

A Lego Model to Help Inform Participants at the British Columbia Biobank Deliberation

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Introduction

Stored collections of human biological material, or biobanks, are accessed for a variety of purposes, including research, and are subject to various regulations which differ throughout Canada and the world. To address the associated issues, the W. Maurice Young Centre for Applied Ethics at the University of British Columbia hosted a deliberative engagement on biobanking in British Columbia. However, the volume and complexity of information on biobanks makes it challenging to learn quickly. In order for participants to deliberate on the topic, it is important they understand the key features, governance mechanisms, and possible outcomes and implications of biobanks.

A multicolour Lego® model of the process of biobanking was a novel method of sharing information with participants at the British Columbia Biobank Deliberation. Here, I describe the model and its implementation at the event by situating it within the theoretical background of public engagement and deliberative democracy, and by providing a brief overview of participant uses for and reactions to the model.

Engaging the Public on Issues in Science and Technology

Throughout the world it is increasingly popular to engage the public in discussions about science and technology. Since the early 1970s, surveys and education programs were used to assess and increase public understanding of science and technology¹. This “mission to inform” was in part an attempt to allay fears attributed to a lack of knowledge in these areas. However, this approach to public involvement has since come under heavy criticism^{2,3}, including claims that experts were ignoring the public’s ability to provide a

variety of valid knowledge, and, more importantly, were failing to identify real and substantive sources of public fear that should be considered in the development and regulation of science and technology.

Additionally, calls for public engagement stem from several problems associated with representative democracy. Known as democratic deficits, these include: elected representatives’ lack of accountability to the public; the inadequacy of expert consultation to inform public policy; and the controversy over policies made by experts in the public’s presumed best interests⁴. The relationships between governments, representatives, and publics are inadequate. Public engagements, such as citizen juries and deliberative polls⁵, incorporate the objectives of deliberative democracy, which aims to increase information transfer, broaden perspectives, create respect for, and promote legitimacy of the decision-making process⁶. Deliberative public engagements therefore allow the exchange of information and opinions, encouraging a wide range of perspectives to inform sustainable policy.

British Columbia (BC) Biobank Deliberation

The BC Biobank Deliberation was held in Vancouver on April 21 and 22 and May 5 and 6, 2007. Twenty-one demographically-stratified participants, recruited by random-digit dialling from the five health regions of BC, completed the event⁷. One large, professionally moderated group was divided into three small groups of six to eight participants, each facilitated by a graduate student. Each group had a note-taker, and observers were also present in the large group. All sessions were audio-recorded and transcribed⁸.

The two goals of the event were to explore the values and interests that need to be respected when determining the

roles and operations of biobanks, and to test a model for public involvement in policy-making. Participants were informed of the scientific and social perspectives related to biobanking by means of an information booklet written specifically for the event, a collection of supplementary readings, five expert and stakeholder presentations on the first afternoon, a private website, and a physical model of biobanking constructed with Lego[®], to which the focus of this paper now moves.

Modelling the Process of Biobanking

The model was a tool for information transfer conceived to be informative, inclusive, and interesting. It was not constrained by referring to a particular example, nor was its presentation influenced by specific interests of experts or stakeholders. The model had three goals: First, to visually enhance the written or presented descriptions of biobanks and the process of biobanking; and to address a variety of learning styles and facilitate understanding of an abstract idea. Second, to raise and demonstrate important issues related to biobanks and their governance, and to enable reflection on deliberated design choices. Third, to involve participants by creating interest in the topic of biobanking, and by promoting interaction with the physical model.

The physical model is a multicolour Lego[®] creation made from five 15” square bases arranged in linear succession. Each square represents a different stage in the process of biobanking. The first square depicts a multicultural and diverse *Community*, representative of where individuals, and therefore biological samples, come from. The second square shows the *Health Centre*, where samples are collected and often tested for clinical purposes prior to being stored or destroyed. The third square, *Processing/Storage*, is composed of a lab where samples are processed, and a facility where samples and information are stored – this square is representative of a possible type of biobank. The fourth square shows three public or private *Research Laboratories*. Here, samples may also be clinically tested and stored, or be may sought for use in research. As laboratories can amass collections of samples, they may also represent a possible type of biobank. The fifth square is the *Outcomes* square. It is coupled with a black box containing representations of different outcomes and consequences related to biobanks, such as new drug development, that can be introduced to participants in order to initiate discussion on different issues.

The model was introduced to participants in the first presentation on the first morning of the event. The model was positioned on a table in the middle of the room and

participants were encouraged to crowd around it and interrupt with questions at any time. Afternoon presenters were encouraged to refer to the model during their talks, and three of the five presenters did so. The model was physically available throughout the event, as well as through laminated posters in two of the small groups, and as printed pictures given to each individual. Other efforts were made throughout the event to incorporate the model into aspects of the discussion, such as during introductions and for explanations in which it was useful.

Overall, participant responses to the model were positive. During the large group discussion on the second day of the event, one participant stated:

“Something I liked about yesterday was the model of the whole biobank situation... because it provides an excellent graphic representation. It’s bright and colourful, so it sticks in your mind. And it’s like an anchor for various ideas.”

A participant comment in regard to the model on the private website reads:

“It quickly enables one to follow the sequence of events we discussed, plus, you have the flexibility to adapt to different scenarios.”

Other comments were received during the large group discussion and by email. On the exit evaluation forms, the model scored 4.3 on the first weekend, and 4.4 on the second weekend (out of a possible score of 5). During the telephone interviews that took place between four and nine weeks after the event, fourteen participants gave positive feedback when asked about the model, commenting that it was “visible”, “touchable”, “colourful”, and “inclusive”. One participant would have liked more information, and two participants were neutral, indicating that while the model may have been helpful to others, they were neither helped nor hindered by its use. As one participant put it, “It didn’t do nothing for me.”

The model was used in the small group deliberations for a variety of purposes. One group used the model to clarify how a biobank works. Other groups identified missing pieces of the model, such as a police station and a satellite tower, representing discussions about security and the media, respectively. One group rallied around the model to identify the characters they would each play in their report back to the large group, using, for example, the Spiritual Centre (a component of the community) as a reminder of the possible religious and cultural roles and ideals possibly impacted by biobanking.

Conclusion

Participants must be informed to a certain degree about the topic of deliberation. This presents a challenge for an abstract and variable concept, such as biobanks. As a visually stimulating creation, the Lego[®] model helped to illustrate the components, process, and possibilities of biobanking. The model achieved its three main goals, as demonstrated by its use in both the large and small group deliberations. It was implemented as a tool for clarification, facilitating understanding; it helped identify missing elements, raising important issues; and it created interest and interaction, revealed in the positive comments from participants throughout the event. While it may not have been strictly necessary for deliberation, the model helped many participants visualize the biobank and work through the issues; it proved to be a memorable, colourful, and creative addition to the BC Biobank Deliberation.

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¹ John Pennington, "From 'deficit' to democracy: Dialogue, deliberation and public participation in the biosciences" (2005), online: International Conference on Engaging Communities. Brisbane, Australia at <<http://www.engagingcommunities2005.org/abstracts/Pennington-John-final.pdf>>.

² Mairi Levitt, "Public consultation in bioethics. What's the point of asking the public when they have neither scientific nor ethical expertise?" (2003) 11(1) Health Care Anal. 15.

³ Patrick Sturgis & Nick Allum, "Science in society: re-evaluating the deficit model of public attitudes" (2004) 13 Public Understand. Sci. 55.

⁴ Michael Burgess & James Tansey, "Democratic deficit and the politics of 'informed and inclusive' consultation". In E. Einseidel & R. Parker (eds), *Hindsight and Foresight on Emerging Technologies* (Vancouver: UBC Press, forthcoming).

⁵ J. Abelson, P-G. Forest, J. Eyles, P. Smith, E. Martin, F-P. Gauvin, "Deliberations about deliberation: Issues in the design and evaluation of public consultation processes" (2003) 57 Soc. Sci. Med. 239.

⁶ David Held, *Models of Democracy* (California: Stanford University Press, 2006).

⁷ Holly Longstaff & Michael Burgess, "Recruiting for representation in public deliberation on the ethics of biobanks" (2007), online: Electronic Working Papers Series. W. Maurice Young Centre for Applied Ethics, University of British Columbia at <<http://gels.ethics.ubc.ca:8213/ge3ls-arch/ge3ls-arch-working-papers>>.

⁸ Michael Burgess & Kieran O'Doherty, "Deliberative public engagement related to governing biobanks: Final report" (2007), online: Electronic Working Papers Series. W. Maurice Young Centre for Applied Ethics, University of British Columbia at <<http://gels.ethics.ubc.ca:8213/ge3ls-arch/ge3ls-arch-working-papers>>.