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# Enhancing citizen engagement in cancer screening through deliberative democracy

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# Enhancing citizen engagement in cancer screening through deliberative democracy

## **Abstract**

Cancer screening is widely practiced and participation is promoted by various social, technical, and commercial drivers, but there are growing concerns about the emerging harms, risks, and costs of cancer screening. Deliberative democracy methods engage citizens in dialogue on substantial and complex problems: especially when evidence and values are important and people need time to understand and consider the relevant issues. Information derived from such deliberations can provide important guidance to cancer screening policies: citizens' values are made explicit, revealing what really matters to people and why. Policy makers can see what informed, rather than uninformed, citizens would decide on the provision of services and information on cancer screening. Caveats can be elicited to guide changes to existing policies and practices. Policies that take account of citizens' opinions through a deliberative democracy process can be considered more legitimate, justifiable, and feasible than those that don't. 2013 The Author.

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## Enhancing Citizen engagement in Cancer Screening through Deliberative Democracy

Lucie Rychetnik, Stacy M. Carter, Julia Abelson, Hazel Thornton, Alexandra Barratt, Vikki A. Entwistle, Geraldine Mackenzie, Glenn Salkeld, Paul Glasziou (2013)

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### Abstract

Cancer screening is widely practiced and participation is promoted by various social, technical, and commercial drivers, but there are growing concerns about the emerging harms, risks, and costs of cancer screening. Deliberative democracy methods engage citizens in dialogue on substantial and complex problems: especially when evidence and values are important and people need time to understand and consider the relevant issues. Information derived from such deliberations can provide important guidance to cancer screening policies: citizens' values are made explicit, revealing what really matters to people and why. Policy makers can see what informed, rather than uninformed, citizens would decide on the provision of services and information on cancer screening. Caveats can be elicited to guide changes to existing policies and practices. Policies that take account of citizens' opinions through a deliberative democracy process can be considered more legitimate, justifiable, and feasible than those that don't.

In 2007 in New Zealand, 80 women aged 40 to 49 years were selected randomly from the electoral roll and invited, by letter, to participate in answering an important policy question: Should the New Zealand government offer free screening mammograms to women of their age? Of those original 80 women, 46 could be contacted, 17 agreed to take part, and the first 12 to reply were invited to attend (1). The 11 women who were able to attend the first meeting believed, like many citizens in developed countries (2,3), that screening for cancer was a good thing to do. They all supported mammography for women of their age. The group was briefed on the topic on a Wednesday evening. That Friday they heard presentations from a range of cancer screening experts, with opportunities to ask questions, examine the evidence, and deliberate among themselves with support from an independent moderator. The next morning they conferred again, and then, with no advisors present, they reached a conclusion on the question posed. Their answer? At 10 : 1, they now voted against recommending government provision of mammographic screening for women aged 40 to 49 years. They also provided two lists: a list of reasons for their decision, and a list of provisos for their decision (1).

We cite the example above to illustrate the process of deliberative democracy, an approach that has been proposed and modelled around the world to elicit citizens' values and priorities on challenging or controversial issues (4–9). In this commentary, we propose that application of deliberative democracy methods to inform policies about cancer screening is timely and offers great potential in terms of enhanced accountability. We will describe what deliberative democracy methods entail and their potential contribution to health policy, why such an approach is needed to inform cancer screening, and what types of policy questions might be considered.

### **Deliberative Democracy Methods: What They Are and What They Offer**

Deliberative democracy methods are used to engage citizens in formal iterative dialogue on important and complex problems. There are many forms of deliberative methods available, including citizens juries, consensus conferences, deliberative polling, study circles, and citizens assemblies, as well as emerging options online (9,10). Such methods engage participants in a two-way process of information exchange between the sponsor (e.g., government or other agency) and the public, thus distinguishing them from other types of citizen engagement, such as public communication (where the sponsor informs public) or public consultation (where the public informs the sponsor) (10,11). The primary goal of deliberative democracy is to bring peoples' opinions and values into a policy process while attempting to address concerns that public opinion may be ill-informed, poorly considered, or insufficiently responsive to alternative points of view (12–15). Hence most deliberative methods share the following essential core elements: they 1) provide balanced factual information; 2) seek to include people with diverse perspectives and potentially conflicting views; 3) create opportunities to reflect and discuss issues freely and to challenge and test competing claims; and 4) are potentially transformative for the participants. These elements are intended to ensure the views arrived at are informed, robust, and reliable (6,8,10,11,16). Policies that take account of citizens' opinions through a deliberative democracy process can be considered more legitimate, justifiable, and feasible than those that don't (17).

Public deliberations can be affected by the questions posed, the choice of presenting experts, and the self-selection of participants. An early experiment with these methods has been subject to much controversy because it was framed in a process of health-care rationing (18). Clarity about the purpose and scope of deliberations, intended representation, and the recruitment of participants will enhance the validity and relevance of the output (19). Other process measures to support credible deliberations include random selection of participants, a steering committee to oversee selection of presenting experts, and an independent facilitator (20). A trial of public deliberation methods overseen by the Agency for Healthcare Research and Quality will provide important empirical data on the strengths and limitations of alternative approaches (21). Also important are broadening the reach and scale of public deliberations and finding the best way of integrating the outputs of deliberations into policy decisions (22). Research in these areas would offer important synergies with existing initiatives that seeks to enhance citizen engagement in health research, such as the Patient-Centred Outcomes Research Institute (23,24).

Finally, to avoid public disillusionment, it is important to clarify whether a deliberation is integral to a policy development process or conducted for research or advocacy. For real policy impact, there must be genuine commitment from policy makers to incorporate the results into their decisions (5). Deliberative democracy does not replace the formal moral reasoning offered by ethicists (25). But by creating conditions in which members of the public can have informed discussions of collective problems [and reframe the problems if required (26)], deliberative processes can result in more just

and accountable recommendations on what ought to be done and contribute to more responsive policies (8,22,27).

### **Why Deliberative Democracy Has Merit for Cancer Screening Policy**

Deliberative methods are particularly useful for questions in which values, ethics, and evidence are important and people need time to fully understand and consider all of the relevant issues (8,17). Deliberative methods can also identify areas of common ground on contentious issues and investigate balanced solutions to difficult problems (11,17). Deliberative democracy is thus most valuable for the following policy conditions (5,7,17):

1. When the issue is of great public importance (e.g., affects many people or affects a smaller number of people profoundly, consumes considerable public funds, is about the public good or what “we” as a community should do);
2. When the impact of a policy decision is morally significant (e.g., there are important conflicts between ethical considerations such as beneficence, respect for autonomy, reciprocity, or justice);
3. When the policy decision requires an understanding of the evidence but cannot be resolved by technical or scientific evidence alone (e.g., there is disagreement among experts, decision depends strongly on the values people hold, and opinions are likely to be diverse); and
4. When there is ongoing controversy and need for resolution (e.g., the status quo is contested, debates are divisive as advocates push in different directions, or there is scope to inform and enhance the legitimacy of a politically sensitive decision).

The remainder of this paper outlines how these conditions apply to cancer screening and how deliberative democracy methods offer a way forward.

### **The Public Importance of Cancer Screening**

The past three decades have led to wide-spread institutionalization of many types of cancer screening. Most of this is conducted in three contexts:

- 1) dedicated programs organized at a population level (e.g., government programs screening for breast cancer, cervical cancer, and bowel cancer);
- 2) opportunistic screening offered within health-care encounters [e.g., Prostate-Specific Antigen (PSA) testing for prostate cancer (28)]; and
- 3) through tests purchased by individual consumers in a commercial market [e.g., full- or part-body computed tomography scans for lung, colon, or other cancers (29)].

In most developed countries, recommended forms of screening for cancers such as breast cancer, cervical cancer, or bowel cancer have been actively promoted, with the public encouraged to participate through recruitment strategies such as television advertisements and targeted invitation letters or reminders. Participation rates are often identified as key performance indicators for centrally organized programs (30). There is often also poor understanding of the limitations and downsides of cancer screening, both among the general public and among clinicians (3,31–33). Technological developments and their promotion by those with interests in the new technologies

have further contributed to the rise in cancer screening (34–36). And privately and commercially available screening options continue to increase (37). Thus in a positive-feedback cycle, the promotion of screening has fed public expectations and public demand, and governments have in turn responded to the public discourse about cancer screening rights and entitlements (35). Notably, even cautious changes to screening guidelines can lead to vocal backlash from clinicians, public advocates, and politicians when the revisions involve scaling back established screening activity (38–41). As a result, it can be difficult to revise cancer screening policy in line with the evolving evidence when this suggests a need to screen less.

Concerns about the risks and harms of cancer screening are growing in the medical literature, particularly regarding PSA screening for prostate cancer (28) and, increasingly, mammography for breast cancer (42,43). There are also concerns that screening for all types of cancer is being practiced as an unquestioned component of routine health care (44). For example, doctors may recommend or initiate PSA testing without discussing the limitations or potential harms with their patients (45), and most pamphlets on mammography promote the benefits of screening but don't address its limitations and harms (46–49). And although some screening, such as for cervical cancer, is widely accepted as beneficial, physicians may incorporate it into routine health examinations without patients understanding what has been done or the potential implications for them (50,51). Such concerns raise the challenge and importance of informed consent in cancer screening (52–54) and the need for decisions about participation to be appropriately supported (55,56) and highlight the benefits of shared decision making (57). It is also apparent that some people prefer to be advised and want clear expert guidance on what to do (58–60).

### **The Moral Significance of Cancer Screening**

Cancer screening raises a number of ethical concerns about issues such as consent, respect for autonomy, non-maleficence, and justice. These concerns arise from the nature of screening (61) and appear heightened with screening for cancer. The ethically important characteristics of screening that make the public accountability of policy and practice imperative include:

- the targeting of people who have no identified symptoms, thus potentially converting healthy individuals into patients (this problem is worse when there are substantial rates of overdiagnosis) (62);
- the initiation of screening by the health sector and not by the individuals to be screened (i.e., a screening program, other health sector body, or health-care provider raises public awareness of the risk of cancer and promotes the apparent need to be screened); and
- the delivery of screening to very large numbers of people, of whom some will benefit but some will be adversely affected.

All screening is based on the rationale that early detection and early treatment of disease can benefit health and well-being, but it should only be offered when there is good evidence that the potential benefits outweigh the potential harms (63–65). Early evaluations found some benefits from cancer screening, but subsequent evidence also identified a number of harms. Harms can arise from overdiagnosis of indolent cancers (28,43,49,66–69) and the strong imperative to treat, as well as from false negatives, false positives, and invasive confirmatory tests (70–73). New screening technologies with increased sensitivity (e.g., magnetic resonance imaging for breast cancer screening) raise concerns about increasing overdiagnosis and overtreatment of cancers (42,74–77).

As the uncertain balance of benefits and harms becomes more apparent, greater attention is being given to supporting adequately informed choice and respecting individual autonomy rather than pursuing active recruitment to maximize the uptake of cancer screening (56,78,79). Yet even offers of screening have potential to harm individuals if those who decline are left with guilt about their choice or anxiety about whether they made the right decision (56,80,81). The public perception, created by the health sector, that cancer screening is good feeds, in turn, normative expectations of screening as the “right” thing to do. Many believe that even an 80-year-old who chooses not to be screened for cancer is irresponsible (32). To undo the notion that to participate in screening is a form of obligation (41,82) will require shifts in current perceptions about the benefits and harms of cancer screening and changes to cancer screening policy and practices.

Cancer screening can also serve or undermine social justice (83). Those concerned about justice in screening often emphasize equity of access to screening services and have sought to increase recruitment among cultural minorities or groups of lower socioeconomic status. But equal access does not ensure social justice, and other considerations must be taken into account. For example, a favourable balance of the benefits and harms of screening in the particular target group is vital, as is the availability of sufficient, affordable, and high-quality treatment for those in whom cancer is detected. Further, how screening is offered is important, including whether communications support or undermine respect, personal security, and self-determination (51,77). Strong persuasion tactics may diminish individuals’ opportunities to be informed about the harms of screening, erode their ability to reason clearly about their screening choices, or undermine their sense of personal security if it generates new fears about developing cancer. Such effects occur at collective as well as individual levels, so that when particular populations are targeted, the undermining of social justice can be amplified. When the benefit/harm ratio is finely balanced, these problems are less likely to be countered by real improvement in health outcomes.

### **Evidence Alone Is Not Sufficient to Guide Cancer Screening Policy and Practice**

Many developed countries employ systematic processes to guide evidence-based recommendations and policies on cancer screening, incorporating rigorous criteria for reviewing the technical evidence (84–86). But final judgments on the overall merits of policies on cancer screening are informed by the values of the decision makers, as the relative benefits and harms, the probabilities of these occurring, and the costs of screening must be subjectively weighed and valued (87). The interrelated policy and practice questions of primary public interest are: What types of cancer screening should be offered, to whom, and how should this be done? These evaluations have practical implications for which types of cancer screening should be centrally organized and publicly funded (88) and what community-level regulations, or even restrictions, should be imposed when evidence of a potential net harm becomes more apparent. It has also been suggested we need transparent conversations about the opportunity costs of cancer screening relative to other interventions, such as primary prevention of cancer (e.g., human papillomavirus vaccination, obesity prevention) and cancer treatment services (see Box 1) (40).

The substantial harms associated with some forms of cancer screening may become so concerning as to sway the distribution of resources, but people vary in what harms and costs they consider worthwhile to save a life (1).

**Box1: Important questions for cancer screening policy and practice that draw on evidence and values and could be informed by deliberative democracy methods**

1. For which cancers should screening be offered?
2. To whom should this screening be offered (e.g., age groups)?
3. How should this screening be offered?
4. For which cancers should screening be centrally organized and publicly funded?
5. What regulations, or even restrictions, should be imposed when the potential for a net harm becomes apparent?
6. What proportion of resources for cancer should be allocated to screening relative to other interventions, such as primary prevention and cancer treatment services?

Population-level decisions to support screening also create dilemmas for individuals. To make an informed choice, potential participants weigh uncertain personal benefit against uncertain harms, and questions such as “Will this test save my life?” and “Will this test harm me?” cannot be answered to guide their choice. Thus, although policy decisions require different types of considerations to those undertaken in clinical settings, both kinds of decisions have implications that require an explicit examination of ethics and values, as well as the scientific evidence.

**Some Forms of Cancer Screening are Hotly Contested and There Is a Need for Resolution**

Some of the main controversies in cancer screening have emerged when new evidence is presented to challenge the status quo, such as when a systematic review has major implications for an existing screening program [e.g., (68)]. The stakes become even greater when evidence-based guidelines are revised to recommend less frequent screening [e.g., (89,90)], or no screening [e.g., (66,91,92)] against the prevailing trends of clinical practice. As noted before, screening for prostate cancer has always been disputed. For example, in a 2002 “PSA Storm,” two experts opposed to PSA screening in the San Francisco Chronicle were bombarded with “accusations, abuse, and threats” (93). More recently the creator of the PSA test wrote that he “never dreamed that my discovery four decades ago would lead to such a profit-driven public health disaster” (94,95). Updated evidence (96,97) and a revised US Preventive Services Task Force recommendation against prostate cancer screening have added firmer ground to deliberations but have not resolved what the appropriate policy and practice response should be (91,98,99).

Expert opinion is also divided on the implications of current evidence for continuing to offer mammography screening (69,100–105). Mammography was already a “highly emotional” controversy in 1977, with experts strongly divided on whether screening programs would “save many lives” or “produce potentially fatal illness” (106). More than 30 years later, the potential harms of the since well-established screening programs are again hotly contested (42,57). Such conflicts result in confusing public communication [e.g., (107)] and can erode public trust in clinical and public health expertise (108).

**A Way Forward to Guide Cancer Screening Policy and Practice: Combining Evidence and Citizens’ Values Through the Methods of Deliberative Democracy**

The New Zealand case study cited at the beginning of this commentary provides a striking example of the potential value of a focused deliberative process to facilitate informed public examination of a cancer screening policy. The process generated detailed information on what these informed women considered important and why for a mammography policy that might affect them. This

information included detailed provisos for their decision, such as that although they would not recommend commencing mammography for women aged 40 to 49 years, the existing policy of allowing access to free screening from age 45 should not be changed back to 50 (1). Another deliberative process on colorectal cancer screening, conducted in Ontario, Canada, identified important public concerns that had not been considered by the previously consulted scientific expert panel. This included the lack of public information about all screening options and the potential impact on the patient–provider relationship for those who don’t wish to be screened (12,17). Many stakeholders contribute to cancer screening policies, including clinician groups, laboratories and device manufacturers, patient advocacy groups, cancer charities and research groups, screening funders, and service providers, but there has been limited formal engagement of the public who are potential recipients of screening. The information derived from a deliberative democracy process can redress this by providing important guidance on cancer screening policies in the following ways:

- Citizens’ values and priorities are made explicit, thereby revealing what really matters to people in cancer screening, and why;
- Decision makers can see what informed, rather than uninformed, citizens would decide on the provision of services and information on cancer screening;
- Caveats can be elicited to guide potential changes to existing policies and practices;
- The information gained can be used to communicate about cancer screening policies, thus potentially increasing both the legitimacy and perceived legitimacy of the policy process; and
- The information gained can also contribute toward supporting individuals making decisions about screening, enabling them to develop and clarify their own values and priorities by comparing them with the values and priorities of others.

As indicated earlier, the process of deliberation on cancer screening must pay attention to issues of representation and recruitment (e.g., whether deliberations should recruit from the general population or only from the target group for a particular type of screening). It may be important to strike a balance between those who have not yet participated in a type of screening (e.g., PSA testing or mammography) and those who have already been screened—with and without adverse effects. Also important is policy-level commitment to the outputs of deliberations. There should be clear and demonstrable links between the public deliberation process and screening policy decisions, so everyone is clear on how the output of deliberations will be considered by relevant decision makers. And finally, longer-term commitments to a number of deliberations over time that address a range of different cancer screening policy decisions will offer a more complete picture of what citizens value in cancer screening and why than one-off deliberations around a single topic.

In conclusion, cancer screening is an important public issue and government policies must somehow accommodate and reconcile disputed interpretations of the evidence. Although independent evidence-based expert advice on cancer screening is essential, government policies are invariably also influenced by the prevailing political climate, resource and other constraints, and the beliefs and priorities of those with political influence (38,39,109). For cancer screening policies to be sufficiently accountable, it is essential that policies also reflect the priorities and values of affected citizens. We propose that deliberative democracy methods could assist in resolving important questions about existing cancer screening practice and programs and improve future public accountability in this highly contested area.

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