An Australian Approach to the Policy Translation of Deliberated Citizen Perspectives on Biobanking

Caron Molster\textsuperscript{a}  Susannah Maxwell\textsuperscript{a}  Leanne Youngs\textsuperscript{a}  Ayla Potts\textsuperscript{a}  Gaenor Kyne\textsuperscript{a}  Fiona Hope\textsuperscript{a}  Hugh Dawkins\textsuperscript{a–c}  Peter O’Leary\textsuperscript{a–d}

\textsuperscript{a}Office of Population Health Genomics, Department of Health, \textsuperscript{b}Centre for Population Health Research, Curtin Health Innovation Research Institute, Curtin University of Technology, \textsuperscript{c}School of Pathology and Laboratory Medicine, University of Western Australia, and \textsuperscript{d}School of Women’s and Infants’ Health, University of Western Australia, Perth, W.A., Australia

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\textbf{Abstract}

\textbf{Background:} Deliberative public engagement is recommended for policy development in contested ethical areas. Scholars provide little guidance on how deliberative outputs can be translated to policy. This paper describes the processes we undertook to design a deliberative public forum for citizens to develop recommendations on biobanking that were adopted as health policy. \textbf{Method:} The 4-day forum, held in 2008 in Perth, Western Australia, was designed in collaboration with academic experts. Deliberant recommendations were recorded in a formal report presented to policymakers. Deliberations were audio-taped and transcribed. Translation involved transcript analyses, comparison of recommendations to other stakeholder views and post-forum consultations. \textbf{Results:} Sixteen citizens made recommendations on ethical, legal and social issues related to biobanking. Most recommendations were translated into biobanking guidelines, with which Western Australia government health agencies must comply. The value of deliberative public participation in policy-making was most evident when trade-offs in competing interests, hopes and concerns were required. Translation issues included the impact of a small number of participants with limited socio-demographic diversity on procedural and policy legitimacy. \textbf{Conclusions:} Assessing the sufficiency of diversity in citizen representation was central to the deliberation-to-translation process. Institutional context facilitated the uptake of deliberation and translation processes. The use of these processes influenced policy substance and credibility among stakeholders and contributed to the state government directive that policy compliance be mandatory. We urge others to publish deliberation-to-translation processes so that best-practices may be identified.

\textbf{Introduction}

Western Australia (WA) is uniquely placed for involvement in biobank research. With a leading edge data linkage capability, biobank data can be linked to data from long-established population collections, including hospitalizations and health service use, birth and death registrations, cancer and other diseases requiring statutory notification \cite{1, 2}. This enables the formation of powerful, data-rich resources for health and medical re-
search and, coupled with local bioinformatics capabilities, means WA has a competitive advantage for attracting science investment in biobank research [3].

Despite these capabilities and the existence of 80 biobanks under the custodianship of the WA government (excluding hospital pathology collections), in 2008 there were no government-endorsed policies or best-practice guidelines in Australia (or to our knowledge globally) for the establishment, governance and use of human biobanks for research purposes. To address the situation in Western Australia, we initiated the development of a state government policy, in the form of best-practice guidelines for human biobanks, genetic research databases and associated data [4]. Internationally, in 2010 in an initiative unrelated to ours, the Organization for Economic Co-operation and Development (OECD) released guidelines on biobanking for its member states [5]. Prior to the final release of the OECD guidelines, in 2009 a draft version was made available for public comment. At this time, we were planning the public consultation phase of our policy development cycle.

In a pluralist democracy, such as Australia, public policy should balance the interests of all policy stakeholders and be founded on a sound understanding of the range of citizen beliefs and shared values in relation to the policy issue [6, 7]. In relation to human biobanking and research, there are contested ethical dimensions, competing public interests and diverse perspectives on how to trade off these inter-
ests [7, 27–30]. According to theorists and practitioners [30–39], deliberative processes should enable more informed citizens to collectively decide their shared values and acceptable trade-offs in public interests through a process of fair, inclusive and respectful reasoning with each other. The information output from these processes should be reflective policy advice from citizens that contributes to more legitimate and accountable policy-making and higher quality policy decisions in terms of ‘better’ protecting the public interest. Policy-makers who implement deliberative exercises are expected to publicly document the deliberative processes used and the information outputs that are obtained. They are also expected to publicly document the processes by which the citizen policy advice was considered in policy-making and the reasons for any deliberants’ recommendations not being included in the final policy.

In attempting to meet these requirements, we found little practical guidance in the literature in terms of how deliberative outputs can or should be translated to policy. Further we could not find examples in the literature of how the translation has been undertaken by other government policy-makers. This ‘deliberation to policy’ gap is acknowledged by O’Doherty and Hawkins [6] who attest that the link is not ‘automatic’ and that little attention has been directed to theoretical and practical recommendations in this area. In response to this gap in the literature (and to address the deliberative norms of transparency and publicity), the purpose of our paper is to present the deliberative processes used and the information outputs from our forum and describe the processes by which we translated these outputs to policy. We also provide our perspective on the impact of deliberative public engagement on our policy development process.

Methodology

Public Deliberation Process

In November 2008, a 4-day deliberative public engagement forum on biobanking was held over 2 weekends in Perth, WA. The forum was modeled on a design developed at the W. Maurice Young Centre for Applied Ethics, University of British Columbia and previously used to inform institutional biobanking policy in Canada and the US [31]. A comprehensive description of the forum design and implementation has been documented elsewhere [40]. In summary, the aims of the deliberative exercise were to recruit a mini-public of 15–20 citizens who held a wide enough range of perspectives on biobanking for the exercise to be demo-
cricable and small enough in size to be genuinely deliberative [41]. We aimed to provide written and oral information on expert and other perspectives (e.g. scientists, people with disabilities, religious leaders, ethicists, biobank custodians, and participants) and provide a process for respectful reasoning and collective decision-making.

The expected information outputs were reflective citizen perspectives, shared values and acceptable trade-offs in public interests. The deliberants discussed their hopes and concerns (weekend 1) before making recommendations for public policy on biobanking (weekend 2). Deliberants were encouraged to work towards consensus, although persistent disagreement was an acceptable outcome [37]. On the last day of the forum, deliberants formally presented a final report of their recommendations to policy-makers who promised to consider the advice within the policy development process.

All of the deliberations were audio-taped and transcribed by outsourced specialists. We then simultaneously listened to the audio-tapes and read the transcripts to ensure what was written accurately reflected what had been said in the taped discussions. Where necessary, corrections were made to the transcripts.

Policy Translation Processes

The processes used to translate deliberants’ recommendations to policy incorporated published best-practices for public policy development [42]. The first process involved internal researchers (C.M., S.M., L.Y., A.P., G.K., and F.H.) undertaking a qualitative analysis of the deliberation transcripts. A coding frame of the hopes, concerns and values that emerged from the first weekend was used to code the transcripts of the second weekend. The purpose was to identify the deliberants’ arguments for and against each of their recommendations and facilitate a thematic analysis of the hopes, concerns and values underlying each deliberated outcome. This process also enabled an exploration of what was perceived to be at stake in the areas of persistent disagreement. For each transcript, 2 researchers independently coded each line of the transcripts. The assigned coding was then compared by the researchers and inconsistencies discussed to reach consensus.

The second process involved assessing the economic, social, legal, and political issues associated with the recommendations and comparing each recommendation and area of disagreement against the objectives and scope of the policy, the potential effect on other stakeholders (including the state government) and the impact that the recommendation might make to the policy direction. Each recommendation and area of disagreement was also considered against the contents of the draft OECD guidelines for human biobanks and genetic research databases. Policy decision-makers (P.O.L., H.D.) had decided to use the draft OECD guidelines as a template for the initial drafting of the WA guidelines. We made an assessment as to whether the draft OECD guidelines reflected the intent of the deliberants’ recommendations. Where we considered it necessary we reworded, added to or removed statements in the draft OECD guidelines so that the WA guidelines would accurately reflect the views of WA citizens (and other stakeholders).

The third process involved a series of meetings between researchers and policy decision-makers to discuss the results of the afore-mentioned analyses. From these discussions, decisions were reached on the inclusion or otherwise of the deliberants’ recommendations in the first draft of the policy.

The fourth step involved the engagement of stakeholders in finalizing the guidelines. This included the deliberants who were invited to comment verbally or in writing on the extent to which they perceived their recommendations were (or were not) evident in the policy. The deliberants were also invited to meet with policy-makers to discuss the policy response to their recommendations and to attend the official launch of the guidelines. The broader public was invited to comment on the policy through the Office of Population Health Genomics website (http://www.genomics.health.wa.gov.au), the state government consultation website and the government notices section of WA’s only daily newspaper which reaches the majority of households.

Results

Forum Deliberants

Sixteen deliberants participated in both weekends of the forum. Most were female (n = 12), aged 45 years or older (n = 12), had post-secondary education (n = 11), were English-speaking only (n = 15) and self-identified as non-Aboriginal (n = 16), Christian (n = 8) or nonreligious (n = 8).

Deliberated Policy Recommendations

The underlying principles and important issues identified by the deliberants are shown in table 1. The wording used in the table was ratified by the deliberants, during the forum, as an accurate record of the meaning they ascribed to each important issue. Table 2 lists the recommendations made by the deliberants. They are presented verbatim, that is, as they appeared in the final report presented to policy-makers. The recommendations cover a broad range of topics relevant to biobanking policy including regulation, ethical review, consent, access, benefit-sharing, and communication.

Table 3 shows there were 2 areas of persistent disagreement recorded in the final report. Firstly, deliberants persistently disagreed about biobank participants receiving personal feedback on research findings that directly affected them (e.g. the discovery of a gene that increases their susceptibility to a certain disease). The majority of deliberants thought it should not be mandatory for biobanks to give personal feedback since participants have a right to choose not to know information, particularly if it is for a condition with no known treatment or cure. A minority supported the provision of personal feedback to biobank participants particularly as a ‘right to know’ health conditions that could affect family members. There was also persistent disagreement about whether biobank participants should benefit directly from the research they have participated in.
Table 1. Deliberated overarching principles and important issues

| Overarching principles                                                                                                                                                                                                 | Addressed in policy |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------|
| Biobanks need rules and regulations that protect people, but these should not stop research that will improve people’s lives.                                                                                               | yes                 |
| Biobanks need to be open and transparent.                                                                                                                                                                             | yes                 |
| **Important issues**                                                                                                                                                                                                    |                     |
| **Accountability**: Everyone involved in biobanks should do what they say they are going to do and be held responsible for their actions.                                                                              | yes                 |
| **Altruism**: People, including researchers, should participate in biobanks for the good of society (‘the common good’).                                                                                                 | yes                 |
| **Choice**: Participation in biobanks should be voluntary. People have the right to decide their involvement.                                                                                                         | yes                 |
| **Communication**: The public needs to hear and know about biobanks. It should be easy for the public to access information about biobanks.                                                                               | yes                 |
| **Efficiency**: Biobanks should be efficient with no unnecessary duplication or waste of resources (time and money). Biobanks should be shared among researchers and standardised so they can be linked.       | yes                 |
| **Equality**: Equal distribution and access to the benefits from biobanks for the wider community should happen (e.g. drugs, treatments, cures).                                                                      | yes                 |
| **Excellence**: Biobanks should pursue excellence and adopt international best practice in all areas.                                                                                                                    | yes                 |
| **Funding**: Finance should be available to fund biobanks. Public generosity and financial support for biobanks should be encouraged.                                                                                | yes                 |
| **Independent oversight**: All aspects of biobanking (including researchers and research ethics committees) should be subject to independent monitoring and review. Independent means: no vested interest or stake, not involved in the biobank but has knowledge of biobanks, not [associated with] the research or outcomes. | yes                 |
| **Integrity and trust**: The public should be able to trust biobanks. Everyone involved should behave honestly, ethically and be trustworthy.                                                                             | yes                 |
| **Privacy**: Participant privacy should be protected. Confidentiality is critical and samples/information should be kept secure.                                                                                           | yes                 |
| **Progress**: Researchers should have freedom to progress research that will improve people’s lives. Rules and penalties are important, but should not overly impede research that will benefit the community.                  | yes                 |
| **Respect**: Individual and human rights of participants should be respected. This includes respect for participant choices, information and samples, and respect for their individual moral beliefs.                  | yes                 |
| **Safety and protection**: Biobanks (including information and research) should not cause harm to participants or the wider community. Discrimination should be prevented.                                              | yes                 |
| **Transparency**: Everyone involved in biobanks should be open and transparent about their actions. This will demonstrate integrity, encourage participation in biobanks and ensure information about biobanks is available to the public.     | yes                 |

*The wording in this table has been ratified by the deliberants as an accurate record of the meaning they ascribed to each important issue.*
Table 2. Deliberated citizen recommendations on biobanking

| Recommendations | Addressed in policy |
|-----------------|--------------------|
| **Rules and regulations** | |
| 1. A combination of laws and [ethics] guidelines to regulate and establish biobanks. | yes |
| 2. Biobanks should (primarily) be governed by a set of guidelines to cover all biobanks. | yes |
| 3. Laws should cover gross wrongdoing (actions that harm or do not protect people, that is, participants and the wider community) specific to biobanks with criminal penalties. | no |
| 4. Guidelines should be developed by representatives that include wide areas of the scientific, ethical, medical and general community. | yes |
| 5. Each biobank should have guidelines specific to its own operation following state guidelines. | yes |
| 6. Graduated penalties/consequences depending on the severity of the breach. | no |
| 7. The penalties for the breach should outweigh the possible benefits to be gained by breaching the guidelines/laws. | no |
| **Oversight** | |
| 8. All research projects that use biobanks must have ethics approval. | yes |
| 9. Legislate to set up a register of new and existing biobanks. | no |
| 10. Establish a single state government body that: (a) sets the guidelines for registration, (b) establishes and manages the register of new/existing biobanks, (c) manages the registration process, (d) approves the set up of new biobanks, (e) independently oversees and monitors biobanks, and (f) includes an ethics committee to assess the ethical aspects of applications for setting up a biobank. | no |
| 11. The (state level) ethics committee should include: (a) representatives from wide areas of the scientific, ethical, medical and general community; (b) one subcommittee dedicated to the set up of biobanks; and (c) one subcommittee dedicated to monitoring [ethics committees] and to approve noninstitutional research projects. | no |
| 12. Biobanks need to be registered with the state government body. To be registered a biobank must: (a) agree to abide by the state guidelines, (b) have a good accountability structure, (c) be transparent in its operations, and (d) agree to be monitored [by the state government body]. | no |
| 13. Monitoring should cover, amongst other things: (a) use of and access to samples (including whether participant consent instructions are followed by researchers/biobank), (b) compliance with ethics approvals, (c) collection and storage processes/sites, (d) what happens to the samples/data at the end of research projects and/or the biobank itself, (e) registration process, and (f) set up and operation of the biobank. | yes |
| 14. There should be regular and random auditing at appropriate stages including at the end of research projects and/or biobank. | yes |
| 15. The biobank should pay for monitoring through an annual fee. | no |
| **Biobank participation** | |
| 16. Participation in biobanks should be voluntary. | yes |
| 17. Graduated consent including: (a) consent to single or multiple studies, (b) permission to recontact, (c) option to withdraw samples and data, (d) feedback preferences, (e) when samples must be destroyed, (f) option to choose if identified samples/data can be accessed, and (g) permission to transfer samples to another registered biobank (if original biobank is terminated). | yes |
| 18. Participants should not be paid for providing their samples/data to biobanks, but may receive compensation for costs incurred. | yes |
An example of this, discussed by the deliberants, is when people have a specific condition, choose to participate in a biobank that is used to research this condition and could then have access to discounted medicine or treatments that arise from the research. The majority view was that biobank participants should not directly benefit. The main reasons for this were based on the possibility that it could pressure people to participate in biobanks, unduly impact on vulnerable groups and may not be congruent with the concept of altruism which, deliberants had agreed, should be a motive for participating in biobanks.
Tables 1 and 2 indicate that most of the deliberants’ overarching principles, issues of importance and recommendations were reflected in the policy. Most were directly referenced, for example, the first principle was included in the statement ‘rules and regulations are needed for guidance and protection but should not overly inhibit research that will benefit the community’ (page V of the guidelines) [4]. Other recommendations were indirectly referenced in the policy. For example, the deliberants’ recommended a consent form that offered biobank participants choices across a relatively wide range of issues. Other stakeholders expressed views on the complexity of such a form and the administrative costs that might arise from using such a form. Policy-makers were also aware of studies that noted public perceptions on consent are context-dependent (e.g. the specific risks to biobank participants, purpose of the research) [23, 43]. The WA guidelines thus recommend that the underlying intent of the deliberants’ recommendation (i.e. transparency, autonomy, communication) should prevail in the consent process. Individual biobanks/researchers should consult with potential participants about their information needs and consider the provision of graduated consent options. A list of topics that the deliberants thought should be communicated to potential biobanking participants, as part of the informed consent process, was included in the guidelines.

A minority of deliberants’ recommendations were not incorporated in the policy. These included the establishment of a state governance body and a registry of biobanks maintained by this body. Both of these outcomes were deemed beyond the scope of the guidelines. Importantly, this does not preclude further investigation of these structures in the context of the broader regulatory framework for biobanks and the guidelines do encourage independent monitoring and auditing. Deliberants also wanted laws developed that were specific to biobanks to cover ‘gross wrongdoings’ and proof of destruction of samples/data at the end of research projects or the biobank’s demise. State and federal laws already exist in relation to the ‘gross wrongdoings’ referred to by deliberants and, although not specific to biobanks, these can be applied to biobanking practices. As noted within the guidelines, those involved in biobanking must comply with existing laws and regulation, and annotations to the guidelines detail a range of the relevant laws. Proof of destruction would be difficult to establish, so instead the guidelines recommend that samples and data are disposed of in a manner that protects privacy, that is consistent with consent and that is transparent to participants and the general public.

In terms of the 2 persistent disagreements recorded by the deliberants, legal experts indicate there is no direct provision in Australian law requiring that participants be informed of personally significant research findings [44], and health professionals and scholars have argued that personally relevant feedback should only be considered when it has analytic validity and clinical utility [45, 46]. Balancing stakeholder perspectives, the guidelines recommend that feedback of aggregated results be considered as a minimum. Biobank participants should also receive information, prior to signing the consent form, on whether feedback of personal results will occur, and if so, the type of results this would include and the right not to receive this feedback. Counselling should be offered to those who choose to receive individual feedback. The guidelines also recommend against the release of non-validated individual and aggregate research findings.

The WA guidelines were publicly released in July 2010 [4]. Since then there has been local, national and international recognition of the guidelines. Of particular importance, from a public policy perspective, the Director-General of the Health Department in WA has issued an operational directive requiring all employees to apply the guidelines to biobanks within the custodianship of WA public health agencies. Similarly, the guidelines must be applied by all external researchers who want to link biobank data to data in population health collections that are within the custodianship of WA public health agencies. Internationally, to our knowledge, this is unprecedented in terms of mandated government policy on human biobanking and research.

Information on the design of the deliberative forum and the final report of recommendations from deliberants is publicly accessible on the Office of Population Health Genomics website, along with the state government guidelines on biobanking. A summary of the translation process will be added to the website following the publication of this paper.

Discussion

This paper indicates that most of the public recommendations on biobanking obtained through a deliberative public engagement forum could be (and were) translated to public policy on biobanking and research. Scholars suggest that a number of factors may contribute to the policy uptake of public engagement [6, 33, 34]. Factors that we consider to have been particularly influential on our deliberation-to-policy outcomes are discussed below.
First and foremost the deliberative engagement exercise was well designed and the most appropriate methodology for our policy context where biobanking issues are complex, interrelated, ethical, contested, and largely unknown among the general population. While many of the deliberated outcomes were consistent with other studies on public perspectives of biobanking [24, 47, 48], the value of the deliberative method was particularly evident to us where we obtained different findings from other studies. For example, after consideration of various arguments for and against access to biobanks by commercial companies, including the potential benefits of commercial involvement (e.g. development of pharmaceutical and other treatments), our deliberants deemed such involvement acceptable. Other studies have indicated persistent citizen resistance to the involvement of commercial companies in biobanking [17, 49]. Most of these studies have involved surveys which tend to result in gathering, but not exchanging information and generally are not able to focus, in a single survey, on the complex range of contested issues in biobanking. In contrast, deliberative methodology allows for the sharing of information, exposure to a range of perspectives and competing public interests, and deliberation on how these might best be balanced against each other in public policy.

At the same time, it is important to recognise that the survey studies generally had much larger and more socio-demographically diverse samples than our deliberative public engagement exercise. We acknowledge that our sample size and composition places limitations on the policy translation of the deliberated citizen recommendations. The decision to have 15–20 forum participants was based on expert opinion that this is an optimal number for true deliberation to occur [41]. An option was to implement multiple forums to increase the number of citizens participating yet the costs of this were prohibitive. This serves to highlight one of the trade-offs and the constraints that agencies such as ours must make in the decision-making processes regarding appropriate public participation methodologies.

The lack of socio-demographic diversity in our participants (e.g. youth, non-Caucasian, religions other than Christianity) is problematic since we adopted such diversity as a proxy measure of discursive representation. As we have noted elsewhere [40], within the context of discursive representation, claims of procedural legitimacy are limited when broad inclusiveness is lacking since dominant perspectives may be overrepresented in the deliberative outputs. This then raises questions regarding the justice of translating the deliberative outputs to policy. At question is whether our forum participants represented a sufficiently wide range of public perspectives, including minority and previously unarticulated views [41]. It was apparent to us that the citizens who attended the forum, despite their socio-demographic similarities, did hold differing perspectives at the start of the forum. Forum participants did consider they ‘knew a lot more about other views’ as a result of the forum, and all participants indicated that their own views had been challenged and changed as a result [40]. As such we believe the deliberative outputs did reflect consideration of a reasonable range of public perspectives. On that basis we proceeded to translate the deliberated outcomes to policy. At the same time, we recognise that some citizen perspectives may not have been represented at the forum. For this reason, along with the fact that expressed positions on contested ethical issues are subject to change, the guidelines we developed are to be reviewed in 3 years, and this process should include further public consultation.

The relative ease of deliberation-to-policy translation was facilitated by the fact that the deliberated citizen recommendations were largely similar to the draft OECD guidelines and to the expressed views of other local stakeholders (e.g. researchers, clinicians, ethicists, health consumer advocates, and people affected by genetic conditions) who provided their perspectives through 2 stakeholder forums and a process of written submissions. The deliberated citizen recommendations also reflected academic calls for updated ethical frameworks that are relevant and applicable to genetics research [50, 51]. For example, the deliberants indicated that biobanks should be used for the common good and that this should prevail over the research interests of the initiators and users of the biobank. Meslin and Cho [52] present a similar position in arguing for a new social contract between genetic researchers and the public. Collectively, the similarities undoubtedly heightened the extent to which the deliberants’ recommendations became evident in the policy. We speculate that such translation outcomes may not be possible for policy scenarios where greater divergences from the literature and differences in local stakeholder perspectives are evident.

The third important factor influencing the translation of deliberative outcomes into policy, as suggested by Abelson et al. [33], was the institutional context. Our organizational culture (at the Office of Population Health Genomics) embraces innovation and a willingness to experiment with a range of approaches to community consultation. Senior executives supported the use of a deliberative methodology when this approach to citizen
involvement in policy-making was novel for the Department of Health WA. They were also receptive to the principles of the methodology such as the need for transparency about the process, public access to the deliberated citizen recommendations and public justification for the policy translation (or not) of the recommendations. Substantial human and financial resources were provided to plan and implement the deliberation exercise. In our case, the forum was significantly more resource intensive than other forms of consultation such as surveys. Importantly, the organizational provision of resources for the forum may have been facilitated by an economic boom that was occurring at the time of the forum. Our organizational commitment to deliberative methodologies in less buoyant economic times has to date remained untested.

Finally, we value collaborations with academic experts and had well-established relationships with several of our multi-disciplinary collaborators. These collaborations (e.g. with academic experts in political science, deliberative theory and philosophy, anthropology, law, ethics) were pivotal to the quality of the forum design where emphasis was placed on addressing the principles of deliberative theory. In our view, the quality of design enhanced the potential for policy translation of deliberated outcomes. Our observations suggest that the involvement of a range of expert collaborators also contributed to regard for the public engagement exercise and acceptance of the biobanking guidelines among stakeholders including the deliberants, biobank custodians and participants (actual and potential), researchers, health consumer advocates, and the media [53, 54]. Extending our collaborations with deliberative experts, beyond forum design and implementation, may have facilitated greater theoretical and practical guidance for our deliberation-to-translation processes. This will be considered for future deliberative public engagement exercises.

On the basis of our experience with the translation of deliberated citizen advice to policy, as described in this paper, we recommend deliberative exercises for engaging citizens in public policy development when issues are complex and ethically contested. We encourage other government policy-makers, along with deliberative scholars, to publish their experiences with and views on deliberative engagement and policy translation processes. This may provide further evidence and advice regarding deliberation-to-translation processes that meet both the theoretical requirements of deliberative methods and the practical requirements of public policy-making.

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