Supplement 1

Table S1: Search Strategy

Database Name	Search Strategy	# hits
Ovid	1. (citizen* or patient* or public* or	666
MEDLINE(R)	stakeholder* or deliberat*).mp	
In-Process &	2. (panel* or jur* or deliberat* or conference*	
Other Non-	or dialogue* or poll* or map* or engag*).mp	
Indexed	3. (health* or "public health" or clinical).mp	
Citations, Ovid	4. Polic*.mp	
MEDLINE(R)	5. 1 ADJ 2	
Daily and Ovid	6. 3 AND 4 AND 5	
MEDLINE(R)		
1946 to 2017		
April 13		
Embase 1974	1. (citizen* or patient* or public* or	823
to 2017 April	stakeholder* or deliberat*).mp	
13	2. (panel* or jur* or deliberat* or conference*	
	or dialogue* or poll* or map* or engag*).mp	
	3. (health* or "public health" or clinical).mp	
	4. Polic*.mp	
	5. 1 ADJ 2	
	6. 3 AND 4 AND 5	
Health	1. citizen* or patient* or public* or stakeholder*	52
Evidence	or deliberat*	
(1996-2017)	2. panel* or jur* or deliberat* or conference* or	
	dialogue* or poll* or map* or engag*	
	3. polic*	
	4. 1 AND 2 AND 3	
Health Systems	Filters: Consumer participation in policy and	725
Evidence	organizational decisions, consumer participation in	
(accessed 2017	systems monitoring, consumer participation in	
April 13)	service delivery	
_ ,		
CINAHL (1981	1. citizen* or patient* or public* or stakeholder*	254
to 2017 April	or deliberat*	
13)	2. panel* or jur* or deliberat* or conference* or	
	dialogue* or poll* or map* or engag*	
	3. health* or "public health" or clinical	
	4. Polic*	
	5. 1 W1 2	
	6. 3 AND 4 AND 5	

	Search limits for the above keywords: all authors, all	
	subjects, all keywords, all title information (including	
	source title) and all abstracts.	
Cochrane	1. citizen* or patient* or public* or stakeholder* or	72
Library (Issue	deliberat*	
7 of 12, April	2. panel* or jur* or deliberat* or conference* or	
2017)	dialogue* or poll* or map* or engag*	
,	3. health* or "public health" or clinical	
	4. Polic*	
	5. 1 AND 2 AND 3 AND 4	
Comprehensive	Similar search terms to those identified above were	20
search of	iteratively used to identify pertinent literature.	additional
included study		documents
reference lists,		were
Open Grey,		identified
Grey		
Literature		
Report, and		
targeted		
websites		

Table S2: Conceptual mapping and data extraction form

Coding Domain		
Descriptive Characteristics		
Theme of engagement		Policy about clinical issues (e.g., service re-
		design)
		Policy about public health issues
		Policy about health system issues
Purpose of engagement (from		Circulating information
http://www.nlc.org/documents/Find%		Discussing and connecting
20City%20Solutions/Research%20Inn		Gathering initial input
ovation/Governance-Civic/1-1-types-		Recommending
and-levels-of-public-engagement.pdf)		Deciding and acting
Form of deliberation (from		Citizen panel
http://sro.sussex.ac.uk/47855/1/See_th		Citizens' jury
rough_science.pdf page 41)		Deliberative polling
		Consensus conference
		Stakeholder dialogue
		Internet dialogue
		Deliberative mapping
Document Characteristics		
Year of publication		
Years of data collection (if applicable)		
Methods used/type of paper	a.	Empirical studies
71 11		☐ Systematic review (needs to have explicit
		search and selection criteria)
		□ RCT
		□ Interrupted time series
		□ Before-after study
		□ Cross-sectional
		□ Cohort study
		□ Qualitative study
		□ Case study
		☐ Mixed methods (select other methods as
		applicable)
		□ Other (specify)
	b.	Scholarly Commentaries
		□ Review (not systematic)
		☐ Theory or position paper
		□ Editorial
	c.	Publicly Available Organizational Documents
		□ Evidence or citizen briefs
		□ Discussion paper
Publication status	□P	Peer-reviewed journal
		Non peer-reviewed journal
		Grey literature

Country or region focus (specify)	□ High-income
	□ Low- and middle-income

- 1. Data extractor:
- **2.** RefID (or list source if not from database searches):
- **3.** Title:
- **4.** Authors:
- **5.** Describe the focus of the document (using one phrase if possible)
- **6.** Summary of key findings or insights from the document related to synthesizing and summarizing research evidence to support informed citizen deliberations (e.g. describe in detail the type of policy involved, the structure of the deliberation and the type of evidence used to inform the deliberation) (1-2 paragraphs)

^{*}Categories to revised and supplemented during the title and abstract review phase.

Table S3: Characteristics of the included studies

Title, author, year	Study characteristics	Study Focus	Summary of findings
Assessing the impacts of citizen deliberations on the health technology process Abelson J.; Bombard Y.; Gauvin FP.; Simeonov D.; Boesveld S. 2013	Theme of engagement: Policy about health system issues Purpose of engagement: Recommending Form of deliberation: Citizen panel Methods used/type of paper: Case study Publication status: Peer-reviewed journal Country or region focus: Highincome	Citizens' Reference Panel on the deliberations of a provincial health technology advisory committee and its secretariat, which produce, recommendations for the use of health technologies in Ontario, Canada	The panel met on 5 separate occasions over 18 months. Each day was a facilitated structured deliberation session, preceded by an overview presentation and Q&A on the background of the topic. Background materials were circulated in advance of each meeting including: HTA materials provided by MAS (e.g., evidence summaries, draft recommendations), review articles, newspaper clippings and a workbook, which summarized the key attributes of each technology suitable for a lay audience and the discussion questions for deliberation. Deliberations were a combination of large and small (self-facilitated) group discussions. At the end of each small group deliberation, the group reported back to the large group on thematic summaries of common ground and highlighting points
Citizens' perspectives on personalized medicine: A qualitative public deliberation study Bombard Y.; Abelson J.; Simeonov D.; Gauvin FP. 2013	Theme of engagement: Policy about health system issues Purpose of engagement: Gathering initial input Form of deliberation: Citizen panel Methods used/type of paper: Case study Publication status: Peer-reviewed journal Country or region focus: High-income		A 14-person Citizens' Reference Panel on Health Technologies was convened during five, one day deliberations to discuss ethical and social values around HTA. "Material on each deliberation topic was circulated one week in advance of each meeting using a workbook format which included topic summaries geared toward a lay audience and a set of discussion questions. Relevant newspaper and/or summary articles on the topic were also pre-circulated. Each deliberation featured a presentation by the meeting facilitator a guest presenter, followed by a Q&A session and
Eliciting ethical and social values in health technology assessment: A participatory approach Bombard, Y, Abelson, J, Simeonov, D, Gauvin, F-P 2011	Theme of engagement: Policy about health system issues Purpose of engagement: Recommending Form of deliberation: Citizen panel Methods used/type of paper: Case study Publication status: Peer-reviewed		either externally-facilitated or self-facilitated discussion around pre- circulated questions in large and small groups." A 14-person Citizens' Reference Panel on Health Technologies was convened during five, one day deliberations to discuss ethical and social values around HTA. "Material on each deliberation topic was circulated one week in advance of each meeting using a workbook format which

	journal Country or region focus: High- income		included topic summaries geared toward a lay audience and a set of discussion questions. Relevant newspaper and/or summary articles on the topic were also pre-circulated. Each deliberation featured a presentation by the meeting facilitator a guest presenter, followed by a Q&A session and
Consulting Ontario citizens to inform the evaluation of health technologies: The Citizens' Reference Panel on Health Technologies. Abelson, J.; Wagner, F.; Levin, L.; Bombard, Y.; Gauvin F. P.; Simeonov, D.; Boesveld, S.	Theme of engagement: Policy about health system issues Purpose of engagement: Recommending Form of deliberation: Citizen panel Methods used/type of paper: Case study Publication status: Peer-reviewed journal Country or region focus: Highincome		either externally-facilitated or self-facilitated discussion around pre- circulated questions in large and small groups."
Genetics, insurance and participation: how a citizens' jury reached its verdict. Bennett P; Smith SJ 2007	Theme of engagement: Policy about health system issues Purpose of engagement: Recommending Form of deliberation: Citizens' jury Methods used/type of paper: Case study Publication status: Peer-reviewed journal Country or region focus: Highincome	Reports on the use of a citizens' jury to to explore whether and how genetic testing should be used as a part of a health risk assessment for life insurance.	The Edinburgh Citizens' Jury on Genetic Test Results and Life Insurance aimed to explore whether and how genetic testing should be used as a part of a health risk assessment for life insurance. The 14 member jury, selected to represent the population's diversity, engaged in a three day process. On the first day, expert witnesses presented background information on the basics of life insurance, genetic testing, and existing policy in both domains. The experts involved included a chief Underwriter, a Public Health Geneticist and a Researcher specializing in the intersection between genetic testing and insurance policy. On the second day, three policy advocates presented and defended post-moratorium policy models. On the third and final day, the jurors asked additional questions to a panel of witnesses and advocates before finally presenting a 'verdict' in favor of one policy.
Biobanking in British Columbia: Discussions of the future of personalized medicine through deliberative public engagement Burgess M.; O'Doherty K.; Secko D. 2008	Theme of engagement: Policy about health system issues Purpose of engagement: Recommending Form of deliberation: Citizen panel Methods used/type of paper: Case study Publication status: Peer-reviewed journal Country or region focus: Highincome	Reports on a series of deliberations aimed at gathering citizen input and recommendations to inform the governance and policy of biobanks in British Columbia	The citizen forum occurred over 2 non-continuous weekends, which both included presentations and moderated large-group discussions (where the moderator was not a content expert). Participants received an 18-page booklet including three pages of glossary in advance of the event. The materials were based on the team's review of the relevant literature and media. These reviews were then summarized to target an audience that may have little or no previous knowledge of scientific, regulatory, indigenous, racial, disability and religious perspectives related to biobanking, as well as to provide a diverse and accurate representation of current debates. This booklet was not vetted and instead provided to expert presenters prior to the event, who were asked to expand, challenge and clarify on the booklet,

Managing the introduction of biobanks to potential participants: Lessons from a deliberative public forum O'Doherty K.; Ibrahim T.; Hawkins A.; Burgess M.; Watson P. 2012

Theme of engagement: Policy about health system issues Purpose of engagement: Recommending

Form of deliberation: Citizens'

jury

Methods used/type of paper: Case

study

Publication status: Peer-reviewed

journal

Country or region focus: High-

income

Engaging the public on biobanks: Outcomes of the BC biobank deliberation O'Doherty K.C.; Burgess M.M. 2009 Theme of engagement: Policy about health system issues Purpose of engagement: Recommending

Form of deliberation: Citizen panel Methods used/type of paper: Case

study

Publication status: Peer-reviewed

journal

Country or region focus: High-

income

Involving citizens in the ethics of biobank research:
Informing institutional policy through structured public deliberation
O'Doherty K.C.; Hawkins
A.K.; Burgess M.M.

2012

Theme of engagement: Policy about health system issues Purpose of engagement: Recommending

Form of deliberation: Citizen panel Methods used/type of paper: Case

study

Publication status: Peer-reviewed

journal

Country or region focus: High-

income

Understanding an informed public's views on the role of evidence in making health care

Theme of engagement: Policy about health system issues Purpose of engagement: Gathering

Presents informed public views on the role of evidence in health care decisions if needed. These advance materials were supplemented by a Lego® model, an annotated bibliography with sample articles and media reports, five expert speakers (on scientific practices, privacy/legislation/confidentiality, genetic discrimination, aboriginal perspectives, community benefits) and information researched and introduced by participants provided by experts in response to participant questions. The combination of these efforts served to inform the participants on a wide spectrum of viewpoints concerning biobanks.

Day 1 of the deliberation was geared towards information provision and an introduction to deliberation. Days 2 and 3 were dedicated to deliberating the five topics for which the BioLibrary sought input. Day 4 involved interaction with a panel composed of senior BioLibrary staff and a ratification process of the previous days' resolutions. Deliberations were conducted in the large group (all participants) and three small groups. Expert speakers did not participate in deliberation as the involvement of experts in deliberation can cause lay voices to be marginalized. For each topic, participants received an initial briefing in the large group, followed by detailed discussion and exploration of the topic in the small groups. Importantly, no decisions were reached in the small group discussions. Deliberation with the aim of achieving group recommendations occurred in subsequent large group discussions.

The Community Forum Deliberative Methods Demonstration project, sponsored by the Agency for Healthcare Research and Quality, obtained informed public views on the role of evidence in health care decisions

decisions Carman K.L.; Maurer M.; Mangrum R.; Yang M.; Ginsburg M.; Sofaer S.; Gold M.R.; Pathak-Sen E.; Gilmore D.; Richmond J.; Siegel J. 2016	initial input Form of deliberation: Focus Group Methods used/type of paper: RCT Publication status: Peer-reviewed journal Country or region focus: High- income		through seventy-six deliberative groups involving 907 people overall, in the period August–November 2012. Although participants perceived evidence as being essential to high-quality care, they also believed that personal choice or clinical judgment could trump evidence. All participants were given reading materials before deliberating. The materials described the six components of high-quality care as defined by the Institute of Medicine, followed by plain-language descriptions of medical research, medical evidence, and comparative effectiveness research. Consumer testing of draft materials was conducted during three rounds of in-depth interviews, with nine to twelve people per round. The testing assessed users' understanding and whether materials were perceived as being unbiased. The final materials incorporated consumer feedback. During each deliberative group session, facilitators posed the following question: Should individual patients, their doctors, or both be able to make any health decisions no matter what the evidence of medical effectiveness shows, or should society ever specify some boundaries for these decisions? This overarching question required participants to understand how medical evidence is generated and used and to discuss the trade-offs for individuals and society when evidence is or is not applied in medical decisions."
Does the public think it is reasonable to wait for more evidence before funding innovative health technologies? the case of PET scanning in Ontario Chafe R.; Merali F.; Laupacis A.; Levinson W.; Martin D. 2010	Theme of engagement: Policy about health system issues Purpose of engagement: Gathering initial input Form of deliberation: Citizen panel Methods used/type of paper: Case study Publication status: Peer-reviewed journal Country or region focus: Highincome	In determining whether to fund certain innovative health technologies, the public's opinion was saught to see where their support would lie, and to examine the lay public's views on a case in which patients' publicly funded access to an innovative health technology is being delayed until there is sufficient evidence to justify a coverage decision.	The council meeting began with presentations from four experts, who explained the technology, its relation to other diagnostic imaging modalities, the possible benefits it may have for cancer patients, the possible use of PET scans for diseases other than cancer, and the costs associated with the technology. The experts reviewed the history of the Ontario government's position on funding PET scans, in particular the amount and quality of evidence available about the clinical impact of PET scanning, and provided an update on the status of five clinical trials currently under way in the province. None of the trials were completed at the time of the council meeting. One expert presented arguments for and another provided arguments against the approach Ontario has taken regarding PET scanning. At the start of the second day, another expert who was directly involved in the government's decision to initiate the research trials presented and answered questions from the council. For deliberation, the council was divided into 3 small, facilitated groups to discuss two questions. The groups then met and presented each other their conclusions, and then agreed on a joint conclusion.
Accepting new patients: What does the public think about Ontario's policy? Chafe, Roger; Laupacis,	Theme of engagement: Policy about health system issues Purpose of engagement: Deciding and acting	The College of Physicians and Surgeons of Ontario introduced a new policy on how family physicians should accept new	Citizen deliberants received copies of copies of a new policy concerning how family physicians accept new patients into their practices at the beginning of the session. Following, a family physician, a representative from the College of Physicians and Surgeons of Ontario, and a

Andreas; Levinson, Wendy	Form of deliberation: Citizen panel	patients into their practices and	representative from the Ontario College of Family Physicians presented
2011	Methods used/type of paper: Case study Publication status: Peer-reviewed journal Country or region focus: Highincome	were seeking public input.	their perspectives on various issues relevant to the policy. Deliberants had the opportunity to question all three presenting experts.
Genetics on stage: public engagement in health policy development on preimplantation genetic diagnosis. Cox SM; Kazubowski-Houston M; Nisker J 2009	Theme of engagement: Policy about health system issues Purpose of engagement: Discussing and connecting Form of deliberation: Focus Group Methods used/type of paper: Qualitative study Publication status: Peer-reviewed journal Country or region focus: Highincome	Presents the findings of a theatre-based public deliberation intended to generate informed discourse on the ethics and policy surrounding preimplantation genetic diagnosis (PGD)	The study describes the use of theatre, large group discussions, and small group discussions, to gather public perspectives informing policy on preimplantation genetic diagnosis (PGD), a method used to select for specific genetic characteristics during the in-vitro fertilization (IVF) process. The musical "Orchids", presented 14 times across Canada, was designed to present varied stories and perspectives on what normalcy means in the realm of PGD. Over the course of the play, the audience is introduced to a woman hoping to use PGD to reduce the chance her child has a genetic condition, a woman hoping to use IVF to bypass blocked fallopian tubes, a scientist who reflects positively on the power of genetics to reduce genetic diseases, and a doctor who worries how genetic selection will influence how society views persons with disabilities. Following the musical, the audience immediate split into large group and smaller focus group sessions to discuss their reactions to and the policy implications of PGD. Following, researchers codified and synthesized audience perspectives.
An innovative participatory method for newly democratic societies: the 'civic groups forum' on national health insurance reform in Taiwan. Deng C; Wu C 2010	Theme of engagement: Policy about health system issues Purpose of engagement: Recommending Form of deliberation: Citizen panel Methods used/type of paper: Case study Publication status: Peer-reviewed journal Country or region focus: Highincome	A discussion of national health insurance premium reform in Taiwan	The organizers provided panelists with comprehensible reading materials two weeks in advance that introduced the National Health Insurance (NHI in Taiwan, gave background knowledge on the two issues being deliberated, and outlined the advantages and disadvantages of the decision options posed by each of the six policy questions. A summary of the readings was also prepared. Day 1 contained a presentation about deliberative participatory methods, and an expert lecture on the base issue Panelists were then broken up into their source group (health care provide association, labour union, social welfare organization, patient organization with a moderator to raise policy questions and collect concerns. They then heard expert testimony (3 experts-panel with conflicting viewpoints) and wrote a concluding report. The same process was repeated on day 2, but with the second issue. Each group then reported their preferences on options, along with their rationales.
Animal spare parts? A Canadian public consultation on xenotransplantation	Theme of engagement: Policy about health system issues Purpose of engagement:	6 citizens fora that were held to gauge the public's opinion on conducting xenotransplantation,	Participants received a briefing paper designed to comprehensively cover key scientific and socio-ethical-legal issues in xenotransplantation 1-2 weeks in advance of the deliberation. Day one of the deliberation contains

Einsiedel E.F.; Ross H. 2002	Recommending Form of deliberation: Citizen panel Methods used/type of paper: Case study Publication status: Peer-reviewed journal Country or region focus: High- income	the use of animal cells, tissues and organs for humans.	a social, an introduction, and the screening of a documentary on xenotransplantation. Day 2 was open to the public, and had expert presentations by the following parties: Infectious disease specialist, legal expert, bioethicist, animal welfare representative, and transplant patient. It started with 8-minute presentations by the first set of three experts. Each presentation was followed by a brief opportunity for questions of clarification. The three presentations were then followed by an hour of questions and answers by the citizen panelists. After a brief coffee break, the second set of three experts gave their presentations with a similar interaction pattern. The lunch break allowed the citizen panelists a further opportunity for discussion with the expert panelists. Day 3 had no experts or public present, and contained only discussions of panelists in small groups (independently) and in plenary (moderated), followed by recommendation development.
Stakeholder perspectives and reactions to "academic" cognitive enhancement: Unsuspected meaning of ambivalence and analogies. Forlini, Cynthia; Racine, Eric 2012	Theme of engagement: Policy about health system issues Purpose of engagement: Gathering initial input Form of deliberation: Focus Group Methods used/type of paper: Qualitative study Publication status: Peer-reviewed journal Country or region focus: High-income	Describes the findings of a citizen focus group exploring public perceptions of cognitive enhancement.	The study describes the findings of a citizen focus group exploring public perceptions of cognitive enhancement. To minimize recruitment bias and encourage participation of non-experts, participants remained unexposed to the specific subject of the discussion (CE with MPH) until they received the documentation package. This package included a print media sample of four articles. The articles were chosen from a systematic print media sampling of prior discourse analysis. To maximize the scope of the focus group discussion, articles were selected to reflect variability in content (e.g. details about how students obtain pills, effects, and testimonials), quality of information, overall coverage of ethical issues, length, and country of origin. During the focus groups, participants were first invited to comment generally on CE (i.e. propose definitions and react to the frequency and social acceptability of CE) and then express their opinions regarding the ethical, social, and legal issues related to CE (e.g. safety, justice, and fairness). They were also asked to comment on the potential social and healthcare impacts of CE as well as solutions. Finally, participants were asked to give their impression (i.e. completeness of information, realism) on the media coverage of MPH for CE based on the prompt material. The focus groups were moderated to allow spontaneous expression of opinions.
Citizen Brief: Addressing Health System Sustainability in Ontario Waddell, Kerry; Wilson, Michael G; Moat, Kaelan A; Lavis, John N 2016	Theme of engagement: Policy about health system issues Purpose of engagement: Recommending Form of deliberation: Citizen panel Methods used/type of paper: Evidence or citizen briefs	Each citizen brief summarizes evidence for citizens in advance of its associated citizen panel.	Evidence is summarized for citizen panels in five steps. 1) A steering committee identifies the aim of the citizen panel, options for addressing the problem at hand, and key implementation considerations. This process includes 15-20 interviews with key informants impacted by the issue. 2) Evidence to inform and further understand the problem, options for addressing the problem, and implementation considerations is identified through a comprehensive search of Medline, Health Systems Evidence, and grey literature. Additional databases (e.g. McMaster Optimal Aging Portal, Cochrane Library,

Citizen Brief: Addressing
Nutritional Risk Among Older
Adults in Ontario
Gauvin, François-Pierre; Lavis, John
N; Bhuiya, Aunima; Mahendren,
Mathura
2015

Citizen Brief: Building a Primary-Care'Home'for Every Ontarian Wilson, Michael G; Lavis, John N; Moat, Kaelan A 2016

Citizen Brief: Defining the Mental Health and Addictions' Basket of Core Services' to be Publicly Funded in Ontario Waddell, Kerry; Bullock, Heather; Lavis, John N 2016

Citizen Brief: Engaging Communities in Setting Priorities for Home and Community Care in Northeastern Ontario Gauvin, Francois-Pierre; Lavis, John N; Warry, Wayne; Neufeld, Eva 2015

Citizen Brief: Enhancing Access to Patient-centred Primary Care in Ontario Wilson, Michael G; Waddell, Kerry; Lavis, John N 2016

Citizen Brief: Exploring Models for Pharmacist Prescribing in Ontario Gauvin, Francois-Pierre; Lavis, John N; McCarthy, Lisa 2015

Citizen Brief: Improving Care and Support for People with Multiple

Publication status: Grey literature Country or region focus: Highincome

All other cited studies share the same characteristics as the above

Health Evidence, etc.) will be included depending on their relevance to the panel topic. At least one researcher reviews each included paper to appraise quality using the AMSTAR scoring criteria and extract key findings.

3) Information identified through interviews and literature are summarized into a citizens brief with the following structure: context, problem, options, implementation considerations, questions.

Chronic Health Conditions in Ontario Gauvin, François-Pierre; Wilson, Michael G; Lavis, John N; Abelson, Julia 2014

Citizen brief: Improving care and support for unpaid caregivers in Ontario Wilson, Michael G; Gauvin, François-Pierre; Ploeg, Jenny 2014

Citizen Brief: Improving Pain and Symptom Management in Cancer Care in Ontario Moat, Kaelan A 2015

Citizen Brief: Improving the Delivery of Complex Cancer Surgeries in Canada Gauvin, François-Pierre 2014

Citizen Brief: Integrating Data Across Sectors for Public Service Improvement in Ontario Moat, Kaelan A; Wicks, Mikayla; Wilson, Michael G 2016

Citizen Brief: Meeting the Future Home and Community Care Needs of Older Adults in Ontario Wilson, Michael G; Gauvin, François-Pierre; Lavis, John N 2014

Citizen Brief: Planning for the Future Health Workforce of Ontario Moat, Kaelan A; Ciurea, Ileana; Waddell, Kerry; Lavis, John N 2016 Citizen Brief: Sharing Health Information with Older Adults through Online Resources in Canada Moat, Kaelan; Gauvin, François-Pierre; Lavis, John N 2014

Citizen Brief: Strengthening Care for Frail Older Adults in Canada Wilson, Michael G; Waddell, Kerry; Guta, Adrian 2016

Citizen Brief: Strengthening Care for People with Chronic Diseases in Ontario Wilson, Michael G; Lavis, John N; Moat, Kaelan A; Guta, Adrian 2016

Citizen brief: Improving access to palliative care in Ontario Gauvin, F.; Abelson, J.; Lavis, J. 2013

Citizen brief: Improving end-of-life communication and decision-making in Ontario Gauvin, F.; Abelson, J.; Lavis, J. 2013

Effect of Public Deliberation on Attitudes toward Return of Secondary Results in Genomic Sequencing Gornick, Michele C.; Scherer, Aaron M.; Sutton, Erica J.; Ryan, Kerry A.; Exe, Nicole L.; Li, Ming; Uhlmann, Wendy R.; Kim, Scott Y. H.; Roberts, J. Scott; De Vries, Theme of engagement: Policy about health system issues Purpose of engagement: Discussing and connecting Form of deliberation: Citizen panel Methods used/type of paper: Before-after study Publication status: Peer-reviewed journal Country or region focus: Highincome

Reports on the opinions of participants regarding return of secondary results in genomic sequencing before and after a deliberative democracy session, as well as the methods of the session.

To inform participants about the issue, the organizers developed two 35-min educational presentations. The first, entitled "What can we learn from sequencing our genes?" described the science and technology behind genomic sequencing. The second, "Ethical issues in sequencing our genes," offered an introduction to the bioethical issues that attend genomic medicine. The presentations were developed using an iterative process between study team members, the advisory panel, and the expert presenters; among the goals was to provide DD attendees with a balanced presentation of the pros and cons and benefits and risks of this new technology in an effort to minimize bias to the best of our ability. These two presentations were followed by an explanation of proposed policies

Raymond G. 2017			regarding the return of secondary findings when these findings revealed medically actionable results, adult-onset conditions, and carrier status.
What Does the Public Think of Placebo Use? The Canadian Experience Huston P. 2004	Theme of engagement: Policy about clinical issues (e.g., service re-design) Purpose of engagement: Gathering initial input Form of deliberation: Citizen panel Methods used/type of paper: Case study Publication status: Peer-reviewed journal	Reports on the process and outcomes of deliberative dialogue conducted to gather perspectives on the use of placebos in medicine.	As a part of the National Placebo Initiative in Canada, a deliberative dialogue was conducted to gather perspectives on the use of placebos in medicine. A dialogue guide was prepared for the sessions, which provided a primer on placebo-controlled trials (PCTs). The guide presented three approaches to placebo use in clinical trials. For each of the approaches, a structured exposition of the placebo issue was presented that included: What is the issue? What is the broad remedy? What would this mean (possible actions)? Arguments in support of this approach. Arguments in opposition to this approach.
	Country or region focus: High-income		The Committee made every effort to offer a balanced presentation on placebos. Care was taken to give "equal time" for each perspective, both in the dialogue guide, and during the consultation. For example, there were four points for and against each approach, to ensure that there was no weighting or perception of weighting in the presentation of the approaches. During the consultation, the pros and cons of each approach was discussed for approximately 30 minutes. Participants received the dialogue guide prior to the one-day session. The sessions began in the morning with a video which presented an overview on the current use of placebos in clinical trials, the policies that guide its use, how research ethics boards and regulatory agencies assess PCTs, and the different perspectives that people hold about the future use of PCTs. Following this, participants considered each approach and discussed what they liked and disliked about each approach. In the afternoon, they developed a "common ground" or consensus based on the morning's dialogue. They then worked in small groups to discuss three scenarios to test their common grounds and reflect.
From passive subject to active agent: The potential of Citizens' Juries for nursing research	Theme of engagement: Designer babies and genetic testing Policy about health system issues Purpose of engagement: Gathering	A discussion on the potential to use citizens' juries to elicit social values, recommendations, etc., using	A portion of this paper spoke to witness selection. Its findings were the following: The selection of witnesses to present evidence to jurors requires careful consideration. There are perhaps four categories of witness. First, witnesses as to fact might provide evidence on, for example, the incidence
Iredale R.; Longley M. 2007	initial input Form of deliberation: Citizens' jury Methods used/type of paper: Qualitative study	two case studies on Designer Babies and Genetic testing.	and prevalence of specific diseases, or on how particular procedures work. Their role is to inform the Jury. Second, witnesses as to opinion will seek to persuade the Jury of a particular case. Third, witnesses as to personal experience will convey to the jurors how the issues they are discussing might impact on people – the experience of losing a child, for example, or

Publication status: Peer-reviewed journal Country or region focus: High-income

Assessment of a multimediabased prospective method to support public deliberations on health technology design: participant survey findings and qualitative insights Lehoux, P.; Jimenez-Pernett, J.; Miller, F. A.; Williams-Jones, B. 2016 Theme of engagement: Policy about health system issues Purpose of engagement: Discussing and connecting Form of deliberation: Internet dialogue Methods used/type of paper: Case study Publication status: Peer-reviewed journal Country or region focus: Highincome

Details a unique, multimedia focused approach to educating citizens in advance of a public deliberation discussing health technology design

of suffering a stroke. Finally, evidence can be provided through other means than human witnesses; the use of video evidence, for example, can be a cost-effective and accessible means of explaining some issues. Taken together, the witnesses in a Citizens' Jury should be able to present every significant argument relevant to the issue under consideration, equally effectively. Often two witnesses will debate one issue in an adversarial way, arguing for and against a point. Witnesses should be chosen based on their expertise and the choice of suitable witnesses should ultimately be determined by the steering committee to avoid suggestions of bias. For the Citizens' Jury on Designer Babies the preliminary research we conducted with young people around Wales revealed that they wanted to hear most evidence from those with personal experience of the issues, such as families living with a genetic condition or parents trying to select the sex of a future child. A comprehensive range of witnesses is necessary (10–12 people over three days would be typical), each of whom should be briefed thoroughly about the purpose of the Jury and what is expected of their evidence. They should also provide a summary of their argument in advance and biographical details. In the case of both the Designer Baby and Genetic Testing Juries these summaries were issued to jurors at the start of each day, and were accompanied by a glossary of key scientific terms. Typically, witnesses talk for a short time (10-15 min) and then are questioned by jurors with the aid of the moderator.

The deliberation coordinators developed prospective sociotechnical scenarios - a methodology wherein individuals are confronted with scenarios that highlight various ethical dilemmas or moral perspectives that can arise during the complex relationships between individuals, society, and technology. Each of the six scenarios were informed by literature reviews which examined the moral landscape of their associated themes. For each theme, the deliberation coordinators identified how plausible techno scientific developments may interact with the moral landscape and pose regulatory or policy challenges. Following, videoclips telling the story of each scenario were developed. These videoclips were shared with participants through two settings. In the first, a face to face deliberative workshop, participants watched each videoclip and then shared with the group 2-3 features of the technology they saw as desirable, and 2-3 that were not. Following, the group held a discussion on potential ways to improve the technology. In the second, an online forum, participants "were invited to view a brief animation explaining the study, to read the six scenarios, to view the videos and to respond to questions to kick-start

online deliberations. Participants were able to return to the forum whenever they wished, comment on each other's comments and "like" comments." Biobank participation and Theme of engagement: Policy A south chicago focus group of The engagement was held over two days, with a total of 4 sessions. Each of returning research results: about health system issues 45 African-American the sessions began with a twenty-minute educational slide presentation in Purpose of engagement: Gathering order to inform participants on key biobank issues, and was followed by perspectives from a individuals who were four topic-matched focus group sessions to facilitate discussions. assembled to discuss 1) overall deliberative engagement in initial input Form of deliberation: Deliberative South Side Chicago. interest in biobank

> polling Methods used/type of paper: Case

Publication status: Peer-reviewed journal

Country or region focus: Highincome

Educational content presented on Day 1 Session A included types of participation, broad consent, biobanks, genetics, genetic conditions, and genetic research. During Session B informed consent, potential benefits and harms of biobank-based and recontact; 2) root causes of research, privacy and re-identification were presented. distrust and potential biobank strategies to facilitate trust; 3)

In the public interest: Assessing expert and stakeholder influence in public deliberation about biobanks MacLean S.; Burgess M.M. 2010

Lemke, Amy A; Halverson,

2012

Colin; Ross, Lainie Friedman

Theme of engagement: Policy about health system issues Purpose of engagement: Recommending Form of deliberation: Citizens' iury Methods used/type of paper: Case Publication status: Peer-reviewed iournal Country or region focus: Highincome

Report on the design and analysis of a public deliberation that incorporated expert and stakeholder knowledge without their involvement as deliberators.

perceived positive and negative

aspects of receiving research results; and 4) strong interest in

receiving and managing their children's research results.

> It has been previously noted that citizens involved in public deliberations may be overwhelmed by the technical and experiential information provided. Moreover, citizens may be reluctant to voice their own opinions when "experts" are involved in the discussion. The aim of this article is to report on the design and analysis of a public deliberation that incorporated expert and stakeholder knowledge without their involvement as deliberators. Participants in British Columbia, Canada, were invited to participate in a two-weekend deliberative debate on biobank policy & how they would wish to design a biobank. The first day included a half-day of stakeholder and expert presentations about the benefits of biobanks for research and health, genetic discrimination, 'privacy, privacy principles and legislation, and confidentiality', Aboriginal perspectives on genetic research, and community benefits of biobanks & ethics of research. The rest of the first weekend focused on informing participants about a range of issues surrounding biobanks through both presentations and group discussions. Stakeholders were available to fill in gaps of knowledge by addressing additional topics such as government, ethical concerns, minority concerns, etc. Moreover, citizen stakeholders were available to share experiences as patients or caregivers.

> A 12-day break between events encouraged participants to reflect, gather information, talk to others, and consider the issues in the context of their own lives. Participants could pose questions and discuss issues with one another and pose questions for stakeholder and expert speakers on a private

Public Perceptions of Ethical Issues Regarding Adult Predictive Genetic Testing Martin, D. K.; Greenwood, H. L.; Nisker, J. 2009

Theatre as a public engagement tool for healthpolicy development. Nisker J; Martin DK; Bluhm R; Daar AS 2006 Theme of engagement: Policy about health system issues Purpose of engagement: Gathering initial input Form of deliberation: Citizen panel Methods used/type of paper: Qualitative study Publication status: Peer-reviewed journal Country or region focus: Highincome

Theme of engagement: Policy about public health issues Purpose of engagement: Gathering initial input Form of deliberation: Focus Group Methods used/type of paper: Qualitative study Publication status: Peer-reviewed journal Country or region focus: Highincome

Reports on the discussions of audience members of a play regarding genomic testing, and their opinions about what policy should be developed on the matter. website. Stakeholder and expert speakers did not have direct access to the participant website, but were able to answer questions via communication with a team member who would post answers on the website for participant viewing.

Across all presentations, the organizers of the deliberation aimed to discuss the scientific, social and ethical consequences of (1) genetic research. This included the scientific background—to understand the reasons for proposing a biobank, including population-based research and the critiques and limitations of some designs. (2) the social, legal and ethical consequences of biobanking—to understand the range of perspectives and interests relevant to biobanking and related research. (3) Diverse perspectives—to understand differing points of view, values, and concerns that arise from the cultural and personal experiences of citizens.

The 70 minute play, Sarah's Daughters, is the story of a young woman living in fear of hereditary breast cancer. Script research included key informant interviews, and a search of scientific and scholarly writings. The play was designed to incorporate scientific information about BRCA gene mutations, the prevention, diagnosis and treatment of BRCA gene-related breast and ovarian cancer, and access to genetic counselling and testing in this regard. The plot line focuses on the story of one woman, her family and a close friend, and provides the necessary scientific information in a personal context. The play in telling this story stimulates audience members to reflect in potential ethical issues, and comment if they are moved to. The play describes a women's tacit knowledge that she is at risk for hereditary breast cancer, as both women in her family, her grandmother and mother, who survives the Holocaust died of breast cancer at a young age, but that she did not qualify for BRCA gene counselling and testing in Canada as she lacked five family members with this diagnosis.

The study aimed to explore theatre as a public engagement tool for health-policy development. A series of 12 nested case studies was conducted, with each case study consisting of a performance of a 70-min play, specifically written to educate citizens to scientific, clinical, and psychosocial issues of adult predictive genetic testing, and to foster empathy for persons immersed therein; and a 1-h audience discussion that was taped and transcribed for qualitative analysis. The script was based on key informant interviews, literature review, attention to popular media, and six script readings for key informants and communities. Key informants included women with a family history of premenopausal breast cancer, oncogene scientists, physicians (family physicians, oncologists, geneticists), genetic

counsellors, nurses, members of the Jewish community, insurance company executives, and members of the general public. The play was designed to incorporate scientific information about the BRCA gene and about the prevention, diagnosis and treatment of BRCA-related breast and ovarian cancer. It also drew on events that occurred in Ontario, Canada regarding the availability of the test for this gene, which was initially offered only in a research context and later was challenged by the company that developed the initial test. By focusing on the story of one woman, her family and her friends, the play also aimed to place the ethical and scientific issues in a context that was accessible and engaging. This was a 2.5 day jury in which participants heard from expert witnesses, Engaging the public in Theme of engagement: Policy To assess the feasibility of about health system issues who described how decisions for health technologies were made, engaged priority-setting for health using a citizens' jury to elicit Purpose of engagement: Gathering public values on health in small and large group scenario-based priority-setting exercises (rate the technology assessment: importance of each technology on a scale of 1-5, justify the criteria on findings from a citizens' jury. initial input technologies and to develop Menon D; Stafinski T Form of deliberation: Citizens' criteria for setting priorities for which the decisions were based), created a ranked list of technologies 2008 health technology assessment (where for each technology, they heard from a patient with the condition, a iury clinician treating the condition, policy-maker involved in reimbursement, Methods used/type of paper: Case (HTA). and manufacturer of the product). Structure of information presentation: study On the first day, presentations were given that: (1) discussed the need to Publication status: Peer-reviewed iournal make tough but fair decisions regarding which health technologies to fund Country or region focus: Highpublicly, (2) defined HTA and its role in informing such decisions (i.e. what HTA is and why it is done), (3) introduced the main HTA-producing income organizations in Canada The second day began with presentations from expert witnesses. Senior administrators and policy-makers from the Capital Health Authority and the Alberta Ministry of Health and Wellness described how priority-setting decisions for new technologies are made at the regional and provincial levels in Alberta. At the end of each presentation, jurors had an opportunity to 'interrogate' witnesses during a question and answer period. **Informing public health policy** This study reports the outcome and evaluation of a public deliberation to Theme of engagement: Policy This study reports the outcome about health system issues and evaluation of a public develop recommendations for how biobanking should be managed in through deliberative public engagement: Perceived impact Purpose of engagement: deliberation to develop Western Australia. Prior to the forum, participants were given a 36 page on participants and citizen-Recommending recommendations for how booklet that discussed policy issues pertaining to genetics and biobanking. Policy issues were framed to present multiple viewpoints. To increase government relations Form of deliberation: Citizen panel biobanking should be managed Methods used/type of paper: readability, the booklet included a glossary of terms, was written in lay Molster C.; Potts A.; in Western Australia. English, and included varied media (pictures, diagrams, etc.). The booklet's McNamara B.; Youngs L.; Qualitative study information was gathered and synthesized from a range of sources included Publication status: Peer-reviewed Maxwell S.; Dawkins H.; peer reviewed articles, the media, and grey literature. To further aid O'Leary P. iournal 2013 participant understanding, local experts, health advocates, and health Country or region focus: High-

income

Blueprint for a deliberative public forum on biobanking policy: were theoretical principles achievable in practice?
Molster, Caron; Maxwell, Susannah; Youngs, Leanne; Kyne, Gaenor; Hope, Fiona; Dawkins, Hugh; O'Leary, Peter 2013

Theme of engagement: Policy about health system issues Purpose of engagement: Gathering initial input Form of deliberation: Citizen panel Methods used/type of paper: Case study Publication status: Peer-reviewed journal Country or region focus: Highincome

consumers presented short information sessions on their perspectives on the policy issue during the first day of the forum.

The deliberation was held over 2 weekends, 2 weeks apart. Information was framed for 'difference and deliberation' which involved exposing deliberants to multiple perspectives on the policy topics, using multi-media including written, oral and spatial forms of communication, recruiting for diversity and structuring the forum to facilitate extended exploration of the issues, perspectives and personal experiences of deliberants. Decisions about expert and stakeholder involvement in the forum considered the objectives of inclusiveness, informative relevance, critical engagement and encouragement of deliberation. At least 2 weeks prior to the forum, a 36page booklet on biobanking perspectives and ethical issues was posted to deliberants. The booklet included a glossary of terms and 'technical jargon' and was based on information drawn from academic peer-reviewed publications, grey literature and media articles. Deliberants were also provided with an annotated bibliography of academic and grey literature and a two-dimensional model of the core biobanking processes. All of these information sources were prepared by the research team and adapted from the resources developed by UBC. Deliberants also participated in an experiential activity designed by the research team to highlight some of the ethical issues inherent in biobanking processes. Presentations were made on the first day of the forum. Three presenters were 'experts' with technical knowledge (i.e. a biobank custodian, genetic researcher, lawyer/ethicist), and three were stakeholders (i.e. father of a child participating in a disease biobank, female survivor of breast cancer with negative experiences of genetic research and a woman who is blind and from a minority ethnic background with concerns about discrimination). Presenters were encouraged to draw on personal experiences and advised to provide a level of information sufficient to stimulate thoughts on what biobanking research will mean for deliberants personally and for people with other perspectives. To avoid expert and stakeholder 'capture' through undue influence on deliberants, the presenters were allocated a defined length of time to speak, debates among presenters were prevented, and direct presenter access to deliberants was limited to moderated question and answer sessions. The information was further supplemented by an annotated bibliography and a 2D model of core biobanking processes. Day 1 contained an opening address, policy-maker's address, icebreaker, task overview, survey, presentations, and questions. Day 2 involved small group deliberations, report back to large group, and reflections. Day 3 began with a policy-

maker's address, followed by a recap of day 1 and 2, small-group deliberations, report back to large group, recommendations, and large-group consensus-building. Day 4 mirrored day 3, and finished with a formal report preparation and the decision-maker's response.

Deliberative Engagement Methods for Patient-Centered Outcomes Research Morain, Stephanie R.; Whicher, Danielle M.; Kass, Nancy E.; Faden, Ruth R. 2017 Theme of engagement: Policy about health system issues Purpose of engagement: Gathering initial input Form of deliberation: Citizen panel Methods used/type of paper: Qualitative study Publication status: Peer-reviewed journal

Country or region focus: High-

income

Describes the design and development of a deliberative engagement session and provides the example of DES in the context of patient-centered outcomes research.

Short plenary presentations are alternated with small group discussions. The plenary presentations provide key information relevant to topics derived from the research question. Presentations should be kept short (10– 15 min each) and introduce only one or two key topics at a time, to minimize participant burden and to promote understanding. Presentations should provide balanced, factual information, and be sufficiently comprehensive to allow participants to form informed opinions. For example, during a plenary presentation introducing the three consent models we explored in our study, we introduced pros and cons of each model that we believe represented debates in the literature. Researchers should consider having DES informational materials reviewed by experts outside of the research team with differing opinions on the policy issue. While this practice can increase the time needed to design a DES, it should minimize the risk that the information provided to participants is biased. All DES materials, including slides and handouts as well as surveys and group guides, should also be pilot tested with individuals similar to those who will participate in the DES to ensure that those materials are easy to understand.

Yes, the government should tax soft drinks: findings from a citizens' jury in Australia Moretto N.; Kendall E.; Whitty J.; Byrnes J.; Hills A.P.; Gordon L.; Turkstra E.; Scuffham P.; Comans T. 2014

about public health issues
Purpose of engagement:
Recommending
Form of deliberation: Citizens'
jury
Methods used/type of paper: Case
study
Publication status: Peer-reviewed
journal
Country or region focus: Highincome

Theme of engagement: Policy

Reports on a citizen jury conducted to document public perceptions on taxing sugary drinks.

The study reports on a citizen jury conducted to document public perceptions on taxing sugary drinks. The jurors were asked to reach a verdict and make recommendations about taxation as an obesity-prevention strategy based on evidence provided by clinical, policy and academic expert witnesses from a wide range of perspectives. The jurors were able to "cross-examine" the experts who provided evidence and recall "witnesses" to assist them in making their recommendations. Topics witnesses covered included the nature of overconsumption in children; expenditure on healthcare; health prevention and costs associated with obesity; findings from The Australian Diabetes Obesity and Lifestyle Study; food industry and voluntary measures to address obesity; examples of current food labels; educational programs; campaigns and food advertising; examples of taxation on food and drinks in other countries; information on the regulation of the tobacco industry; background of childhood obesity and associated health issues; the prevalence of obesity in children and adults in Queensland; rates of childhood obesity in Australia; Body Mass Index and risks associated with excess weight; nutrition and activity levels of

Involving a citizens' jury in decisions on individual screening for prostate cancer Mosconi P.; Colombo C.; Satolli R.; Carzaniga S. 2016 Theme of engagement: Policy about public health issues Purpose of engagement: Recommending Form of deliberation: Citizens' jury Methods used/type of paper: Case study Publication status: Peer-reviewed journal

Country or region focus: High-

income

Presents the design and outcomes of a citizen's jury exploring whether the UK National Health Service (NHS) should discourage or recommend the prostate-specific antigen (PSA) as an individual screening test for prostate cancer in 55–69 years old men.

children; causes of overweight and obesity; and costs associated with obesity in Queensland; Overview of taxation processes; snack foods; overview of processed meats; household expenditure of food and drinks; overview of the nature of sugar; overview of strategies to prevent childhood obesity; and clinical experience treating obesity in children.

Following all discussions, jurors engaged in two deliberation sessions led by the facilitators to develop a verdict and recommendations on taxation. . This study was designed to document a citizen's jury exploring whether the UK National Health Service (NHS) should discourage or recommend the prostate-specific antigen (PSA) as an individual screening test for prostate cancer in 55-69 years old men. An ad hoc information booklet was prepared on the basis of a review of the literature. To collect any pertinent document, a public call was launched; learned societies, patients' and consumers' associations and public health offices were directly invited by e-mail. The 25 documents submitted were examined. A sample of consumer/patient organizations' websites was also visited to catch topics of interest. The draft of the booklet was discussed by the promoters, the steering group and with the PartecipaSalute-GRAL, a group of patients and consumers' representatives. The final topics of the 30-page booklet are (1) What is the PSA test, (2) PSA test for prostate cancer screening—benefits and harms, (3) estimate of costs, (4) a table summarizing international and national guidelines, (5) General information about screening and overdiagnosis, (6) General information about prostate cancer, its incidence and prevalence in Italy, (7) What a citizen jury is and why it was organized on this topic, (8) Suggestions on how to find more information with links to web sites, (9) Glossary.

Nine experts were invited to the two-day meeting with jurors: four epidemiologists—some of them part of a national screening group—a urologist, a general practitioner, an oncologist, a health policy maker, and an expert in health economics. Topics covered are reported in Appendix A. Interviews with three middle-aged men were presented in videos (Appendix A). The first and second days the experts gave their talks and discussed with the jurors. A final debate was organized between a clinician and a health policy maker on the pros and cons of opportunistic PSA screening. In the afternoon of the second day, a four-hour closed-doors session was dedicated to the discussion among the jurors to deliberate. One representative of the jurors was responsible for drafting the deliberation, presenting it to the experts and promoters at the end of the second day, and writing the final document in collaboration with the facilitator.

	Theme of engagement: Policy about health system issues Purpose of engagement: Recommending Form of deliberation: Citizens' jury Methods used/type of paper: Case study Publication status: Peer-reviewed journal Country or region focus: Highincome	Reports on the findings of a citizen's jury regarding best practices surrounding the introduction of biobanks to potential donors.	
	Theme of engagement: Policy about health system issues Purpose of engagement: Recommending Form of deliberation: Citizen panel Methods used/type of paper: Case study Publication status: Peer-reviewed journal Country or region focus: Highincome	A public deliberation on biobanks was led to elicit recommendations on social and ethical issues surrounding biobanks.	Information was presented via a brochure, graphic illustration of a biobank, annotated bibliography, media reports, a physical model of a biobank, a private website for questions, and 5 expert and stakeholder speakers. On the first day, the expert and stakeholder speakers addressed the participants on issues pertaining to biobanking, followed by question and answer sessions. The speakers represented a range of perspectives, including those of pathologists hoping to benefit from biobanking, privacy and First Nations' advocates concerned with potential negative implications of biobanks, and a firsthand account of genetic discrimination. The speakers were chosen to reflect a wide range of positions on biobanks so that subsequent discussions were less likely to be 'captured' by any given set of values or interests. Deliberation followed the following procedure: Day 1: expert and stakeholder speakers; Day 2: facilitated small group deliberations on hopes and concerns (focus on points of consensus but also points of disagreement); Day 3 (second weekend): task: come up with design recommendations for a BC biobank; Day 4: Large group deliberation to discuss conclusions of small groups.
Structuring public engagement for effective input in policy development on human tissue biobanking O'Doherty K.C.; Hawkins A. 2010	Theme of engagement: Policy about health system issues Purpose of engagement: Recommending Form of deliberation: Citizens' jury Methods used/type of paper: Case study Publication status: Peer-reviewed journal	Describes how public deliberation can increase its uptake the policy process by engaging on practical policy issues for which input is needed, as opposed to abstract ethical principles.	The study describes how public deliberation can increase its uptake the policy process by engaging on practical policy issues for which input is needed, as opposed to abstract ethical principles. To illustrate its point, the study describes the process and outcomes of a public deliberation on biobanking. To identify practical issues for the deliberation, the first stage of planning involved a mapping of a British Columbia BioBank's collection, storage and research procedures to identify a comprehensive list of 'areas of ethical ambiguity' (i.e. junctures where, given current accepted best practice principles and generally agreed upon ethical guidelines, managers of the biobank were nevertheless uncertain what the most

Country or region focus: High-income

appropriate course of action should be.)

Twelve topics were identified, which were later reduced to five that were most pertinent to the procedures, protocols and operations of the biobank, and that could realistically be covered in sufficient depth within the time constraints of a four day deliberative public engagement. Deliberants were not expected to have any prior knowledge of biobanking, and received information through an information booklet, expert/stakeholder presentations representing range in opinions on biobanks, an annotated bibliography and a private website. Deliberation occurred in both small and large group sessions, and was facilitated to promote participation, respectful listening and thorough discussion.

The five topics and the specific contentious issues within each of them were written up in the form of a workbook that was used by facilitators to structure the deliberation during the actual event. The workbook also served to ensure that the deliberations and the conclusions eventually reached by participants remained within the parameters of recommendations that the Biolibrary was realistically capable of taking into account in their governance structure.

The workbook was divided into five sections, each dedicated to one of the topics identified above. Each section included an introductory paragraph outlining the main characteristics of the problem, and the particular questions that participants were asked to discuss and use to formulate recommendations for the Biolibrary. Each section also included additional information in the form of vignettes, explanations of relevant terminology, examples of recommendations from the previous (unstructured) public engagement on biobanking conducted in BC, and recognised pros and cons.

This study was extracted separately from other papers reporting on the same deliberation for the unique insight it brings into the process used to prepare information for citizens.

The study aimed to gather perspectives from a citizen's jury on whether the New Zealand government should offer free mammography screening to all women aged 40–49 years. Participants met on a Wednesday evening (introduction), all day Friday (expert presentations and interrogation) and Saturday morning (deliberation). Experts were chosen to represent the range of views on mammographic screening in this age group. They were a public health physician at the National Screening Unit of the Ministry of

Making policy decisions about population screening for breast cancer: The role of citizens' deliberation. Paul C; Nicholls R; Priest P; McGee R 2008 Theme of engagement: Policy about public health issues Purpose of engagement: Gathering initial input Form of deliberation: Citizens' jury Methods used/type of paper: Case

Describes perspectives from a citizen's jury on whether the New Zealand government should offer free mammography screening to all women aged 40–49 years.

	study Publication status: Peer-reviewed journal Country or region focus: High- income		Health (a neutral policy advisor), a breast surgeon and member of the New Zealand Breast Cancer Foundation (an advocacy group in favour of breast screening for women from 40), and an epidemiologist from the University of Otago, Christchurch (who was opposed to the implementation of breast screening for women under age 50).
			At the introduction, jury members were informed about the questions, given copies of standard criteria for assessing screening programmes [12] and all current New Zealand pamphlets on mammographic screening, and had the opportunity to clarify the questions. At the second session, the experts gave presentations, each followed by questions and small group discussion. A published decision aid for screening mammography at 40 years was also viewed [13]. On the final day, the jury deliberated on the question and reached a conclusion."
Public priorities for Ontario's health system: A report of the citizens' reference panel on Ontario health services [Ontario] Pricewaterhouse, Coopers 2011	Theme of engagement: Policy about health system issues Purpose of engagement: Recommending Form of deliberation: Citizen panel Methods used/type of paper: Case study Publication status: Grey literature Country or region focus: Highincome	Reports on the process and outcomes of a citizen panel developing recommendations for Ontario health system reform	A panel of citizens were convened to develop recommendations for health reform in Ontario. Over the course of several weekends, they were exposed to expert presentations and group discussions on intended to develop an understanding of Ontario's health system. These included lectures on the history of medicare, Ontario's demography, the health system's architecture, health economics, preventative medicine, community partners in health (e.g. YMCA), the management and connections between various branches of care (family, community, long term), health administration, ehealth, the importance of various providers, health systems in other jurisdictions, and finally chronic disease, mental health, & aging.
			Throughout and following these lectures the attendees were engaged in group discussions, scenario planning (i.e. thinking through how the system might deal with particular patients), and drafting recommendations.
Engaging the public in healthcare decision-making: results from a Citizens' Jury on emergency care services Scuffham, P. A.; Moretto, N.; Krinks, R.; Burton, P.; Whitty, J. A.; Wilson, A.; Fitzgerald, G.; Littlejohns, P.; Kendall, E. 2016	Theme of engagement: Policy about clinical issues (e.g., service re-design) Purpose of engagement: Gathering initial input Form of deliberation: Citizens' jury Methods used/type of paper: Case study Publication status: Peer-reviewed journal	Describes the setup and outcomes of a citizen jury on the redesign of emergency department service provision.	During the three consecutive days, jurors listened to 12 expert witnesses reflecting a wide range of stakeholders across six evidence and two panel sessions on the topic of optimizing access to and provision of emergency care. Jurors questioned the witnesses and clarified the evidence presented to them. Any unanswered questions were followed-up with witnesses and responses were relayed to jurors.

	Country or region focus: High-income		
Determining social values for resource allocation decision-making in cancer care: A Canadian experiment Stafinski T.; McCabe C.; Menon D. 2014	Theme of engagement: Policy about health system issues Purpose of engagement: Gathering initial input Form of deliberation: Citizens' jury Methods used/type of paper: Case study Publication status: Peer-reviewed journal Country or region focus: High-income	2 citizen's juries formed to elicit social values in resource allocation in cancer care	2 independent citizens' juries were held with the same witnesses and exercises, each running 4 deliberative sessions. Each expert witness (an oncologist, a senior cancer service delivery decision maker, a senior health service delivery decision maker, an ex-senior government decision maker responsible for funding policies and a cancer patient advocate (3 male, 2 female)) described his/her roles in the provincial health system and the types of decisions they faced. The pressures they confronted in making resource allocation decisions (between patient populations with different characteristics) were described and discussed with the jurors. In this way, the jury acquired a better understanding of the complexities of resource allocation decision-making, particularly in an area such as cancer care, which impacts almost every individual at some time or other. The layout of the sessions was as follows: Session 1- introductory presentations; Session 2- a day in the life of each of the expert witnesses; Session 3- An exercise was run wherein small groups had to select 5 of 10 technologies for funding and identify the values considered to be important for decision-making; Session 4- Potential implications of a "no" decision were presented in regards to 3 technologies that were not universally funded and jurors were given the opportunity to change their minds.
Community perspectives on the use of regulation and law for obesity prevention in children: A citizens' jury Street, Jackie M.; Sisnowski, Jana; Tooher, Rebecca; Farrell, Lucy C.; Braunack- Mayer, Annette J. 2017	Theme of engagement: Policy about public health issues Purpose of engagement: Gathering initial input Form of deliberation: Citizens' jury Methods used/type of paper: Case study Publication status: Peer-reviewed journal Country or region focus: High-income	Reports on a citizen jury regarding policy options for addressing childhood obesity.	On day 2, participants interacted at a single table with expert presenters and in one hour-long session small groups worked with single experts rotating across groups. As far as possible, in the time available, the jury was provided with a range of evidence and viewpoints. In particular, the research team recognized that public health decision-making does not occur in a vacuum free of competing political priorities and therefore perspectives which were not public health derived were also represented (for example, industry perspectives)