Journal of Public Deliberation

Volume 9 | Issue 1 Article 5

4-30-2013

# Public Deliberation in Health Policy and Bioethics: Mapping an emerging, interdisciplinary field

Julia Abelson
*McMaster University*, abelsonj@mcmaster.ca

Erika A. Blacksher
*University of Washington*, eb2010@u.washington.edu

Kathy K. Li
*McMaster University*, likk2@mcmaster.ca

Sarah E. Boesveld
*McMaster University*, boesves@mcmaster.ca

Susan D. Goold
*University of Michigan*, sgoold@med.umich.edu

## Recommended Citation

Abelson, Julia; Blacksher, Erika A.; Li, Kathy K.; Boesveld, Sarah E.; and Goold, Susan D. (2013) "Public Deliberation in Health Policy and Bioethics: Mapping an emerging, interdisciplinary field," *Journal of Public Deliberation*: Vol. 9 : Iss. 1 , Article 5.
Available at: https://www.publicdeliberation.net/jpd/vol9/iss1/art5

# Public Deliberation in Health Policy and Bioethics: Mapping an emerging, interdisciplinary field

## Abstract

For over two decades, the "deliberative turn" has rooted itself in the fields of health policy and bioethics, producing a growing body of deliberation in action and associated academic scholarship. With this growing use and study of citizen deliberation processes in the health sector, we set out to map this dynamic field to highlight its diversity, interdisciplinarity, stated and implicit goals and early contributions. More specifically, we explored how public deliberation (PD) is being experimented with in real-world health settings, with a view to assessing how well it is meeting current definitions and common features of PD. Our review provides an informative and up-to-date set of reflections on the relatively short but rich history of public deliberation in the health sector. This emerging, interdisciplinary field is characterized by an active community of scholars and practitioners working diligently to address a range of bioethics and health policy challenges, guided by a common but loosely interpreted set of core features. Current definitions and conceptualizations of public deliberation's core features would benefit from expansion and refinement to both guide and respond to practice developments. Opportunities for more frequent cross-disciplinary and theory-practice exchange would also strengthen this field.

## Keywords

public deliberation; deliberative processes; health policy; bioethics

## Acknowledgements

A version of this paper was presented to a group of practitioners and scholars who participated in a symposium on public deliberation in health policy and bioethics at the University of Michigan in September 2010. This two-day symposium, organized by Julia Abelson, Susan Goold, and Erika Blacksher, asked the twenty-five researchers in attendance to reflect on questions about rationales, methods, uses, and impacts of public deliberation in the health sector. The papers in this symposium set reflect some of the work, thought, and constructive criticism that resulted. We thank our colleagues for an intellectually invigorating and rewarding experience. We also thank the Canadian Institutes of Health Research (through a grant led by Julia Abelson) and the University of Michigan Center for Ethics in Public Life for supporting this endeavour.

## INTRODUCTION

For a little over two decades, the “deliberative turn” has rooted itself in the health field, producing a growing body of deliberation in action and associated academic scholarship. The growing popularity of citizen deliberation processes in the health sector should not be surprising. Their emphasis on informed, value-based reasoning and collective problem solving is appealing to a sector where some of society’s most ethically controversial, fiscally challenging and politically charged decisions are made. Indeed, one of the earliest examples of the use of public deliberation to inform health policy is the now-famous Oregon Health Plan case, in which Oregonians were invited to provide guidance for prioritizing the medical conditions to be covered by the state’s Medicaid program (Crawshaw et al., 1985).

Serious experimentation with public deliberation in the health sector began in the 1990s in the UK’s National Health Service (NHS) where a variety of methods such as deliberative polling, citizens panels and citizens juries were used to inform local health care priority-setting decisions (Bowling, Jacobson & Southgate, 1993; Bowie, Richardson & Sykes, 1995; Lenaghan, New & Mitchell, 1996; Lenaghan, 1999; Coote & Lenaghan, 1997; Cookson & Dolan, 1999; Dolan, Cookson & Ferguson, 1999). This activity has been replicated to a lesser degree in other jurisdictions around the world, mostly through ad hoc researcher-initiated studies (Abelson et al., 1995; Bostwick, 1999; Stronks et al., 1997; Smith & Wales, 1999; Einsiedel, 2002; Abelson et al., 2003; Forest et al., 2004; Abelson et al., 2007; Menon and Stafinski, 2008; Secko et al., 2009; O’Doherty and Hawkins, 2010; DeVries et al., 2010). However, the establishment of several high-profile citizen deliberation processes and structures over the last decade suggests that public deliberation may be gaining some traction among policymakers as a mechanism for incorporating public values into health policy decision-making processes. In the early 2000s, for example, the principles of democratic deliberation inspired the design of twelve citizen dialogues held across Canada, which informed the recommendations tabled by a government-appointed royal commission, tasked to weigh in on the future of health care in Canada (Maxwell, Rosell & Forest, 2003). At approximately the same time, the UK body which oversees the assessment of health technologies – the National Institute for Health and Clinical Excellence (NICE) – created a 30-member Citizens Council to provide a source of social values input to inform their expert-driven, evidence-based health technology assessment process (Rawlins, 2009). The establishment of NICE’s Citizens Council has, in turn, influenced the creation of two legislatively mandated public deliberation structures in Canada, one that provides advice on the Province of Ontario’s pharmaceutical benefits program

(Statutes of Ontario, 2006) and the other that provides advisory input on the performance of the Quebec health system (Government of Quebec, 2005).

Given the growing use and study of citizen deliberation processes in the health sector, we think there is merit in mapping this dynamic field to highlight its diversity, interdisciplinarity, stated and implicit goals and early contributions. More specifically, we are interested in exploring how public deliberation (PD) is being experimented with in real-world health settings, with a view to assessing how well it is meeting current definitions and common features of PD. Our motivation for this assignment was fuelled by our experiences as scholars and practitioners of public deliberation faced with the challenges of implementing and assessing PD within varied social and political contexts. To carry out this task, we drew on a selected body of empirical studies to examine the questions of how PD is operationalized in relation to its theorized goals. We hope that our results will offer some critical reflection on current definitions and how they might be expanded and strengthened.

## METHODS

We carried out a targeted search of the published literature with a focus on original articles of empirical studies of public deliberation methods, practices and evaluations in the related fields of bioethics and health policy.

### *Sources, search strategy and article screening*

Twenty databases of published English-language literature in the medical, health, social sciences and humanities were searched from 2000 to 2012. Search terms were developed through an iterative process to identify key component terms of interest such as: 1) public; 2) engagement, involvement, and deliberation; 3) bioethics and health (care) policy. Searches were carried out using different combinations of terms within each database to ensure that relevant material was not missed. The following two search strategies were undertaken: Search #1: (“public deliberat*") and (health* or ethics* or (health policy)) and (("public engage*") or ("public involve*")); search #2: ("public deliberat*") and KW=(health* or bio* or ethics). The collection of articles yielded through these searches was further screened to eliminate duplicates, and to include only empirical studies, which included “deliberation,” “deliberate” or “deliberative” in the title or abstract. This search was complemented by a review of our respective literature databases constructed through previous work in the field and by our knowledge of scholarly and practice-based activity in the public deliberation field.

### *Review and analysis of selected articles*

Our search yielded a set of 31 articles published between 2000 and 2012, which are described in Appendix 1 and discussed below. As a collection, this body of work helps us to describe the work being carried out in this arena and how it has evolved over the past decade. A second phase of our analysis involved the selection and in-depth exploration of a subset of the papers summarized in Appendix 1. Eleven papers were selected with the aim of covering a broad range of study aims, jurisdictions, decision contexts and approaches to design. A detailed review of these articles was carried out to extract relevant information corresponding to the core features of PD as described in a recent review of the PD literature (Blacksher et al., 2012). This review was used as the basis for our critical examination of current approaches to using PD to address health system challenges.

## DESCRIBING THE FIELD

Our selective review of the public deliberation and health literature yielded a rich set of empirical studies that have examined the *use and outputs of public deliberation* or *explored and assessed its design feature(s)*. The bulk of the studies reviewed were carried out at the local/regional, provincial/state or national level in Canada, the US, and the UK, with selected representation from Australia, Taiwan, and Israel (Rogers et al., 2009; Molster et al., 2011a, 2011b; Guttman et al., 2007, 2008; Deng & Wu, 2010).

As Appendix 1 illustrates, the studies we reviewed cover a wide range of *policy decisions, levels and content areas*. Building on its early roots, there continues to be a strong emphasis on the use of public deliberation to inform local and state/provincial level *planning and priority setting* decisions such as planning for flu pandemics, setting local health goals, designing health services and locating health facilities (Abelson et al., 2003; Abelson et al., 2007; Rogers et al., 2009; Baum, Jacobsen & Goold, 2009). Public deliberation also continues to be used as a source of values input to inform various *policy decisions* related to the coverage of health services and more recently, health technologies (Bracci, 2001; Grogan & Gusmano, 2005; Paul et al., 2008; Bombard et al., 2011; Menon & Stafinski, 2008). The field is equally well represented by deliberations covering an expanding range of research ethics and regulatory policy issues including xenotransplantation, surrogate consent, biobanking and genetic testing (Einsiedel, 2000, 2002; DeVries et al., 2010; Molster 2011, 2012; Maclean & Burgess, 2010; Longstaff & Burgess, 2010; O'Doherty & Hawkins, 2010). And while fewer in number, we also unearthed several noteworthy examples of deliberations used to inform large-scale health reform processes in Canada, Israel and Taiwan where major decisions about the structure, financing and organization of health systems were under review (Maxwell, Rosell & Forest, 2003; Guttman et al., 2007, 2008; Deng & Wu, 2010).

Despite a proliferation of *methods* now associated with the deliberative approach, the studies we reviewed continue to ascribe fairly generic labels to the form of deliberation being undertaken (Appendix 1, column 3). A notable exception is the citizen jury method, which is more consistently and accurately described across studies, likely due to the pioneering efforts of Ned Crosby and his founding of the Jefferson Center for New Democratic Processes in 1974 (Jefferson Center, 2013). As the field has evolved, there has been greater specification of the core features of deliberation, and more consistency within research groups that have established track records in the field. However, method descriptions continue to be characterized by incompleteness or ambiguous terminology, challenging efforts to draw lessons from the field.

In contrast to the overall lack of method specificity, details about the *recruitment and selection of participants* is carefully tailored to the study context (Appendix 1, column 4). Common approaches include stratified random sampling from an available source (e.g., electoral rolls, community organization directories, etc.), and purposive sampling through various advertising methods (e.g., newsletters, websites, local media) followed by stratification on key demographic variables to ensure heterogeneity in the composition of deliberation participants. The field would benefit from more critical review of different recruitment methods and their rationales, which, to date, have been only superficially examined (Longstaff & Burgess, 2010).

### *How the field of PD in health has evolved*

Public deliberation scholarship in the health field has evolved considerably over the last decade. Prior to 2003, the literature focused mostly on case studies *documenting the outputs of public deliberation* in various decision-making contexts with only limited attention to specific aspects of deliberation such as how it was implemented, with what success and to what extent its features aligned with the theory underpinning deliberative democracy. Since then, the field is characterized by more critical reflection and an emphasis on assessing its achievements. Bracci (2001) laid the early foundations for the *development of evaluation and ethics frameworks* through the evaluation of the patterns and ethical dimensions of state-level public deliberation and their influence on priority-setting and resource allocation. Similarly, Einsiedel and colleagues'

(2002) work has inspired more rigorous evaluations of public deliberation through the use of a priori evaluation criteria and principles and comparative evaluation designs (Abelson et al., 2003; Grogan & Gusmano, 2005; Molster, 2011, 2012; Abelson et al., 2007; Timotijevic & Raats, 2007). More recently, De Vries and colleagues (2010) have attended to these issues even further by *developing and testing measures of "quality deliberation."* While much of this activity has emphasized the evaluation of procedural elements, some attention is also being given to exploring the *role of context in public deliberation*, which involves unpacking the complex relationships between external environments, institutional settings and decision-making processes, and how these shape deliberation activities and their impacts (Abelson et al., 2007; O'Doherty & Hawkins, 2010; Jones & Einsiedel, 2011). Continued attention to these outcome-related dimensions of public deliberation is essential to answering central questions about its impacts on health policy decisions.

### *The interdisciplinarity and diversity of the field*

Our selective review of published literature reveals that no single outlet for scholarly work exists in the field, although there appear to be preferred publication venues (Table 1). Of the 31 papers summarized in Appendix 1, two interdisciplinary health journals – *Social Science and Medicine* and *Health Expectations* – have published just over 40% of the papers. Beyond these two dominant outlets, however, the work is distributed fairly evenly across a diverse set of interdisciplinary health, social science and science journals.

| **Table 1: Journals publishing public deliberation studies**<br>(# of publications/journal) |
|---|
| Social Science and Medicine (7) |
| Health Expectations (6) |
| Health Policy (3) |
| Public Understanding of Science (3) |
| Public Health Genomics (2) |
| Health, Risk & Society (1) |
| British Medical Journal (1) |
| American Journal of Bioethics (1) |
| Journal of Applied Communication Research (1) |
| Science Communication (1) |
| Science and Engineering Ethics (1) |
| Qualitative Research (1) |
| State Politics and Policy Quarterly (1) |
| Communication Theory (1) |
| Journal of Public Deliberation (1) |

## EXAMINING ITS CORE FEATURES

As highlighted in the previous section, public deliberation and its core features have been translated into the health field in variety of ways and with different purposes. Drawing on an extensive body of theoretical work, Blacksher et al., (2012) propose the following minimum definition for public deliberation:

> (1) the provision of balanced, factual information that improves participants' knowledge of the issue; (2) the inclusion of diverse perspectives to counter the well-documented tendency of better educated and wealthier citizens to participate disproportionately in deliberative opportunities and to identify points of view and conflicting interests that might otherwise go untapped; and (3) the opportunity to reflect on and discuss freely a wide spectrum of viewpoints and to challenge and test competing moral claims. (p. 3)

Each of these three elements emphasizes a different core feature or goal for deliberation. The first emphasizes the goal of ensuring that citizens are properly *informed* about the issue under deliberation; the second establishes the importance of paying careful attention to the *representation* of relevant and divergent perspectives; and the third focuses on the *process* created for free and open exchange to facilitate values-based reasoning. Blacksher and colleagues go on to stress the normative nature of public deliberation and its focus on reaching collective judgments about what "we ought to do," which bear on the more pragmatic goals of locating *common ground* and producing a *set of deliberation "outputs" that can inform policy decisions*. There has been much discussion in the literature about the merits and associated problems with each of these goals, but much less attention paid to how they are operationalized as unique or complementary features of deliberative practice (Blacksher et al., 2012). For example, what does it actually mean to include diverse perspectives in a deliberative process? What does a deliberation space look like that facilitates value-based reasoning? And to what extent have the architects of deliberation in the health field encouraged movement towards collective judgments and common ground, while ensuring that participants have the time and space to disagree and to air departures with dominant voices and interests?

Through our in-depth review of the subset of 11 papers, we examined how each element of the proposed minimum definition was articulated and put into practice through the design and implementation of various public deliberation initiatives in the health field. A detailed set of findings including verbatim excerpts from the papers we reviewed are presented in Appendix 2 and critically examined in the following sections.

### *Information provision and knowledge acquisition: Convergence of approaches*

Within the subset of papers we reviewed, we found that information provision, as a core element of PD, was attended to quite carefully (Appendix 2, column 3). Most if not all efforts included as the principal information source a summary or briefing about the deliberation topic prepared by the research team responsible for running the deliberation. Presentations and/or Q&A sessions with content experts were offered as a complementary source in a number of initiatives, and in some cases, relevant "stakeholders" were invited to present a range of positions or interests on the issue. While not explicitly stated, this dual approach, with its primary emphasis on the synthesis of information by the research team, rather than invited experts, reinforces the commitment to providing "balanced, factual information." Indeed, some have identified criteria used to guide the preparation of information materials such as comprehensiveness, accessibility and objectivity (Einsiedel, 2002). While there appears to be convergence on the general approaches to informing participants, these have not been supported by rigorous evaluation to determine the most effective or efficient combination of information dissemination modalities.

### *Representation, representativeness and diversity: conflicting approaches and conflated ideas*

The issue of which perspectives to "represent" in the deliberative process, and how to do this was the source of considerable ambiguity and divergence across the PD initiatives we reviewed (Appendix 2, column 2). Stated goals varied from seeking the statistical representation of community and population characteristics to more abstract notions of including "diverse perspectives" which may or may not include demographic diversity. Different emphases were also given to the goals of representing the interests of those "affected" by an issue or content area versus intentionally seeking a more "disinterested" set of perspectives. A notable gap in the examples reviewed were explicit references to representing "untapped" viewpoints as described in Blacksher et al.'s (2012) minimum definition, suggesting that this feature has not been adopted in practice.

The goals of representation and diversity were approached in other important ways in the PD initiatives reviewed, typically through efforts to ensure that the deliberation process itself allowed for a diversity of perspectives to be shared. This subtle yet critical distinction between representing a *diversity of population characteristics* vs. a *diversity of viewpoints* points to a weakness in our minimum definition and how the concepts of representation and diversity have been addressed in the PD literature to date. More specifically, notions of *representing* a diversity of perspectives through the recruitment process (e.g., by socio-demographics, interest characteristics, etc.) seemed to be conflated with the notion of designing a deliberative process that allows for a diversity of viewpoints to be shared (irrespective of the representativeness of participants). Some of the studies we examined were directly concerned with one concept or the other but rarely distinguished between the two or described how both might be achieved.

### *Value-based reasoning: specifying its key features*

As one approaches the intricacies of deliberation, the feature of moral or value-based reasoning is particularly challenging to specify, let alone decipher from accounts of public deliberation. What are its inherent features? How do we know when it is present? And what are the necessary conditions for supporting it? The studies we reviewed provided few clear depictions of how value-based reasoning was explained to deliberation participants and carried out (Appendix 2, column 4). For example, were values frameworks presented *a priori* or were participants expected to engage in value-based reasoning *tabula rasa*? That said, a number of supporting conditions appear to be associated with value-based reasoning. First, and most obviously, it occurs within structured task-oriented discussions. More specifically, discussions within smaller "break-out" groups is the typical setting used to identify the values underpinning various positions on an issue. The nature of these discussions is sometimes described as "collective problem solving," where individuals "with different backgrounds, interests, and values listen, understand, potentially persuade and ultimately come to more reasoned, informed and public-spirited decisions" (Abelson et al., 2007, p. 2117). Many studies referred to two-step processes that involved an initial plenary discussion emphasizing common understanding of the deliberation topic, followed by small-group activity, reporting back and large-group discussion.

Moral or value-based reasoning also involves the complementary activities of knowledge acquisition, questioning and debate – all routinely cited in the studies we reviewed. More specifically, PD initiatives referred to participants "challenging," "questioning," "justifying" and "debating" each other and invited experts. While the act of identifying "ethical challenges," "tensions" and "trade-offs" suggests the presence of free and open exchange, it still falls short of specifying the precise elements of value-based reasoning. Only a small number of studies we reviewed identified "normative criteria" to support a particular position or recommendation or used existing "moral frameworks" to guide deliberations (Bennett & Smith, 2007; Bombard et al., 2011). Building on these examples would be a fruitful avenue to explore in future work in this area.

### *Finding common ground: the need for greater transparency*

Deliberative processes emphasize shifts from individual to collective stances. The act of reaching common ground and yielding collective outputs are its archetypal features. We found many clear statements of the type of collective output sought or obtained from deliberations (Appendix 2, column 5). For example, participants were described as "reaching a verdict," "producing recommendations," "developing majority opinions" and "reaching reasoned, informed and public-spirited decisions." Yet, as with our discussion of value-based reasoning, few details were provided about the steps taken to arrive at these outputs. For those approaches that were described more explicitly, they differed substantively, suggesting different epistemological approaches to the deliberative enterprise. For example, some PD initiatives sought "majority" and "dissenting" opinions as their collective output, acknowledging from the outset that consensus was never the goal. Others emphasized the process of identifying shared values and areas of agreement (qualitatively) and "collective preference statements" (quantitatively). A compromise position taken in a number of initiatives was one of "working towards consensus while allowing for disagreement." Regardless of the desired output for deliberation, the lack of clearly described methods for producing them needs to be addressed if they are to be given serious consideration (e.g., Who synthesizes the deliberation discussions and how? What is the process for vetting the outputs with deliberation participants?)

Underlying these operational issues is a perplexing set of ambiguities. While the studies we reviewed included clearly identified outputs, the diversity of these outputs is striking. Moreover, their alignment with the related goal of yielding collective judgments on social issues (i.e., what we ought to do) is unclear and also likely to vary considerably. For example, does reaching a verdict, which is the goal of a citizens' jury, involve the same collective effort as developing recommendations or producing majority and dissenting opinions? And are these outputs, as well as efforts to identify shared values, moving citizen deliberators enthusiastically toward the goal of locating common ground without having thoroughly canvassed their views about what ought to be done? These issues have been fiercely debated in the broader PD literature but have not received the same level of attention as PD has been rolled out in the health field.

### *Informing policy through public deliberation*

While the vast majority of public deliberation efforts in the health field have been initiated by researchers, they are motivated by a strong desire to address real-world policy problems and to inform relevant policy processes. We observed a variety of relationships between the initiators of public deliberation processes and relevant "policy receptors" (Appendix 2, column 6). Three types of relationships were generally observed: i) researcher-initiated PD activities which resulted in a report or recommendations that were presented or submitted to a relevant policy/decision-maker; ii) decision-maker-initiated activities designed to inform a particular policy process (less common); and iii) PD activities resulting from collaborations between researchers and decision-makers that yield public input on a particular topic while providing opportunities to study various aspects of deliberation. The establishment of formal links between PD and relevant policy decisions through the types of relationships described here would certainly appear to facilitate the uptake of PD outputs. However, efforts to document the impacts of PD on policy have begun only recently in the health field and have revealed the complexity of linking PD outputs to decision-making, the long-term horizons required to trace PD impacts, and the need for further conceptualizing about what constitutes "use" or "uptake" of PD outputs.

For example, Jones and Einsiedel (2011) traced the "institutional learning" impacts of a deliberative public consultation that employed a citizens' jury model in the early 2000s (Einsiedel, 2002). Their results revealed that despite the lack of substantive policy change, the exposure to the method of public deliberation facilitated a shift in institutional culture, which was reflected in a greater openness to including a broader set of actors in the policy process. And in their evaluation of the early years of the NICE Citizens Council, Davies et al., (2006) observed the Council's initial lack of "embeddedness" within the inner workings of NICE and the need to strike the right balance between maintaining the Council's independence from the sponsoring organization and ensuring that its outputs were on the organization's radar. Council members called for greater clarity about their role in relation to NICE decision-making and for greater transparency about how their input would be used. These findings were supported recently by Abelson et al., (2013) where a citizens panel established to inform the health technology advisory process in Ontario, Canada exerted various impacts on the HTA process that were mediated by direct exchange between citizens and experts, to clarify roles, promote accountability and build trust. As these examples illustrate, even when fully supported, public deliberation operates within a complex array of organizational settings and political structures that shape the degree and manner in which it is likely to exert tangible influences on policymaking and other aspects of collective problem-solving.

## DISCUSSION

This mapping exercise is neither an exhaustive nor a comprehensive review of the full spectrum of public deliberation activity in the health field. By restricting our focus to peer-reviewed literature, we are aware that we have excluded learning from a rich field of practice, which has supported the study of public deliberation in the health field. Equally, our limited but deliberately narrow search parameters (e.g., empirical studies; deliberat* in the title or abstract) have excluded important theoretical contributions as well as empirical work that may have aspired to the principles of public deliberation without using its label (e.g., Ginsburg, Goold & Danis, 2006; Goold et al. 2005). Despite these omissions, we believe that our review provides an informative and up-to-date set of reflections on the relatively short but rich history of public deliberation in the health sector. We have explored the various ethical controversies and public policy problems that these types of processes have sought to address, and how the approaches used and features examined, have evolved over time.

Our review reveals a small but active interdisciplinary community of scholars and practitioners working diligently around the world to address a range of bioethics and health policy challenges using the principles of deliberative democratic theory. The desire to contribute to pressing health challenges has been a strong motivator within this community. Public deliberations have been undertaken to provide values input to national health reform initiatives and to local pandemic flu planning; they have contributed to the assessments of ethically controversial new technologies and have assisted communities to prioritize health services and benefits packages within constrained budgets. Despite a growing number of deliberative methods available (e.g., juries, panels, deliberative polling), most processes used in the health field ascribe to generic principles to allow for maximum tailoring to decision-making and issue contexts.

When it comes to operationalizing the principles of deliberative democracy theory, the subset of empirical studies we reviewed fared well, at first glance, in meeting a minimum definition provided for public deliberation. With few exceptions, clear efforts were made to inform participants, to represent a diversity of perspectives, to engage in free exchange and value-based reasoning and to locate common ground that would produce outputs that could potentially inform a set of decisions. In this sense, our minimum definition aligned quite well with what we found in practice. However, once we moved beyond this superficial level, to observe *how* each of these elements were implemented, we were struck by the degree of heterogeneity and ambiguity with which these core features have been operationalized, which are likely driven by the limitations of current definitions, the limited attention paid to them, or both. For example, the concepts of representation and diversity appear to be conflated in public deliberation studies, calling for greater specification of these goals and how they are to be achieved (i.e., through participant recruitment, through the deliberative process or both). Similarly, more attention needs to be given to clarifying, for practical purposes, what is required for value-based reasoning that produces collective judgments to occur. This could be done in two potentially complementary ways: i) inductively, through in-depth qualitative analyses of deliberative processes; and ii) by drawing on ethics and normative theory to provide models and frameworks. Finally, despite the strong motivations and formal links being established to ensure that the outputs of public deliberation inform decision-making, much more work is needed to understand what “use” and “uptake” of PD consists of and how to measure it.

In reflecting on this mapping exercise and the areas we have identified for further development, we see numerous opportunities for disciplinary and interdisciplinary scholars to contribute to this emerging, interdisciplinary field and to help expand, strengthen and more fully operationalize the proposed minimum definition. Communications and psychology scholars would provide valuable expertise to evaluate and improve the quality of the informational and social interaction features of PD. Philosophy and ethics expertise would bring needed rigor to the moral reasoning endeavour. Policy analysts are needed to map and assess the PD-policy linkages. Beyond these valuable disciplinary contributions, we see an even more critical role for more frequent and meaningful interactions between PD theorists and practitioners to learn from and enrich each others’ work.

## CONCLUSION

Our examination of citizen deliberation processes in the health sector has revealed a solid set of contributions covering a broad range of content areas, jurisdictions and aims. As experimentation and interest in citizen deliberation continues to grow, scholars and practitioners need to be rigorous in their approaches to design, implementation and evaluation. Current definitions and conceptualizations of PD’s core features would benefit from expansion and refinement to both guide and respond to practice developments. Opportunities for cross-disciplinary exchange have facilitated this type of work already and should continue. We look forward to the next wave of innovations and experiments in this dynamic field.

**Appendix 1. Summary characteristics of empirical studies of public deliberation in health policy and bioethics**

| Citation | Jurisdiction | Deliberation Method(s) | Participant Recruitment & Selection | Decision (type) | Decision (content) | Study Aim |
|---|---|---|---|---|---|---|
| Einsiedel & Eastlick (2000) | Canada – provincial (British Columbia, Alberta, Saskatchewan, Manitoba) | Deliberative: Citizen panel (over 2 weekends) | Recruitment: Advertisements and news coverage<br>Selection: 15 citizens selected from 356 applications received; demographic balance sought (gender, age, education and occupation) | Policy development and regulation | Food biotechnology | To *examine* the use of a citizens' conference approach as a tool for direct public participation on technological issues |
| Bracci (2001) | United States – state (Oregon) | Public hearings and community meetings (n=60), telephone surveys (n=1000) | Not reported | Priority setting and resource allocation | Health services management | To *evaluate* the patterns of public deliberation and ethical dimensions of the Oregon experiment using a civic bioethics model (civic republicanism, norms for democratic deliberation as ethical communicative practice) |
| Einsiedel (2002)<br><br>*See also Einsiedel & Ross (2002)* | Canada – regional (6 cities) | Deliberative: Citizen panel over 3 days at each of the 6 regional sites | Recruitment: Invitations sent to random sample (2500 residents per site)<br>Selection: Demographic diversity sought | Policy development and regulation | Xenotransplantation | To *evaluate* a Canadian public consultation on xenotransplantation with particular focus on the deliberative citizen fora |
| Einsiedel & Ross (2002)<br><br>*See also Einsiedel (2002)* | Canada – regional (6 cities) | Citizens' jury over 3 days at each of the 6 regional sites | Not reported | Policy development and regulation | Xenotransplantation | To *describe* the citizen panelists' recommendations to hold off on proceeding with clinical trials and the rationales behind this |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | | | recommendation |
| Abelson & Eyles (2003) | Canada – regional (2 local health agencies) | Deliberative: Citizen panel (3 types: mail, telephone, face-to-face) | Recruitment: Participants selected using stratified sampling from local community organizations (organization type, men and women); participants randomly assigned to one of the three deliberative methods | Priority setting | Health goals | To *examine* the effects of introducing different opportunities for deliberation into a profess for obtaining public input into a community health goals priority setting project |
| Maxwell, Rosell & Forest (2003) | Canada – regional (12 sites) | 1-day dialogue sessions at each of the 12 regional sites | Random selection of participants; representative cross section of Canadian population sought Inclusion: English or French speaking citizens aged 18 years and over; Exclusion: people working in the health care system | Priority setting | Health services reform | To *describe* the process, outputs and influence of the ChoiceWork dialogue method on the work of a royal commission on health care. |
| Grogan & Gusmano (2005) | United States – state (Connecticut) | Deliberative democracy through Medicaid Managed Care Council (met monthly) | Participants in the MMC Council were a range of groups affected by and interested in Medicaid policy; "Connecticut's MMC deliberation was reasonably inclusive, perhaps because excluded groups had fought for | Policy development and implementation | Health services reform | To *examine* deliberation among stakeholder representatives in the design and implementation of the reform of Medicaid health care policy in Connecticut in the mid-1990s |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | their inclusion" (p.137) | | | |
| Abelson & Forest (2007) | Canada – regional (5 health regions) | Deliberative: 1-day (6h) face-to-face meetings at each of the 5 research sites | Recruitment: Stratified random sampling of 'active citizens' through local community organizations<br>Selection: Most senior volunteer member (or equivalent) from each invited participant organization | Planning and resource allocation | Health services | To *assess* the feasibility and to *determine* the outcomes of implementing a generic public deliberation method across different *community, organizational and policy* contexts. |
| Bennett & Smith (2007) | UK – regional | Citizens jury charged to reach a 'verdict' (over 3 days) | Potential jurors obtained from electoral register; stratified by employment status, age, sex, housing tenure; final sample evenly split across categories | Policy development | Genetic testing and access to life insurance | To *consider* the strengths and limitations of citizens juries as a research method to elicit ideas about complex policy decisions; and to *examine* the outcomes of one citizens jury on genetic testing and life insurance |
| Guttman (2007)<br>*See also Guttman et al (2008)* | Israel – national | Series of 6 regional panels (over 5 months) and a national assembly; group facilitation and small group discussions | Recruitment: Stratified national sample<br>Inclusion: Hebrew, Arabic or Russian speaking<br>(selection process not reported) | Priority setting | Not reported<br>"Participants were asked to consider four healthcare policy questions" (p.418) | To *explore* existing theories of deliberation, and to *describe* the deliberative procedures used in an Israeli public consultation initiative |
| Timotijevic & Raats (2007) | United Kingdom – national | Deliberative: citizens' workshop (1 day) and citizens' jury (2-5 days) | Recruitment:<br>i) selection of geographic area (voting and demographics similar | Policy development | Food retailing | To *evaluate* two deliberative methods of public participation in food policy development – the citizens' workshop and the |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | to national average)<br>ii) recruitment of participants through invitations to community voluntary organizations and projects associated with older people<br>Selection: Stratified approach used (age, gender, educational attainment) to allocate participants to workshop or jury | | | citizens' jury based on assessments of i) participants' and observers' perceptions of the processes and outcomes of the deliberative approaches; and ii) evaluation criteria based on the characteristics of the process |
| Guttman et al (2008)<br>*See also Guttman (2007)* | Israel – national | Deliberative: a series of regional (within local 'parliaments' in 6 regional sites) and a national assembly; group facilitation and small group discussions | Recruitment: Stratified random sample of 1500 people from the adult population (over-sampling of minorities and new-immigrant populations); prospective participants contacted by phone | Priority setting | Equity and priority regarding the provision of health services | To *engage* Israeli citizens in discussion on four healthcare policy questions related to equity in health services and priorities for determining which medications and treatments should be included in the basket of national health services |
| Pidgeon & Rodgers-Hayden (2007) | UK – regional (West Yorkshire) | Citizens jury (bi-weekly meetings for 5 weeks – 1 session introduction, 6 'witness' sessions, 3 recommendation sessions) | Recruitment of a cross-section of residents<br>Selection: volunteer respondents to publicity and recommendations to the research team by word of mouth | Priority setting | Nanotechnology | To *explore* 'upstream' public engagement and the extent to which public dialogue may play a role in heath risk characterization |

| | | | | | | |
|---|---|---|---|---|---|---|
| Menon & Stafinski (2008)<br>*See also Stafinski, Menon & Yasui (2012)* | Canada – regional | Deliberative: citizens' jury (over 3 days) | Recruitment: Letters of invitation to participate in telephone screening survey mailed to 1600 randomly selected residents<br>Exclusion criteria: health-care professionals, members of special interest/advocacy groups<br>Selection: Purposive and random sampling techniques to select a jury with demographic and socioeconomic profile comparable to that of the region | Priority setting | Health technology | To *assess* the feasibility of using a citizens' jury to elicit public values on health technologies and to develop criteria for setting priorities for health technology assessment (HTA) |
| Paul et al (2008) | New Zealand – national | Citizens jury (over 1.5 days) | Random sample of women selected from general and Maori electoral rolls; 80 invited to participate<br>Inclusion criteria: women aged 40-49 years, no breast cancer diagnosis<br>Selection: First 12 women to reply were invited to attend | Policy development | Cancer screening | To *test* a method of assessing whether a well-informed community would support or reject a policy decision about cancer screening |
| Baum, Jacobsen & Goold (2009) | United States – municipal (4 counties in | Focus groups: 4 focus groups (one in each county), 90 | Recruitment: Flyers and advertisements (electronic | Planning and policy development | Public health (pandemic control) | To *evaluate* and determine public willingness to accept and comply with social |

| | | | | | | |
|---|---|---|---|---|---|---|
| | Southeast Michigan) | minutes each | distribution and posting in public venues);<br>Selection: 8-10 adults in each group, selected for employment status and parenting status | | | distancing measures in a pandemic, and to understand the ethical standpoints of public health practitioners on this issue |
| Evans & Kotchetkova (2009) | United Kingdom – regional | Mixed: cumulative process of in-depth expert interviews and focus groups (patients, carers and lay citizens) that ended with a 1-day roundtable workshop | *Focus groups*<br>Recruitment: Patients and carers recruited through local diabetes clinic; lay people recruited through schools and University online notice boards; (selection process not reported) | Policy development and clinical decisions (treatment) | Type 1 diabetes treatment options | To *understand* the relationship between qualitative research and public engagement with science and technology, and critically *evaluate* the experiences and outcomes of the deliberative process |
| Rogers et al (2009) | Australia – state (South Australia) *urban only | Deliberative forum (one 2-day forum) | Ongoing random selection from a weighted database to fulfill predetermined criteria for age, sex, employment, household income; continued until all participant spots filled | Planning | Pandemic influenza | To *use* a deliberative forum to elicit community perspectives on communication about pandemic influenza planning, and to *compare* these findings with current communication policies |
| Deng & Wu (2010) | Taiwan – national | Deliberative: 2-day forum consisting of members from health care provider associations, labour unions, social welfare | Recruitment: Participants recruited from 4 types of groups with interests in the policy issue<br>Selection: Maximum 2 representatives per | Policy reform | Health insurance (the basis on which health insurance premiums should be calculated, and allocation of financial burden of | To *develop* a participatory method suitable for new democracies and to *evaluate* the effects of the deliberative forum |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | organizations and patient organizations | group | | premiums among stakeholders) | |
| DeVries & Stanczyk (2010) | United States – state (Michigan) | Deliberative: all-day session with small group discussions | Recruitment: Direct mailing lists of local Alzheimer groups; advertisements on University research website and in local Alzheimer group newsletters<br>Inclusion criteria: living within driving distance of deliberation site<br>Selection: participants randomly assigned to either PD session or control group | Policy development and regulation | Clinical research in Alzheimer's disease and ethical issues in surrogate-based research | To *develop* measures for, and *assess*, the "quality of deliberation" which include i) equal participation by all members of the session; ii) respect for the opinions of others; iii) willingness to adopt a societal perspective; and iv) reasoned justification of one's position |
| Longstaff & Burgess (2010)<br>*See also MacLean & Burgess (2010)* | Canada – provincial (British Columbia) | Public event (2 weekends), which included stakeholder and expert presentations, moderated small and large group discussions and deliberations | Random digit dialing to collect a participant group that did not include stakeholders; stratified (provincial health region, demographics) | Policy development and regulation | Biobanks – secondary use of human tissues for prospective genomic and genetic research | To *demonstrate* how the representativeness of sampling approaches can be based on the key objectives of the deliberation |
| MacLean & Burgess (2010)<br>*See also Longstaff & Burgess (2010); Walmsley* | Canada – provincial (British Columbia) | Public event (2 weekends), which included stakeholder and expert presentations, moderated small and large group | Recruitment: Random-digit dialed demographically stratified sample (sampled for demographic diversity by occupation, sex, | Policy development and regulation | Biobanks | To *examine* the use of deliberative democracy as an approach to understand citizens' views on secondary use of human tissues for prospective genomic and genetic research |

| | | | | | | |
|---|---|---|---|---|---|---|
| *(2011)* | | discussions and deliberations | religion, ethnicity) | | | |
| O'Doherty & Hawkins (2010) | Canada – provincial (British Columbia) | Deliberative: 4-day deliberative public engagement (which included a deliberation workbook, and structured deliberation on biobanks) | Recruitment: Letters of invitation sent to 5000 random households selected by post code<br>Selection: 224 individuals expressed interest; 25 individuals selected to achieve demographic stratification (age, gender) | Policy development and regulation | Biobanks | To *examine* how results of public engagement on the topic of biobanking can be relevant and useful to the institutional and regulatory context |
| Bombard et al (2011) | Canada – provincial (Ontario) | Citizen panel (5 one-day meetings) | Recruitment: Stratified, random sampling approach<br>Selection: 'Civic lottery system' to blindly select 14 participants from the respondent pool (stratified by gender, age, region) | Policy development | Health technology assessment | To *elicit* a set of ethical and social values from citizens to guide the HTA policy process, and to *explore* the feasibility of using participatory approaches to elicit these values |
| King & Heaney (2011) | UK – national (Scotland) | Two citizens juries (1-day each): rural citizen jury and urban citizen jury | Purposive recruitment of lay representatives from local health care organizations based on demographic characteristics (age, gender, ethnicity, social background) | Implementation and priority setting | E-health (implementation and research priorities) | To *report* on the findings of two modified citizens juries exploring public perspectives on e-health |
| Mackenzie & O'Doherty (2011) | Canada – provincial (British Columbia) | Minipublic (small groups of citizens engaged in intense | Random-digit dialing to obtain a demographically | Policy development | Salmon genomics | To *explore* how to provide democratic input on issues that are technically and |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | deliberations for short periods of time) (over 2 weekends) | stratified sample for BC (occupation, age, sex, religion, ethnicity) | | | temporally complex, with a focus on minipublics |
| Molster et al (2011)<br>*See also Molster et al (2012)* | Australia – regional (1 city) | Public forum (4 days over 2 weekends) | Not reported (see Molster et al 2012) | Policy development | Biobanks | To *describe* the design process of developing a deliberative public forum, and to *describe* how deliberative outputs were used in policy decision-making processes |
| Pesce, Kpaduwa & Danis (2011) | United States – regional (1 city) | Small group deliberation (n=43 small groups) | Recruitment: Flyers and newspaper ads Inclusion criteria: between ages 18 and 65, income <200% of federal poverty threshold (selection process not reported) (n=431) | Priority setting | Health disparities, socioeconomic interventions for health | To *examine* whether the public accept public deliberation to set priorities and appreciate the social determinants of health, and to *engage* low income urban residents in a deliberative exercise |
| Walmsley (2011)<br>*See also MacLean & Burgess (2010)* | Canada – provincial (British Columbia) | Public event (2 weekends), which included stakeholder and expert presentations, moderated small and large group discussions and deliberations<br>Focus of Walmsley 2011 – one of the small groups that the author facilitated | Recruitment: Random digit dialing supplemented with demographic stratification (ethnicity, religion, occupational group, gender) | Policy development and regulation | Biobanks | To *consult* the BC public about core values that should guide biobanking, drawing upon deliberative democracy theories and tools<br>To *describe* innovative efforts made to record both consensus and persistent disagreements |

| | | | | | | |
|---|---|---|---|---|---|---|
| Molster et al (2012)<br>*See also Molster et al (2011)* | Australia – regional (1 city) | Public forum (4 days over 2 weekends) | Recruitment: Stratified random sampling (age, sex, education, geographic location, religious status, health status, language, Aboriginality); goal of discursive representation | Policy development | Biobanks | To *describe* a deliberative public forum on biobanking and to facilitate critical examination of its design |
| Stafinski, Menon & Yasui (2012)<br>*See also Menon & Stafinski (2008)* | Canada – regional (2 regions in Alberta) | Two citizens' juries (each over 2.5 days) | Recruitment: See Menon & Stafinski (2008) | Resource allocation | New health technologies | To *assess* the impact of citizens' juries on participants' preferences, specifically whether jurors' views of factors that may be considered during resource allocation decision making for new health technologies changed following participation in the jury |

**Appendix 2. Analysis of the implementation of core features of public deliberation within selected studies**

| Citation | Representation & Diversity | | Information to prepare participants | | Values-based reasoning *(moral, 'ought', discussion forums*) | Collective *(how did they seek to locate common ground?)* | Policy-informing *(decision-making receptor, uptake)* |
|---|---|---|---|---|---|---|---|
| | Objective | Actual | What | By whom | | | |
| Einsiedel & Ross (2002) | Reported in companion paper - overall goal was demographic diversity | Not reported (discussed in companion paper in the context of what constitutes a fair and representative process) | Briefing paper contents to meet following criteria:<br>i) comprehensiveness;<br>ii) accessibility;<br>iii) objectivity<br>Expert panel available to answer questions from citizen panel members | Prepared by research team<br>Relevant experts (clinical, legal, bioethics, animal welfare and patient) | Citizen panel discussions and deliberations, in small groups and plenary | Non-facilitated small groups reported critical issues and preliminary positions to plenary (recorded for further discussion in the large group)<br>Key recommendations developed by the large group with "overall majority response" reported | Government health ministry outsourced public deliberation to non-government organization "to ensure that the … process was at arm's length from the ministry" (p.584) |
| Abelson et al (2007) | Organizations through which participants were recruited were "chosen with the goal of achieving comparable representation" across organization type | Stratified random sampling process; politically and socially active local citizens recruited through local community | Provision of standardized information materials tailored to the local issue | Research team | Plenary and small group sessions<br>Method described: collective 'problem-solving' discussion "to allow individuals with different backgrounds, interests and values | "A combination of structured and unstructured aggregation of input" (p.2118) | Public deliberations designed and implemented through researcher-decision maker collaborations<br>PD reports produced and shared with participating |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | (health provision, health-related, well-being) (p.2119) | organizations | | | to listen, understand, potentially persuade and ultimately come to more reasoned, informed and public-spirited decisions" (p.2117) | | organizations with varied uptake documented |
| Bennet & Smith (2007) | "To secure the diverse resources for deliberation that a wide range of backgrounds delivers" (p.2490) | Participants selected to represent socio-demographic characteristics of interest (i.e., gender, employment status, homeowners vs. renters) | Aim: "to provide the jury with the information and resources they would need to examine their case" (p.2491)<br>Knowledge building presentations to provide essential background information | Expert witnesses | "A key finding from this research is that … [a Citizens' Jury] can also express and develop normative ideas collectively … The Jury offered a balanced account of *how things are*, but it also negotiated, from complex starting points and amid a variety of competing interests, a vision of how things *ought to be*" (p.2495)<br>Method: "Rather than leaving their values to one side, jurors began to move towards discussing the normative criteria upon which the 'best' model could be decided" (p.2495) | Jury was charged to reach a 'verdict' following deliberation; verdict determined through majority vote (not unanimous) | 'Verdict' was "intended as an intervention in public debate" (p.2491) |
| Guttman et al (2008) | Recruitment of participants from | Professionally moderated | Aim: "to enhance the | | Discussions about equity in the context | "Regional groups were charged with | Participants' summaries were |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | diverse backgrounds; specific interest in health care issues not required | discussions helped to ensure that all participants had the *opportunity to express their views* | competence of the discussion" (p.181) | | of co-payments for health care technologies | producing a group summary of their views and recommendations regarding each policy issue, including diverging perspectives" (p.182)<br>Task of summarizing was "guided by the principle that consensus was not required and that diverse perspectives should be heard and included" (p.182) | presented to the Minister of Health and the Health Council |
| | | | Written background materials and presentation (history and structure of the healthcare system, description of policy problems) | Research team | | | |
| | | | Position papers | Various stakeholders | | | |
| | | | Health policy experts available for Q&A | | | | |
| Baum, Jacobsen & Goold (2009) | Recruitment guided by interest in obtaining perspectives from those *likely to be affected* by pandemic response measures | Participants represented interests of affected parties (i.e., employed, parents of young children) | Short educational session about influenza and pandemics | Not reported | Deliberations identified various ethical challenges and tensions (e.g., personal autonomy vs. community well being; fair distribution of burdens and benefits of policy actions) | Deliberation outputs reported as "discussion themes" generated through qualitative, thematic analysis (no explicit effort to summarize or reach common ground described) | Not reported |
| Rogers et al (2009) | Recruitment guided by goal of | "Potential members | Two-page evidence | Research team | Format: facilitated group discussion of | "Members were asked to act as | No formal decision-maker partner, |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | statistically representing South Australia population | were randomly selected from a database weighted by age, sex and geographical location to reflect accurately the South Australian population" (p.332) | summaries on pandemic influenza and communication<br>Briefing presentations with opportunity for Q&A precede discussions | <br>Experts in infection control, virology, ethics, public policy | hypothetical scenarios<br>Participants deliberated in small groups, brainstorming, and large group discussion | 'citizens' and 'community representatives' rather than as 'individuals'" (p.333)<br>"Participants were encouraged to state and discuss their views, seek further information from experts, then reach a broad consensus in their responses" (p.333) | however results have been provided on request to the Australian Government pandemic influenza sub-committee |
| King & Heaney (2010) | Recruitment of jurors from local health organizations to represent a range of demographic characteristics and experience with committees | Rural jury (n=10)<br>Urban jury (n=12)<br>Even balance of men and women, most jurors between ages of 50-70, all British, all had at least some experience of presenting their views in a committee environment | Pre-circulated introductory package (e-health description, aims of the jury, set of questions to be debated)<br>Watching a DVD<br>Two 'witness' presentations of opposing perspectives about e-health | Research team<br>Research team<br>Clinicians | Facilitated debate of the pre-set questions; key points could be agreed upon, and "if there were dissenting views, jurors were encouraged to discuss and debate these" (p.4) | Qualitative thematic analysis of the debate<br>"If the debate had been facilitated in a more adversarial style, or if the jurors had been forced to make resource constrained choices, it may have generated more conflicting views, which jurors would then have had to work | Not reported |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | through and reconcile” (p.8) | |
| MacLean & Burgess (2010) | Participants were recruited to achieve demographic diversity | Participant details not reported | Presentations<br>“The rest of the first weekend focused on informing participants about a range of issues surrounding biobanks” (p.488) through moderated small and large groups | Stakeholders and experts: “The objective for choosing a range of expert and stakeholder speakers was … to provide a diverse range of interests and experiences that would complement [other] information” (p.490) | Moderated small groups of seven to eight participants enhanced participation and respectful engagement<br>Break between first and second deliberation events “encouraged participants to reflect, gather information, talk to others, and consider the issues in the context of their own lives” (p.488) | Small and large group deliberations concluded with a final large group session where participants presented their results, including points of disagreement and consensus<br>“While asked to report as a group, some participants rejected majority decisions and chose to defend their own positions” (p.492) | Not reported |
| Bombard et al (2011) | To achieve socio-demographic and geographic balance | Participants were selected by geographic region and stratified by gender and age bracket | Pre-circulated workbook (topic and evidence summaries, relevant articles)<br>Summary presentation at beginning of each meeting | Research team<br>Meeting facilitator or guest presenter | Iterative process of participants reflecting on a pre-circulated list of ‘moral questions’, articulating their own values, and mapping these onto their evaluation of specific technologies<br>“Using Hofmann’s | “This participatory process allowed members to find common ground around trade-offs and collectively articulate values to guide decision-making” (p. 140)<br>Core values identified through | Deliberative process designed in collaboration with decision-maker partner<br>Deliberation outputs reported routinely at monthly provincial health technology advisory committee meetings |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | Q&A session during meeting | Meeting facilitator | questions, members distilled what they perceived to be the fundamental values at stake for the health care system in adopting new health technologies” (p.138) | qualitative thematic analysis by research team members followed by member checking with participants | and through final report; evidence of uptake documented for several technologies reviewed |
| Pesce et al (2011) | To select a “segment of the population *greatly affected* by decisions regarding social services” (p.790), i.e., at or below 200% of federal poverty threshold | All participants were urban residents with low incomes (under the federal poverty threshold) | Simple written explanation of socioeconomic determinants of health and their relationship to health disparities<br>Information booklet describing interventions | Research team<br>Research team | “Participants took turns nominating and justifying interventions… Participants discussed each recommendation, giving reasons for agreeing or disagreeing with them” (p.792) | “Benefits selected by large groups through consensus, or by majority vote if consensus could not be achieved” (p.792)<br>Qualitative analysis of transcripts to identify overarching themes across groups | Hypothetical exercise conducted in partnership with local health department |
| Molster et al (2012) | Recruit a mini-public of citizens who held a wide enough range of perspectives on biobanking for the exercise to be democratic and small enough in size to be genuinely deliberative | “Socio-demographic characteristics were used as proxy measures which might be associated with different public views” (p.3, Molster et al., 2011) | Written and oral information provided by “relevant experts and other perspectives” (e.g., scientists, people with disabilities, religious | Arranged by research team | “All participants indicated that their own views had been challenged and changed as a result of deliberation” (p.89)<br>“The expected information outputs were reflective of citizen perspectives, shared values and | “Deliberants were encouraged to work towards consensus, although persistent disagreement was an acceptable outcome” (p.84) | Translation of deliberative outputs into policy:<br>i) qualitative analysis of deliberation transcripts;<br>ii) meetings between the research team and decision maker partners to draft policy; |

| | | | |
|---|---|---|---|
| | leaders, ethicists, biobank custodians)” (p.84) | acceptable trade-offs in public interests. The deliberants discussed their hopes and concerns before making recommendations” (p.84) | iii) stakeholder engagement<br>“Most recommendations were translated into biobanking guidelines, with which Western Australia government health agencies must comply” (p.82) |

## References

Abelson, J., Lomas, J., Eyles, J., Birch, S. & Veenstra, G. (1995). Does the community want devolved authority? Results from deliberative polling in Ontario. *Canadian Medical Association Journal*, *153,* 403-412.

Abelson, J., Eyles, J., McLeod, C., Collins, P., McMullan, C. & Forest, P-G. (2003). Does deliberation make a difference? Results from a citizens panel study of health goals priority setting. *Health Policy, 66,* 95-106.

Abelson, J., Forest, P-G., Eyles, J., Casebeer, A., Martin, E. & Mackean, G. (2007). Examining the role of context in the implementation of a deliberative public participation experiment: Results from a Canadian comparative study. *Social Science & Medicine, 64,* 2115-2128.

Abelson, J., Bombard, Y., Simeonov, D., Boesveld, S. & Gauvin, F-P. (2013). Assessing the impacts of a deliberative participatory structure on the HTA process in Ontario, Canada: The Citizens' Reference Panel on Health Technologies. *International Journal of Health Technology Assessment in Health Care,* in press.

Baum, N., Jacobsen, P., & Goold, S. (2009). "Listen to the people": Public deliberation about social distancing measures in a pandemic. *The American Journal of Bioethics, 9(11),* 4-14.

Bennett, P. & Smith, S. (2007). Genetics, insurance and participation: How a Citizens' Jury reached its verdict. *Social Science & Medicine, 64,* 2387-2498.

Blacksher, E. Diebel A., Forest, P-G., Goold, S. & Abelson, J. (2012). What is Public Deliberation? *Hastings Center Report, 42(2),* 14-17.

Bombard, Y., Abelson, J., Simeonov, D. & Gauvin, FP. (2011). Eliciting ethical and social values in health technology assessment: a participatory approach. *Social Science & Medicine, 73(1)*, 135-144.

Bostwick, M. (1999). Twelve Angry Citizens: Can citizens' juries improve local democracy in New Zealand? *Political Science, 50(2*), 236–246.

Bowie, C., Richardson, A., & Sykes, W. (1995). Consulting the public about health service priorities. *British Medical Journal*, *311*, 1155–1158.

Bowling, A., Jacobson, B., & Southgate, L. (1993). Explorations in consultation of the public and health professionals on priority setting in an inner London health district. *Social Science and Medicine*, *37(7),* 851–857.

Bracci, S. (2001). Managing health care in Oregon: the search for a civic bioethics. *Journal of Applied Communication Research, 29(2)*, 171-194.

Bodenheimer, T. (1997). The Oregon Health Plan—Lessons for the Nation (first of two parts). *New England Journal of Medicine, 337,* 651-655.

—. (1997). The Oregon Health Plan—Lessons for the Nation (second of two parts). *New England Journal of Medicine, 337,* 720-723.

Cookson, R., & Dolan, P. (1999). Public views on health care rationing: A group discussion study. *Health Policy*, *49(1–2*), 63–74.

Coote, A., & Lenaghan, J. (1997). *Citizens' juries: Theory into practice*. London, U.K.: Institute for Public Policy Research.

Crawshaw, R. Garland, M., Lobitz, C. et al., (1985). Oregon Health Decisions: An experiment with informed community consent. *Journal of the American Medical Association, 254,* 3213-3216.

Davies, C., Wetherell, M., & Barnett, E. (2006). *Citizens at the Centre: Deliberative Participation in Health Care Decisions.* Bristol, U.K.: The Policy Press.

Deng, C-Y. & Wu, C-L. (2010). An innovative participatory method for newly democratic societies: the "civic groups forum" on national health insurance reform in Taiwan. *Social Science & Medicine, 70,* 896-903.

DeVries, R., Stanczyk, A., Wall, I., Uhlmann, R., Damschroder, L. & Kim, S. (2010). Assessing the quality of democratic deliberation: a case study of public deliberation on the ethics of surrogate consent for research. *Social Science & Medicine, 70,* 1896-1903.

Dolan, P., Cookson, R., & Ferguson, B. (1999). Effect of discussion and deliberation on the public's views of priority setting in health care: Focus group study. *British Medical Journal*, *318*, 916–919.

Einsiedel, E. & Eastlick, D. (2000). Consensus conferences as deliberative democracy. *Science Communication, 21(4),* 323-343.

Einsiedel, E. (2002). Assessing a controversial medical technology: Canadian public consultations on xenotransplantation. *Public Understanding of Science, 11*, 315-331.

Einsiedel, E. & Ross, H. (2002). Animal spare parts? A Canadian public consultation on xenotransplantation. *Science and Engineering Ethics, 8,* 579-591.

Evans, R. & Kotchetkova, I. (2009). Qualitative research and deliberative methods: promise or peril? *Qualitative Research, 9(5),* 625-643.

Ginsburg, M. Goold, S.D. & Danis, M. (2006). (De)constructing 'basic' benefits: citizens define the limits of coverage. *Health Affairs*, 25(6):1648-55.

Goold, S.D., Biddle, A.K., Klipp, G., Hall, C. & Danis, M. (2005). Choosing healthplans all together (CHAT): a deliberative exercise for allocating limited health care resources. *Journal of Health Politics, Policy and Law*. 30(4), 563-602.

Government of Quebec. 2005. An Act respecting the Health and Welfare Commissioner. L.R.Q. Bill 38, chapter 18, section 28. http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=2&file=/C_32_1_1/C32_1_1.html (accessed on January 12, 2013).

Grogan, C. & Gusmano, M. (2005). Deliberative democracy in theory and practice: Connecticut's Medicaid Managed Care Council. *State Politics and Policy Quarterly, 5(2),* 126-146.

Guttman, N. (2007). Bringing the mountain to the public: dilemmas and contradictions in the procedures of public deliberation initiatives that aim to get "ordinary citizens" to deliberate policy issues. *Communication Theory, 17,* 411-438.

Guttman, N., Shalev, C., Kaplan, G., Abulafia, A., Bin-Nun, G., Goffer, R., Ben Moshe, R., Tal, O., Shani, M. & Lev, B. (2008). What should be given a priority -- costly medications for relatively few people or inexpensive ones for many? The Health Parliament public consultation initiative in Israel. *Health Expectations, 11,* 177-188.

Jefferson Center. Who we are. http://jefferson-center.org/who-we-are/our- people. Accessed 5 March 2013.

King, G., Heaney, D., Boddy, D., O'Donnell, C., Clark, J. & Mair, F. (2011). Exploring public perspectives on e-health: findings from two citizen juries. *Health Expectations, 14(4),* 351-360.

Lenaghan, J., New, B., & Mitchell, E. (1996). Setting priorities: Is there a role for citizens' juries? *British Medical Journal*, 312, 1591–1593.

Lenaghan, J. (1999). Involving the public in rationing decisions. The experience of citizens juries. *Health Policy*, 49(1-2), 45–61.

Longstaff, H. & Burgess, M. (2010). Recruiting for representation in public deliberation on the ethics of biobanks. *Public Understanding of Science, 19(2),* 212-224.

Mackenzie, M. & O'Doherty, K. (2011). Deliberating future issues: minipublics and salmon genomics. *Journal of Public Deliberation, 7(1),* Article 5.

MacLean, S. & Burgess, M. (2010). In the public interest: assessing expert and stakeholder influence in public deliberation about biobanks. *Public Understanding of Science, 19(4)*, 486-496.

Maxwell, J., Rosell, S. & Forest, P-G. (2003). Giving citizens a voice in healthcare policy in Canada. *British Medical Journal, 326,* 1031-1033.

Menon, D. & Stafinski, T. (2008). Engaging the public in priority-setting for health technology assessment: findings from a citizens' jury. *Health Expectations, 11,* 282-293.

Molster, C., Maxwell, S., Youngs, L., Kyne, G., Hope, F., Dawkins, H. & O'Leary, P. (2011). Blueprint for a deliberative public forum on biobanking policy: were theoretical principles achievable in practice? *Health Expectations* [Epub ahead of print].

Molster, C., Maxwell, S., Youngs, L., Potts, A., Kyne, G., Hope, F., Dawkins, H. & O'Leary, P. (2012). An Australian approach to the policy translation of deliberated citizen perspectives on biobanking. *Public Health Genomics, 15,* 82-91.

O'Doherty, K. & Hawkins, A. (2010). Structuring public engagement for effective input in policy development on human tissue biobanking. *Public Health Genomics, 13,* 197-206.

Paul, C., Nicholls, R., Priest, P. & McGee, R. (2008). Making policy decisions about population screening for breast cancer: the role of citizens' deliberation. *Health Policy, 85,* 314-320.

Pesce, J., Kpaduwa, C. & Danis, M. (2011). Deliberation to enhance awareness of and prioritize socioeconomic interventions for health. *Social Science & Medicine, 72,* 789-797.

Pidgeon, N. & Rodgers-Hayden, T. (2007). Opening up nanotechnology dialogue with the publics: risk communication of 'upstream engagement'? *Health, Risk & Society, 9(2).* 191-210.

Rawlins, M. (2009). Background to NICE's Citizens Council. In P. Littlejohns, and M. Rawlins,(Eds.), *Patients, the Public and Priorities in Healthcare* (pp 75-80). Oxford, U.K.: Radcliffe Publishing.

Rogers, W., Street, J., Braunack-Mayer, A., Hiller, J. & The FluViews Team. (2009). Pandemic influenza communication: views from a deliberative forum. *Health Expectations, 12,* 331-342.

Smith, G., & Wales, C. (1999). The theory and practice of citizens' juries. *Policy and Politics, 27(3),* 295–308.

Stafinski, T., Menon, D. & Yasui, Y. (2012). Assessing the impact of deliberative processes on the views of participants: is it 'in one ear and out the other'? *Health Expectations* [Epub ahead of print].

Statutes of Ontario. An Act to amend the Drug Interchangeability and Dispensing Fee Act and Ontario Drug Benefit Act, Bill 102, Chapter 14, 2006.

Stronks, K., Strijbis, A., Wendte, J. F., & Gunning-Schepers, L. J. G. (1997). Who should decide? Qualitative analysis of panel data from public, patients, health care professionals, and insurers on priorities in health care. *British Medical Journal*, 315, 92–96.

Timotijevic, L. & Raats, M. (2007). Evaluation of two methods of deliberative participation of older people in food-policy development. *Health Policy, 82,* 302-319.

Walmsley, H. (2011). Stock options, tax credits or employment contracts please! The value of deliberative public disagreement about human tissue donation. *Social Science & Medicine, 73,* 209-216.