing. Instead the jury proposed a campaign targeting GPs to assist them to provide better quality and more consistent information to their patients. Men's unanimous agreement on information provided by governments and GPs contrasted with the diversity in men's individual preferences on whether or not they get screened themselves	Men prefer to get information about PSA screening directly from their GPs. There were concerns about the discrepancy and variability in quality of information available to men and that some GPs were not following evidence based guidelines. This study showed that informed citizens are able to distinguish between personal preferences and deliberating to make recommendations for the public good. <sup>20</sup> A quantitative analysis of the same study showed that expert provision of information reduced jury members' intentions to screen compared with written information from Cancer Council Australia and Andrology Australia
	Convened by health researchers in Australia and funded by the NHMRC to elicit the informed views of older women on the acceptability of ceasing to invite them to use breast cancer screening services Contributions from the Cancer Council of Australia	2 juries (n=34), both comprising women aged 70-74 with no previous diagnosis of breast cancer, were asked: "Should the organised breast cancer screening programme continue to invite and promote screening to women 70-74 without cost to participating women?" <sup>11</sup>	Both juries found by a majority verdict (16 to 2 and 10 to 6) that invitations to participate in screening should continue to be sent to women in their age group	These women valued being invited to screen—they thought it was an opportunity to access information to enable choice and showed that society recognised and supported older citizens. Evidence that an intervention potentially does more harm than good may not be enough to convince people to give it up: this study found that people may consider other factors important, such as older women being valued and continuing to be offered the same options and choices as younger women
How should care providers and asymptomatic patients manage the risks of overdiagnosis at the point of care?	Convened by health researchers in Australia and funded by the NHMRC to elicit the informed preferences of citizens and potential service users as to how PSA testing of asymptomatic men should be managed in general practice. Contributions from the Prostate Cancer Foundation of Australia	3 juries (n=40); 2 of mixed genders and ages and 1 all male jury aged 37-74; no participants had experience of a prostate cancer diagnosis. They were asked: "Should GPs introduce the topic of PSA testing during appointments with male patients who have no symptoms? Or should they wait until men ask about it?" <sup>14</sup>	In contrast to the RACGP guidelines, all juries concluded (by majority vote) that GPs in Australia should initiate discussions about PSA testing with asymptomatic men over 50	Although GPs might resist raising questions about PSA testing, an informed public prefers them to take on this responsibility because, in Australia, there is a lot of divergent advice in the public sphere, and doctors are perceived to be the best placed to inform and explain the risks and benefits. Juries consistently agreed that discussions with their GP was better than men relying on finding out (or not) about PSA testing and the risks of overdiagnosis from other sources
	Convened by health researchers in Australia and funded by Bond University to explore informed community perspectives around current Australian GP practices of case finding for dementia	1 jury (n=10) of mixed genders aged 50 to 70; no participants (or their immediate family) had experience of Alzheimer's or mild cognitive impairment diagnoses or caring for an individual with these diagnoses. Jury was asked: "Should the health system encourage GPs to practise case finding of dementia in people older than 50?" <sup>22</sup>	In contrast with the RACGP guidelines, the jury voted unanimously against case finding for dementia by GPs. Participants cited lack of effective treatments and potential to negatively impact mental health. Although they disagreed with case finding as it was being practised, jurors drafted a set of	Jurors decided to go beyond the question and suggested changes to the RACGP guidelines to reduce the potential harms of current case finding practices. As above, the study showed that an informed public may have different priorities from those assumed in the clinical guidelines

**Table 1 (continued)**

Question	Sponsors of and reasons for the jury	Specific question and jury characteristics	Verdict	Novel insights
			recommendations to improve future guidelines	

GP=general practitioner; NHMRC=National Health and Medical Research Council; PSA=prostate specific antigen; RACGP= Royal Australian College of General Practitioners

BMJ: first published as 10.1136/bmj.l351 on 30 January 2019. Downloaded from <http://www.bmj.com/> on 19 February 2019 by guest. Protected by copyright.