

Biobanks: Informing the Public Through Expert and Stakeholder Presentations

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Introduction

Over two weekends in April and May of 2007, The Face-to-Face research team of the Genome Canada sponsored “Building a GE3LS Architecture” project brought together a group of demographically stratified citizens to deliberate about the values that should be used to govern biobanks.¹ To provide participants with a broad range of background materials, a biobank-information booklet, reference binders and access to a private website were provided on or before the first day’s meeting. The first day of the event included stakeholder and expert presentations followed by question and answer sessions; in presenting a range of perspectives about biobanks and genetic testing and research, both experts and stakeholders acted as presenters, not active participants.

Throughout the deliberations, moderated small groups of seven to eight participants enhanced participation and respectful engagement. Professionally moderated large groups provided a forum for presenting reports from small groups, which enhanced the diversity in subsequent small group discussions. Large group sessions had non-participant observers while small groups were kept private. Collaborators at the Mayo Clinic² used this design as a basis for a deliberative public engagement in September 2007. While agreement or consensus on some issues was thought to be desirable, the primary goal of this event was to assess whether the deliberation was informed and supportive of a range of perspectives. Participants were not assumed to have any previous relevant technical and stakeholder knowledge to be able to deliberate and create policy choices surrounding these ongoing debates.

Discussion: Involving Experts and Stakeholders as Presenters and Not as Active Deliberants

Three concerns were addressed in determining how best to involve expert speakers. Experts may intimidate participants or stifle deliberations by being present throughout deliberations, participants may engage more with experts and stakeholders than one another and finally, participants may feel they do not know enough about the relevant issues to engage with representatives as equals. Given these concerns, stakeholders and experts served as presenters and large group observers, and not as active deliberants.

Experts can be distinguished from stakeholders based on factors related to their roles in deliberations. Commonly, experts have a vested professional interest in a given area and are not expected to be able to address all possible concerns, including ethical or minority considerations, or to advocate for everyone who might be affected by a policy choice. Experts are necessary to the process because citizens often lack the knowledge and information to evaluate science or policies.³ Stakeholders compliment experts by raising issues based on life experience that are not within the realm of expert concerns. Both groups have topically related expertise and are invested in the advancement of research in certain areas. They also bring histories that provide assumptions about avenues of research likely to be successful. In this sense, both groups have the credibility to inform as well as to potentially “capture” a deliberation.

Four components were considered to be a necessary part of the expert and stakeholder presentations: (1) basic scientific background regarding biobanking; (2) ethical, social and legal concerns specific to biobanking; (3) diverse perspectives, including scientific and personal experience;

and (4) inclusion of commonly underrepresented voices, such as aboriginal perspectives. Five stakeholder and expert speakers gave 15-minute presentations to the participants followed by five-minute question and answer sessions. Following the five presentations, there was a 20-minute panel session where participants were encouraged to pose questions to whomever they chose.

Peter Watson, Director, Tumour Tissue Repository, BC Cancer Research Centre, and Professor of Pathology, University of Victoria, spoke about the benefits of biobanks, describing the use and storage of biological samples. Daryl Pullman, an ethicist on the Medical Faculty, Memorial University, and board member of the Canadian Institutes of Health Research (CIHR) Institute of Genetics, spoke on community benefits of biobanking. Doris Cook, an indigenous researcher who helped develop recent CIHR Guidelines for Health Research Involving Aboriginal Peoples, presented aboriginal perspectives on genetic research and biobanking, describing an overarching concern about disrespect among the health research community for many aboriginal people. Barbara Farlow spoke as a mother whose daughter, Annie, died under circumstances that she believes constitute genetic discrimination. Nola Ries, a legal scholar at the University of Victoria, addressed legal and ethical aspects of privacy issues including security of biological information and health documentation.

Time spent with speakers was limited throughout deliberations in order to mitigate the possibility of stakeholder capture. Speakers were not permitted to sit in on small group discussions because having them in the rooms may make certain participants uncomfortable or unwilling to express their opinions. Over the 12-day break that occurred between the two weekend sessions, the website moderator collected, interpreted and posted expert and stakeholder responses to participant questions. Limiting speaker involvement on the website minimized the likelihood that the deliberation would be captured through continued online communication with participants.

Results

Results from the deliberations support conclusions from similar research that participants understood and were able to deliberate many of the topics presented to them, to introduce a range of more diverse factors and outcomes into their deliberation and to acknowledge potential responses to the given problems.⁴ Similarly, participants were able to challenge information from presentations as well as each other. For example, Joan⁵ explains how her group reached agreement in some areas and explains her view while identifying that others in her group rejected it.

Joan: ...I really, really liked the concept of stewardship, the DNA on loan... where the individual retains ownership and the DNA is just on loan to the researchers through the bio-bank. And that the concept is larger than just patenting. It's an awareness at all times that the intent and the interests of the individual who donated in the first place should be paramount, that at every level there should be an awareness of that. That's what I was thinking about in terms of stewardship. It was considered (by other participants) to be totally impractical, totally restrictive to research and absolutely unenforceable...

Participants were not only able to challenge views and issues raised by each other, but also to gain understanding as to why other group members challenged or rejected their views. Dennis suggested that one of the speaker's view might not be representative, demonstrating that participants were able to speak candidly about sensitive issues such as aboriginal community concerns, at least when initiated by an indigenous member of the group (Faye).

Dennis: ...if we listened to Doris yesterday, she seemed to indicate to me that her agency was representative of aboriginal voices. And then you really shocked me this morning... in a surprising sense when you said that there is an age group difference.

Faye: There is.

Dennis: Younger aboriginals may not share the value systems of the band elders or the older generation. You may respect them but you may not share them.

Conclusion

Avoiding stakeholder capture may have been easier given a lack of strong views in the media and public discussion at the time of the event.⁶ That said, excluding experts and stakeholders from a more controversial or polarized topic might not prevent capture when the dominant views are more available to the participants. This analysis shows it is possible to balance between informing participants and avoiding constraints on deliberation arising from frameworks presented by speakers. It is therefore possible to support public deliberation that is informed but not controlled or overtly biased by the provision of technical and stakeholder knowledge.

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¹ The event is summarized in 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>>. Recruitment design is discussed in Holly Longstaff & Michael M. Burgess, “Recruiting for Representation in Public Deliberation on the Ethics of Biobanks” (2007) GE3LS Arch Working Papers No. 003, online: W. Maurice Young Centre for Applied Ethics < <http://gels.ethics.ubc.ca:8213/ge3ls-arch/ge3ls-arch-working-papers>>.

² The research team at the Centre for Applied Ethics, University of British Columbia, is planning collaborations with the Mayo Clinic, United States, and the Office of Population Health Genomics, Department of Health, Western Australia.

³ Susan Dodds & Rachel A. Ankeny, “Regulations of hESC Research in Australia: Promises and Pitfalls for Deliberative Democratic Approaches” (2006) 3 *Journal of Bioethical Inquiry* 95.

⁴ Anne Kerr, Sarah Cunningham-Burley & Amanda Amos, “The New Genetics and Health: Mobilizing Lay Expertise” (1998) 7 *Public Understanding of Science* 41 and Edna F. Einsiedel, “Assessing a Controversial Medical Technology: Canadian Public Consultations on Xenotransplantation” (2002) 11 *Public Understanding of Science* 315.

⁵ Participants’ names have been replaced with pseudonyms.

⁶ 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>>.

