Blueprint for a deliberative public forum on biobanking policy: were theoretical principles achievable in practice?

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Abstract

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Background: Public deliberation is recommended for obtaining citizen input to policy development when policies involve contested ethical dimensions, diverse perspectives on how to trade-off competing public interests and low public awareness of these perspectives. Several norms have been proposed for the design of deliberative methods. Evidence is scarce regarding whether such norms are achievable in practice.

Purpose: This paper refers to principles of deliberative democracy theory to describe a deliberative public forum on biobanking. Practical challenges and contextual facilitators of achieving deliberative ideals are discussed, along with factors that influenced use of the forum output in policy development.

Method: The forum ran for 4 days over two weekends in Perth, Western Australia. Key methodological features were socio-demographic stratification to randomly recruit a mini-public of citizens for discursive representation, provision of information inclusive of diverse perspectives and framed for difference, provision of a fair way for reasoning and collective decision making and adoption of processes to achieve publicity, accountability and independence from undue institutional influence.

Results: Most design principles were achieved in practice, with the fundamental exception of representativeness. Factors influencing these outcomes, and the use of deliberated outputs to develop policy, included institutional characteristics, the design involvement of deliberative experts and quality of the outputs when compared to other consultation methods.

Conclusions: Public deliberations can achieve design ideals and influence (ethics-based) public health policy. The representation of 'hard to reach' citizens and their views needs further consideration, particularly as this relates to the procedural legitimacy of ethical analyses and the just inclusion of deliberative citizen advice within the broader policy-making process.

Introduction

Internationally, there is interest in public deliberation as a means for obtaining citizen input to public policy areas including genetics and population health genomics.^{1–3} Public deliberation is deemed suitable for these areas because they involve ‘democratic deficits’, that is, contested ethical issues, competing public interests and low public awareness of the range of perspectives held in relation to the issues.^{4–10} Expected outcomes of public deliberation include the identification of shared public values, which in a pluralist society should underpin public policy, and acceptable trade-offs among competing public goods and interests that determine the preferable type of society.⁶

Norms and principles for designing public deliberations arise from deliberative democracy theory. Broadly speaking citizens are expected to first learn about and reflect on competing public interests and perspectives. Citizens then respectfully listen to and reason with each other about arguments for and against perspectives. Finally, citizens collectively decide acceptable trade-offs in public interests, shared values and policy preferences.^{9,11} Because ‘complete consensus’ is unlikely, persistent disagreement can be a legitimate outcome.¹² These characteristics distinguish deliberative methods, such as consensus conferences and citizen juries, from other public participation methods founded on aggregation theories of democracy, such as surveys.¹³

While there are claims that the ideals of deliberation may be difficult to achieve in practice, empirical research is not well advanced.^{12,14,15} This has created demands for greater evidence of rigorous design and evaluation, and to this end, several frameworks have been proposed.^{8,13,16} Commonly, these frameworks include criteria such as citizen representation, information provision, procedural structure and outcomes/impact of the deliberation.^{3,17–20} Some frameworks also include contextual factors that may mediate the implementation of deliberative methodologies.^{21,22}

In this paper, these criteria are used to describe a public deliberation implemented in 2008 by the Office of Population Health Genomics (OPHG) in Western Australia (WA) to obtain citizen input for public policy on human biobanking.²³ Biobanks are organized collections of stored biological samples (e.g., blood, DNA) and associated data such as medical, genetic and lifestyle information. Genomic research using biobank resources promises significant benefits but also involves contested ethical issues including consent, privacy protection, access and future unknown research uses.^{24–27} Competing perspectives on the ‘appropriate’ trade-offs of public interests have been expressed by stakeholders including scientists, patient groups, people with disabilities, indigenous/ethnic groups and religious groups.^{28–33} Population survey findings and a media analysis suggested WA citizens were unlikely to be informed of the range of competing perspectives on biobanking.³⁴ In our view, these features of the policy context dictated that public deliberation would be the most appropriate method for obtaining citizen input to policy development.

The intention of this paper is to facilitate critical examination of our forum design, which aimed to explicitly address norms of deliberative democracy. We explore the extent to which our design ideals were achieved in practice and some of the practical challenges of implementing a deliberative exercise within an Australian government institution. This contributes to closing the empirical gap in the literature where the design and use of deliberative approaches has not been widely documented, particularly by health agencies in Australia.³⁵

Deliberative methodology

Our public deliberation was designed as a public forum. It was based on an approach developed at the W. Maurice Young Centre for Applied Ethics, University of British Columbia (UBC) and used to inform institutional biobanking policy in the US and Canada.^{9,36} An OPHG research team (C. Molster, L. Youngs, S.

Maxwell, G. Kyne, F. Hope) coordinated the forum in collaboration with the UBC design team (M. Burgess, K. O'Doherty) and local experts in deliberative facilitation, law, bioethics, anthropology and political philosophy. (S. Dodds, K. Fisher, M. Blake, B. McNamara, S. Niemeyer). Principal policy makers (H. Dawkins, P. O'Leary) committed to deliberative principles embodied in design features, and the Director-General of WA Health authorized the forum. The Department of Health WA Human Research Ethics Committee Ethics granted ethics approval.

The forum had four broad objectives: (i) Inform a representative sample of citizens of the competing interests and perspectives on biobanking, (ii) Provide a fair way in which citizens could consider different perspectives, reason with each other and make decisions collectively, (iii) Obtain information on reflective citizen perspectives, underlying shared values and acceptable trade-offs in public interests and (iv) Influence policy makers to reach decisions that took account of the deliberative outputs. Significant resources were dedicated to the forum, and the cost per participant was higher than other forms of consultation such as surveys. Planning required 12 months which was possible because the proactive nature of the policy meant urgent decisions were not required.

Representation

Ideally, all those affected by policy decisions should have equal opportunity to be involved in deliberative exercises. Theorists acknowledge this is nearly always impossible and that some form of representation is required.³⁷ Our aim was discursive representation. This is different from proportional representation in that the objective is not a statistically representative sample but a sample diverse in public perspectives about the policy issue. This includes minority and/or marginalized voices and those perspectives that previously were unarticulated in the 'sphere of public discourse'.^{6,12} To this end, we intended to recruit a 'mini-public' of 15–20 citizens which would be sufficiently repre-

sentative of public perspectives to be genuinely democratic and small enough to be genuinely deliberative.³⁷

Diversity of perspectives

Because the entire range of public perspectives was unknown, socio-demographic characteristics were used as proxy measures which might be associated with different public views.^{38,39} A random sample was stratified by self-reported age, sex, highest level of education, geographic location, religious status, health status, language spoken at home and Aboriginality. The aim was to over-recruit to 35 citizens to have 15–20 citizens attend the deliberative forum. This anticipated a relatively high drop-out rate in the 6 weeks between recruitment and the commencement of the forum.

Selection process

The sample frame consisted of 600 telephone numbers, names and addresses randomly selected from the electronic version of the WA telephone directory and supplied to an accredited market research agency. Three hundred and sixty-nine numbers were eligible for recruiting citizens to the forum with the remainder primarily disconnected or no longer residential. Each resident in the eligible sample frame was posted a three-page invitation to the forum and then contacted by telephone. The invitation specified the purpose, dates and location for the forum and gave some background information on biobanking, the reasons for seeking public input and the nature of a deliberative forum.

Equity of access

All deliberants were offered \$100 AUD per day to reimburse them for their participation in the 4 day forum. To ensure deliberants from non-metropolitan areas were not financially disadvantaged, they were also offered reimbursements to cover travel and accommodation expenses, to a maximum of \$120 AUD per day. The forum was held at a facility accessible by people with a range of physical abilities, parking was free, and deliberants without transport were provided with taxi vouchers.

Structure of process and procedures

Our event ran for 4 days over 2 weekends with a 12-day break between the first and second weekend. Multiple days were deemed necessary because of the complexity of the policy issue and the need for deliberants to learn about biobanks and then deliberate for long enough to avoid 'premature consensus'.⁴⁰ Table 1 summarizes the broad structure of each day.

Task definition

The first weekend focused on information sharing, learning and creating an environment where deliberants could respectfully engage with each other, exchange arguments for and against their positions and express both consensus and persistent disagreement. The second weekend provided deliberants with a relatively concrete and consensus-oriented activity to apply their perspectives to 'real' policy decisions of how biobanks should be set up and operate in WA.⁹ Before and during the forum, deliberants were advised of the tasks they were expected to perform. At the beginning of the forum, the policy makers explained how the outcomes of the deliberation would be used in the policy-making process and promised the deliberants their policy advice 'would be considered in policy decisions to the greatest extent possible'. At the end of the forum, policy makers listened to the deliberants present their formal report of shared values, recommendations and areas of persistent disagreement.

The agenda for deliberations in the first weekend (i.e. hopes and concerns regarding biobanks) was determined by the design team as an appropriate method of obtaining information on shared public values in relation to biobanking.⁶ Between the weekends of the forum, we summarized the first weekend's discussion transcripts and flip charts into categories of hopes and concerns. At the start of the second weekend, this was ratified by the deliberants as an accurate reflection of their discussions. From the summary, we identified issues that, from a policy development perspective, required further deliberation, and this set the agenda for deliberations in the second weekend. (Table 2) Scholars note that such 'pragmatic structuring' does not necessarily detract from procedural legitimacy.^{41,42}

Deliberation mechanisms

Initial deliberations were undertaken in small groups of up to six deliberants. Small group membership was assigned by the research team to balance more/less vocal deliberants and rotated for each of the deliberation sessions. In total, there was 8 h of small group deliberations. Generally, these sessions were followed by whole-of-group deliberations and collective decision making. The aim was to identify areas of consensus that had emerged from the small group deliberations, work through disagreements and identify areas of persistent disagreement. Consensus was ratified if deliberants did not voice dissent to a restating of the apparent collective position by the lead facilitator.

Table 1 Summary of the deliberative public forum

Day 1	Day 2	Day 3	Day 4
Opening address	Icebreaker	Policy-maker's address	Small group deliberations and report back to large group
Policy-maker's address	Task definition	Reflections	<i>Recommendations C</i>
Icebreaker	Setting of rules	Recap of Days 1 and 2	Large group consensus-building
Task overview	Small group deliberations and report back to large group	Small group deliberations and report back to large group	<i>Recommendations C</i>
Q-survey	<i>Hopes and Concerns</i>	<i>Recommendations A</i>	Formal report preparation
Presentations	<i>Values</i>	Recommendations B	Participant presentation
Question sessions	<i>Important issues</i>	Large group consensus-building	Decision-makers' response
Dinner	Reflections	<i>Recommendations A</i>	Reflections
		<i>Recommendations B</i>	Q-survey
		Dinner	Evaluation survey

Table 2 Agenda for deliberations: Guiding questions developed from discussions of hopes and concerns related to biobanks

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1. What is the best way to achieve a balance between the hope for regulations and the hope for progress?
 2. Who do you trust to set up and run biobanks?
 3. What do biobanks need to be open and transparent about?
 4. Specifically what about biobanks should be monitored and reviewed? How should biobanks be monitored and reviewed?
 5. What do participants need to know before they decide to participate?
 6. Should participants (always) be able to choose what their samples are used for? Should participants be contacted for consent every time their sample is used? If not, when should participants be re-contacted?
 7. Do participants have the right to withdraw their samples and/or data? When? What should happen to the samples and data when a research project finishes?
 8. What feedback should participants get?
 9. Who should/should not get access to biobanks? What should they get access to? What should be the 'conditions of access' (i.e. what criteria should be used to decide whether someone gets access)?
 10. Should commercial companies keep all the profits they make from using biobanks for research?
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The procedural rules for the deliberations were developed by the deliberants. These tended to reflect norms of deliberative processes such as equality of participation ('everyone has an opportunity to speak'), respect for diverse views and other deliberants ('agree to disagree', 'avoid side conversations', 'no such thing as a silly question', 'one person speaks at a time', 'demonstrate respect') and willingness of deliberants to be open to other views and participate in the deliberations ('demonstrate openness to others' views', 'avoid taking offense', 'be an active group member by listening and expressing views', 'speak concisely'). In total, there was five and a half hours of large group discussions.

Reporting

Small group members decided which aspects of their deliberation and decision making to record on flip charts and verbally report back to the whole group. A self-nominated member of the small group undertook the report back. The research team electronically recorded large group consensus and persistent disagreements in a formal report. This was projected onto a screen visible to the deliberants who refined and ratified the wording of each statement. On the final day of the forum, deliberants presented this report to policy makers. In total, three and a half hours was dedicated to the reporting back of deliberant discussions and decisions.

Independence

External checks of independence were implemented to counter any bias resulting from our involvement in forum planning and implementation. Design was theory-driven and guided by external experts in deliberative democracy. A professional facilitator (K. Fisher) from outside Western Australia and with experience in deliberative facilitation was contracted to lead the forum providing both expertise and independence. Deliberants determined the rules for deliberation and had some influence over the forum agenda in that their outputs from the first weekend framed the deliberations of the second weekend. Deliberants chose which aspects of small group deliberations to record and report back to the whole group and ratified the final report as an accurate account of their collective recommendations and disagreements. Deliberants provided feedback on their perceptions of independence in the process and information provided. This included an anthropologist from the University of Western Australia undertaking participant observation and evaluation of the deliberative forum.

Facilitation

The independent facilitator led the day-to-day implementation of the forum and facilitated the whole-of-group deliberations. She aimed to create opportunities for all deliberants to participate, clarify the areas of agreement and disagreement and obtain ratification for group

decisions. The small group facilitators were members of the research team or collaborators who advised the forum design. While these facilitators were not independent of the sponsoring institution, they had knowledge of deliberative ideals and the complex policy issues involved as well as prior facilitation experience. Furthermore, the cost of facilitation was lower. Small group facilitators were provided with facilitation guides covering the purpose of each session, the role of the facilitator and questions to guide and direct the deliberation, but not the content. Facilitators were expected to keep deliberations 'on topic' and ensure all deliberants had the opportunity to speak.

Information provision

Government and academic institutions have previously undertaken consultations regarding public perspectives of biobanking.^{43–50} Some have been criticized because of perceptions of biases in framing and the 'real' purpose of the engagement.^{51–53} Our design attempted to directly address these concerns. We aimed to provide information to deliberants on a range of biobanking perspective, while not being unduly influenced by the interests expressed or held by the sponsoring institution, experts and other stakeholders.⁵⁴ From learning, thinking and deliberating about this information, we expected the deliberants to represent informed public opinion about the policy issues, that is, what the broader public would think if similarly knowledgeable about the issues.³⁷

Framing

Information was framed for 'difference and deliberation' which involved exposing deliberants to multiple perspectives on the policy topics, using multi-media including written, oral and spatial forms of communication, recruiting for diversity and structuring the forum to facilitate extended exploration of the issues, perspectives and personal experiences of deliberants.^{55,56} Decisions about expert and stakeholder involvement in the forum

considered the objectives of inclusiveness, informative relevance, critical engagement and encouragement of deliberation.⁵⁴

At least 2 weeks prior to the forum, a 36-page booklet on biobanking perspectives and ethical issues was posted to deliberants. The booklet included a glossary of terms and 'technical jargon' and was based on information drawn from academic peer-reviewed publications, grey literature and media articles. Deliberants were also provided with an annotated bibliography of academic and grey literature and a two-dimensional model of the core biobanking processes. All of these information sources were prepared by the research team and adapted from the resources developed by UBC. Deliberants also participated in an experiential activity designed by the research team to highlight some of the ethical issues inherent in biobanking processes.

Presentations were made on the first day of the forum. Three presenters were 'experts' with technical knowledge (i.e. a biobank custodian, genetic researcher, lawyer/ethicist), and three were stakeholders (i.e. father of a child participating in a disease biobank, female survivor of breast cancer with negative experiences of genetic research and a woman who is blind and from a minority ethnic background with concerns about discrimination). Presenters were encouraged to draw on personal experiences and advised to provide a level of information sufficient to stimulate thoughts on what biobanking research will mean for deliberants personally and for people with other perspectives. To avoid expert and stakeholder 'capture' through undue influence on deliberants, the presenters were allocated a defined length of time to speak, debates among presenters were prevented, and direct presenter access to deliberants was limited to moderated question and answer sessions.⁵⁴

A private blog site was established for deliberants to communicate with each other outside of the forum. The 12-day break between the two weekends of the forum provided deliberants an opportunity to reflect on what they had learned, have discussions with family, friends and colleagues, gather further information and perspectives and think about what they had learned

in the context of their own lives. The first session of the second weekend involved the deliberants reporting back on their reflections/discussions with others in their social networks.

Challenging Information

Deliberants were encouraged to critically engage with the information provided and had several opportunities to share things they had learned or were questioning and to request more information. Following the presentations, deliberants engaged in facilitated small group discussions to identify questions and challenges to the information presented. These questions were put to the presenters by a self-nominated representative from each small group. In total, two and half hours was dedicated to this questioning process. For questions that arose once presenters had left the forum, the research team followed up to find relevant information. The deliberants had ongoing access (via the research team) to the presenters who had all agreed to be 'on-call' for emailed questions. At the end of the first weekend, deliberants could specify any remaining information they wanted, and this was emailed or posted to them by the research team in the first week of the 12-day break.

Publicity and accountability

Multiple mechanisms were adopted to publicly record the deliberation process, outputs and impact on policy decisions including the reasons policy makers did or did not include deliberants' recommendations in the policy. Deliberants have a copy of their ratified forum report and are informed of other documents (e.g. peer-reviewed articles) as they are published. Deliberants were also invited to make written or verbal submissions on the extent to which their recommendations were or were not evident in the final draft of the policy and had the opportunity through a follow-up forum to be informed about the policy response to their recommendations. Information that the general public can access is available on the OPHG website (<http://www.genomics.health.wa.gov.au>), and the research team has and will continue to respond to requests for informa-

tion including forum documents. Finally, policy makers have specified a review period for the policy which will enable contested policy issues to be reconsidered.⁵⁷

Research and evaluation

Prospective studies are being undertaken primarily to evaluate and compare the perspectives of the forum held by the deliberants, observers, research team, policy-makers, facilitators and collaborators. The adoption of a multi-perspective approach is best practice and will endeavour to provide validity and rigor to the evaluation process.^{22,58,59} A number of data collection methods and analytic approaches were incorporated in the design with data sources including transcriptions of the audio-taped deliberations, event documentation, deliberant surveys and face-to-face interviews, planning reports and the documented reflections of the research team, facilitators, collaborators and policy makers.

This paper focuses on the perceptions of the forum held by the deliberants and members of the sponsoring institution including policy makers, forum observers, facilitators and researchers. Subsequent analyses and papers will cover other aspects of research, evaluation and translation. For example, the citizen advice obtained from the deliberative forum will be published along with the rationales and processes adopted for translating the deliberated citizen advice within the broader policy-making process. Another study involves collaborators at the Australian National University applying q-methodology to quantitatively explore the quality of the deliberations and the role of design elements (e.g. information provided to deliberants) in shaping the final subjective positions of the deliberants.¹²

Design outcomes

Sampling and representation

The characteristics of recruited citizens and those who actually attended the forum (i.e. deliberants) are shown in Table 3. Seventeen deliberants participated in the first weekend of

Table 3 Sampling stratification

Characteristics	Strata requirements		Recruited	Deliberants
	Min	Max	<i>N</i>	<i>N</i>
<i>Sex</i>				
Female	–	16	19	12
Male	8	–	16	5
<i>Age group</i>				
18–30	4	8	8	1
31–44	4	8	8	4
45–64	4	8	15	8
65+ years	4	8	4	4
<i>Highest level of education</i>				
High school	6	10	15	6
Certificate / Diploma	6	10	7	3
University	6	10	13	8
<i>Religion</i>				
None	4	–	14	8
Christian	–	12	17	9
Non-Christian	6	–	4	0
<i>Language spoken at home</i>				
English only	–	14	26	15
West European	1		3	2
East European	1		4	0
Asian	1		1	0
Middle Eastern	1		0	0
Other	–	–	1	0
<i>Residential location</i>				
Greater metropolitan	14	20	28	13
Rural	4	10	7	4
<i>Health status</i>				
No chronic condition	10	–	19	9
Chronic condition		–	16	8
<i>Aboriginal (self-identify)</i>				
No		–	34	17
Yes	1	–	1	0
<i>Biobank participant</i>				
No	–	–	34	16
Yes	–	5	1	1
Total	30	35	35	17

the forum and with one exception all of these returned for the second weekend. Most deliberants were female, aged 45 years or older, had

post-secondary education, were English-speaking only and self-identified as non-Aboriginal, Christian or non-religious. Two hundred and eighty sample frame members who did not want to participate in the forum provided reasons for their decision. The main reasons were lack of time/too busy (24%), not interested (20%), working when the forum would be held (11%), away on the forum dates (10%) or care commitments such as looking after children or a partner (9%).

Deliberants' perspectives

All deliberants completed an evaluation survey on Day 4 of the forum. Scores between 1 (Strongly disagree) and 5 (Strongly agree) were assigned to a range of design elements and procedural outcomes, and most of these were viewed positively (Mean score ≥ 4 of 5) (Table 4). This included all measures of information quality, facilitation and expected influence on policy. Six procedural aspects received positive scores including openness of participants to new ideas, demonstrated respect for the views of others and exploration of underlying reasons for group decisions. Four procedural aspects received mean scores less than 4, these being no one dominated the group discussions, important points were not left out of discussions, feeling comfortable in large group discussions and enough time for small group discussions.

At least 15 of the 16 deliberants indicated that useful sources of information were discussions with other participants, the information booklet and the presentations on the first day of the forum. Twelve deliberants found the articles on the annotated bibliography to be useful, and one participant found the blog site to be useful. All deliberants had requested articles from the bibliography (range of 3–15 articles), and three deliberants posted information on the blog site. In the first session of the second weekend, all deliberants indicated they had discussed biobanks with members of their social networks. Twelve questions from the deliberants arose during the first weekend that required follow-up with presenters. The answers to these questions

Table 4 Deliberant perceptions of deliberation design (*n* = 17)

Statements	Mean score ¹	Statements	Mean score
<i>Event and impact</i>		<i>Processes and procedures</i>	
This forum was well planned ²	5.0	<i>Task Definition</i>	4.5
		I understood what was expected of me during the event ²	
This event met all my expectations	4.5	It was clear to me how my input would be used by the Department of Health WA	4.0
This event was not a waste of time and money ²	4.5	<i>Deliberations</i>	4.5
Events like this are a good way for people to be involved in policy decisions	4.5	Everyone was open to the ideas of others and willing to change their own views	
I think that the recommendations we developed will be used when policies are made about biobanking in WA ²	4.0	Everyone had an equal chance to speak and be heard	4.5
		The views of all participants were respected during this event	4.5
<i>Information</i>		The underlying reasons for decisions were fully explored in the small group discussions	4.5
The information provided before and during the event was clear and easy to understand ²	4.5	I felt comfortable talking in the small group discussions ²	4.0
The presenters on Day 1 were easy to understand and good at communicating	4.5	There was enough time for discussions with everyone together in one group	4.0
This event has had an impact on my views about biobanks	4.5	I felt comfortable talking when everyone was together in one big group ²	3.5
I know a lot more about other views on biobanks than I did before the event	4.5	Important points were not left out of the discussions ²	3.0
I know a lot more about biobanks now than I did before the event	4.5	There was enough time for small group discussions	3.5
During the two week break, I talked with my family and friends about biobanking	4.0	The discussions were not dominated by one person or small group of people ²	3.0
I was given the right information to understand the issues and discuss them	4.0	<i>Facilitation</i>	4.5
The information provided before and during the event was fair and balanced	4.0	The facilitators were unbiased	
I did not get confused and stressed by too much information ²	4.0	The main facilitator was good at getting the whole group to work through disagreements	4.5
There was enough time to ask the presenters questions	4.0	The small group facilitators kept the discussions on track	4.5
		Four days was not too long ²	4.0

¹Maximum score=5; each score has been rounded down to the nearest 0.5.²Indicates statements were asked in the reverse of that presented and have been recoded to a positive statement.

were documented and provided to all deliberants by email or mail during the break between the two weekends.

Sponsoring institution perspective

In our view, the forum was able to address principles of deliberative democracy theory because of several contextual factors. First, a

large investment was made in collaborations with academic experts to design the forum. Because OPHG had not previously undertaken a public deliberation exercise, these collaborations enabled us to learn about deliberative theory, ideals and methodology and build knowledge and skills in this area. This should ensure the planning timeframe for future deliberative exercises is considerably shorter than 12 months.

Second, the corporate culture of OPHG (which values learning and innovation), the existence of trust between the OPHG research team and policy makers and the advocacy of the research team were all critical to overcoming institutional barriers to the use of public deliberation as a means of citizen input to policy. Policy makers expressed some initial resistance primarily because of concerns about the lack of empirical studies on the effectiveness of deliberative approaches. Similarly, the concept of 'discursive representation' was novel for an institution that traditionally adopts consultation processes based on proportional representation and where results can be generalized to the broader population with a statistical margin of error. The research team ensured policy makers and key internal stakeholders learned about, understood and committed to the principles of deliberative public engagement and understood the implications for the policy-making process. Post-forum the research team encouraged continued commitment to the deliberative design, for example, ensuring that actions related to the principle of publicity were fulfilled.

Third, significant human and financial resources were dedicated to the deliberative forum. This was facilitated by the economic climate prevailing at the time the forum was implemented. Western Australia was in the midst of an 'economic boom', and public sentiment towards the government, economy and life in general was positive. In our view, this facilitated executive commitment to fund our relatively unproven public participation method. Funding might have been less likely in a less buoyant economic climate.

In terms of principles we found difficult to put into practice, we could not avoid imposing some structure on the content of deliberations. We had a defined policy mandate and needed the deliberated information outputs to cover the issues within that mandate. Similarly, in answering questions and re-articulating the beliefs or arguments from deliberants, the OPHG facilitators may have imposed some 'expert' framing on the content of deliberations. At the same time, it appeared that the facilita-

tors' knowledge of biobank operations assisted deliberants to more fully understand the complexity of the issues involved, and we doubt whether external facilitators could have assisted the participants in the same way. In our view, the impact of the sponsoring institution, as a result of these design features, was balanced by the attention given to framing information for difference and deliberation and other external checks on independence.

Discussion

This paper provides evidence that a deliberative public forum sponsored by a government institution was able, in practice, to achieve most of the deliberative principles embedded in its design. From the point of view of forum participants and members of the sponsoring institution, the information provided before and during the forum was considered fair, balanced and useful for learning about the policy issues and perspectives of others. This is with the exception of the blog site that was not widely used. This may be because of the older age cohort of participants and a lack of experience with this relatively new mode of electronic communication. Nonetheless, we would consider a blog site for future deliberative exercises because public familiarity with this communication tool is expected to increase over time. Further, the blog site does provide another means of exchanging information and thus catering to different learning and communication preferences.

It is encouraging that the structure of deliberations did appear to provide a respectful way for citizens to reason with each other and work towards consensus. While this is similar to evaluations of other deliberative exercises in the genomics sphere,³ we are not certain, at this point, that our forum participants did actually 'deliberate' (i.e. initiate dialogue, exchange reasons, challenge and defend claims). Similarly, we do not know whether some deliberants did dominate discussions, as was perceived by nearly half of those attending the forum. To obtain more objective measures, we support theorists

who propose empirical investigations of deliberative quality. To this end, we conducted q-methodology surveys and will report on these data in the future.^{14,60,61} A significant minority of our deliberants perceived there was not enough time for small group discussions and that important points were left out of deliberations. In a policy context such as ours, where issues are highly complex, the time allocated for deliberations may need reassessment.

Our deliberants lacked socio-demographic diversity which is problematic, because this indicator was adopted as a proxy measure of discursive representation. Further concerns arise from the limited equity of access to the forum for those with family and work commitments on the weekends of the forum. The under-representation of minority ethnic communities and younger citizens may reflect some of our sampling procedures, such as recruitment being conducted in English and the use of a sample frame that did not contain mobile telephone numbers. These features will need reassessment for future public deliberation exercises. The issue of sampling bias is not unique to our study and has been reported for other deliberative and non-deliberative approaches to public participation in policy development.^{19,34} Various strategies have been proposed for attracting the involvement of 'hard to reach' publics and ensuring all citizens have equity of access to public deliberations. Examples include organizing multiple mini-publics either simultaneously or sequentially^{37,62} and the introduction of societal and institutional changes such as reduced working hours and allowing attendance at public deliberations during work hours without loss of pay.^{37,62}

A more diverse socio-demographic sample would not have guaranteed that all public perspectives were represented at the start of the forum. At question is whether our forum participants represented a *sufficiently* wide range of public perspectives, including minority and previously unarticulated views.³⁷ Within the context of discursive representation, a lack of broad inclusiveness of public perspectives can limit claims of procedural legitimacy because domi-

nant perspectives may be over-represented in the deliberative outputs. In turn, this reduces the robustness of the ethical analyses of policy issues and raises questions regarding the justice of translating the deliberative outputs to policy.⁵⁷

Taking into account the issues around representation, we ultimately decided to consider the deliberative outputs in the broader policy decision-making process. This was for several reasons. First, it was clear that the citizens who attended the forum, despite their socio-demographic similarities, did hold a range of 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 indicated that their own views had been challenged and changed as a result. As such, the deliberative outputs did reflect consideration of a range of public perspectives.

Second, in our view, the policy recommendations from the deliberants were more informed of the complex policy issues and contested public interests associated with biobanks, when compared with the potential output of alternative forms of consultation such as surveys and written submissions.¹ This, we believe, enabled us to make better decisions about acceptable trade-offs among competing public interests as they related to biobanking. Informed, reflective citizen advice is critical in our policy context (i.e. population health and genomics) because often there is no common agreement, in the sphere of public discourse, on the public interests to be served.⁶

Third, information on the forum design and translation of outputs to policy will be publicly available. This provides transparency and accountability to our decision-making processes and an opportunity for the public to learn of, understand and challenge the reasonableness of our decisions.⁶³ To support these measures, we believe it would be useful to examine views of the forum as held by 'hard to reach' groups and the broader general public. Of particular interest would be perceptions of whether the mini-public who attended the forum had the authority to speak on behalf of all those potentially affected by the policy issues and whether the forum does

impart legitimacy on the policy development process.³⁷

Conflict of interest

There are no conflicts of interest.

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