

Evaluating Recruitment Strategies for Biobank Deliberation

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Introduction

In April and May 2007, a research team based at the W. Maurice Young Centre for Applied Ethics, University of British Columbia, held a deliberative public event, “The BC Biobank Deliberation.” To recruit participants for the event, the researchers evaluated eight methods of participant sampling: (1) recruiting proportionately from each of the British Columbia health regions; (2) random digit dialling for limited filters and a small sample; (3) recruiting a large sample that accurately represents the population of British Columbia; (4) recruiting those who are typically absent from deliberative events; (5) sampling from registries; (6) recruiting for enclave representation; (7) avoiding like-minded majorities or those with extreme views; and (8) recruiting for a mix of citizens, politicians, industry representatives, and other stakeholder groups. This article provides a brief overview of the deliberative event, discusses the eight recruitment methods and evaluates them against the research team’s primary objectives.

The BC Biobank Deliberation

The overall goal of “The BC Biobank Deliberation” was to have participants identify key values that should guide a biobank in British Columbia.¹ The research objective was to assess deliberative democracy involving a subset of British Columbians as a means to develop policy advice concerning the secondary use of human tissues for prospective genomic and genetic research. The event involved two weekends at the start and end of a three-week period. The first weekend included presentations by five speakers and an introduction to a physical model that represented biobanks and their connection to research, health care and communities. An annotated bibliography summarizing sample articles and media reports was

available at the meetings for participants to take home in printed form, and was also available on a private website that supported participant-initiated “blogging” on various topics. Participant requests for more information were coordinated by one research team member who engaged experts and stakeholders to provide timely online responses.

The goal of the second weekend was the design of a BC biobank. Following updates about information collected since the first weekend, participants’ time during these two days was divided between facilitated large- and small-group discussions. It was necessary to have a constructive and consensus-oriented goal to motivate participants to move beyond stating views and begin to negotiate policy and argue about key values that ought to guide a biobank. The small groups were constituted to support the ability of every participant to contribute, and facilitated with an emphasis on clear identification of diversity and disagreement.²

Methods

Our goals for the BC Biobank Deliberation were to identify democratic deficits and theoretical challenges, then determine best approach and assessment measures. These goals influenced our recruitment strategies. Determining how well - or if - our event achieved deliberative ideals, such as representation, required that methodological choices be made explicit and transparent so that careful measurement of outcomes would be possible.³



We began by identifying what we considered the essential objective of our public deliberative engagement on biobanks: understanding different views, respectful engagement, informed deliberation and diverse discursive styles and experiences. We then considered eight types of recruitment strategies and evaluated them for time to complete, cost, likelihood that they could achieve their objective, appropriateness for deliberative democracy and the topic of biobanks, and whether performance measures could be designed. The eight methods were: (1) recruiting proportionately from each of the British Columbia health regions; (2) random digit dialling for limited filters and a small sample; (3) recruiting a large sample that accurately represents the British Columbia population; (4) recruiting those who are typically absent from deliberative events; (5) sampling from registries; (6) recruiting for enclave representation; (7) avoiding like-minded majorities or those with extreme views; and (8) recruiting for a mix of citizens, politicians, industry representatives, and other stakeholder groups. Ultimately, we used random digit dialled recruitment to collect a participant group that was stratified for provincial health region and demographic categories derived from census data.

Evaluating Recruitment Strategies

Our sample of 21 diverse participants allowed us to meet each of our key objectives for the 2007 event. An effective method of introducing a diverse range of views (as opposed to a few strongly represented interests) is to include a broad range of participants who are most likely to hold those views. Through effective and respectful moderation, these participants can be invited to share previously unexpressed opinions and will be less likely to employ strategic or reactive positions typical of public political debate. In addition, such participants introduce topics and values to deliberation that could not be collected through literature and media reviews or through expert interviews conducted by our team members.⁴

Our sample also helped elicit varied experiences and perspectives. We encouraged participants to introduce a wide range of views, arguments, narratives, materials and discursive styles. Our goal to have diverse representation threatened to make recruitment impractically complicated, but we managed this issue through other components of the design. For example, representation of strong vested interests is an essential part of a deliberative engagement but inclusion of participants with strong pre-deliberation positions threatens to overwhelm emergent issues and values from those who have not yet been engaged by the issues.

For our biobank deliberation, we elected to manage this through providing access to vested-interest spokespersons without recruiting them into the participating group. We can now evaluate the extent to which participants considered, understood, and used the stakeholder positions through changes on the policy and values ranking and the qualitative analysis of the deliberation.⁵

Conclusions

Constructing a diverse sample does not establish that different perspectives were represented or engaged in the BC Biobank Deliberation. We have demonstrated here how sampling approaches can be assessed and selected based on the key objectives of a deliberative event. Ultimately, surveys, interview results and demographics will assess whether the diverse participant sample included individuals with a range of perspectives that reflects the diversity of views in British Columbia. However, from the perspective of enhancing representation in policy-related discussions of technical issues, this recruitment strategy successfully collected a diverse group of citizens that would be unlikely to deliberate together without this event.

Although detailed analysis of the deliberation is beyond the scope of this paper, we present some initial observations about whether the deliberations represented diverse perspectives. On evaluations and in follow-up interviews, participants reported that they found it valuable to be informed and engaged in respectful discussion with people who hold different views. Initial analysis supports the conclusion that small group discussions were able to stimulate all participants to engage with one another. Some participants who expressed hesitation to speak in early large group discussions strongly voiced minority opinions in the final large group discussion, suggesting that moderation and their involvement in the small groups built their confidence. It seems that diverse members of the public represented in this group were able to engage in moderated, informed deliberation on biobanks, a topic of considerable technical complexity.

Elements of self-selection may have increased the probability that participants would be willing to

engage, although some participants were initially very reticent to speak. Initial analysis of the pre- and post-quantitative surveys suggests that participants' understanding of the issues in relation to policy preferences changed but that there was little reduction in the complexity of their understanding of the issues. This contrasts with other deliberative events that report reduced complexity of perceptions post-deliberation.⁶ We interpret this as a factor indicating successful deliberation as reduced complexity in this context may have indicated individual participants being 'captured' by dominant voices or paradigms.

Other limitations to our recruitment strategy should also be acknowledged. One could argue that our sample is too small to produce recommendations for biobanking policy in British Columbia or beyond. Although our sampling strategy produced a small sample of 21 participants, it was nevertheless large enough to begin to test both logistical and practical components of the event design, enrich existing public and expert discussions and evaluate whether it could be used in the future for a larger event. The sample also under-represented the majority of British Columbians who are working Caucasians without disabilities. However, our goal was not to produce a sample that accurately represents the demographics of the population of British Columbia, which would be cost prohibitive and could undermine the goal of engaging the diversity of interests in the population. Instead, we were seeking to explore methods of addressing problems of inadequate representation in current Canadian policy formation.

We have evaluated whether our recruitment choices enhanced representation of diverse perspectives. The demographics of the resulting sample produced a group of participants with diverse life experiences and reasoning styles that are broader than current participation in public dialogues. Based on the constitution of the participating group, we conclude that recruitment focused on representing diverse perspectives in deliberative engagement enhances representation of public interests in policy over non-deliberative approaches to public involvement.

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¹A biobank is defined for this paper and the project as "a collection of genetic materials and health information for research related to human health. Such information might be used to develop personalized treatments, identify inherited risks for disease, or understand the role of genomic and environmental contributions to health in populations." See James Tansey and Michael M. Burgess, "The Foundations, Applications and Ethical Dimensions of Biobanks" (2004) DEG Electronic Working Papers Series, online: W. Maurice Young Centre for Applied Ethics <<http://www.ethics.ubc.ca/workingpapers/deg/d eg005.pdf>>.

² For more information on the event, see the event website at <http://biobanktalk.ca/> and project final report: Michael M. Burgess & Kieran O'Doherty,



“Deliberative Public Engagement Related to Governing Biobanks: Final Report” (2007) GE3LS Arch Working Papers No. 002, online: W. Maurice Young Centre for Applied Ethics <<http://gels.ethics.ubc.ca:8213/ge3ls-arch/ge3ls-arch-working-papers>>.

³ For more information on evaluation theory and practice, especially ethical aspects of evaluation, see Canadian Evaluation Society, *Guidelines for Ethical Conduct*, online: Canadian Evaluation Society <http://www.evaluationcanada.ca/site.cgi?s=5&ss=4&_lang=en>.

⁴ Holly Longstaff & David Secko, “Media Influence on Biobank Deliberations” (2007) GE3LS Arch Working Papers No. 004, online: W. Maurice Young Centre for Applied Ethics < <http://gels.ethics.ubc.ca:8213/ge3ls-arch/ge3ls-arch-working-papers>>.

⁵ Samantha MacLean and Michael Burgess, “In the Public Interest: Assessing Expert and Stakeholder Influence in Public Deliberation about Biobanks.” (2008) Submitted Public Understanding of Science.

⁶ Robert E. Goodin & and Simon J. Niemeyer, “When Does Deliberation Begin? Internal Reflection versus Public Discussion in Deliberative Democracy”(2003) 51:4 Political Studies 627.