

Defining Deliberative Outputs in a Public Engagement about Biobanks

Kieran O'Doherty & Michael M. Burgess

Introduction

A deliberative event, “D2B2”, designed to inform policy on biobanks was conducted in 2007 as part of the “Building a GE³LS Architecture” project at the W. Maurice Young Centre for Applied Ethics, University of British Columbia.¹ In the research team’s assessment, current policy approaches regarding biobanks manifest a democratic deficit.² Using principles of deliberative democracy,³ the purpose of the D2B2 event was to demonstrate that it is possible to have meaningful public engagement on a complex biotechnological topic, in which participants can be informed expeditiously, while avoiding capture by vested interests, premature consensus, and marginalising minority or non-dominant voices. Although early analysis of the event indicates success on all of these dimensions, the translation of the deliberative content of the event into concrete policy recommendations poses some interesting theoretical challenges. In particular, it is not clear how to define the deliberative output of the consultation in such a way as to provide an authentic representation of participants’ conclusions (both when consensus was achieved and where there were points of persistent disagreement), while minimising the imposition of analytical categories and frameworks of the analyst. That is, the justification of deliberative approaches over other forms of consultation is to add process legitimacy to conclusions; however, this is undermined if the conclusions are attributable more to the analyst than to the participants.

Background

The design of D2B2 involved informing 21 participants⁴ of the key ethical issues concerning biobanks. After this, participants were divided into three small groups in which they worked towards consensus recommendations for the construction of a biobank in British Columbia. On the final day of the consultation, all 21 participants reconvened in

the large group with the aim of synthesising the deliberations of the three small groups into a set of recommendations reflective of the group as a whole. For research purposes, the data of the event consisted of audio recordings of all deliberations, flip chart notes compiled by participants and facilitators during discussions, notes taken by note-takers during discussions and online discussions between participants that took place between meetings. In addition, facilitators prepared three small group reports and one large group report that represented the conclusions reached in each of the small groups, respectively, and in the final large group discussion.

Discussion: Reporting Outputs

As the rationale of the event was to facilitate genuine public involvement in policy making for biobanks, there is an imperative to report the outcomes of the event in a way that lends itself to uptake by policy makers. However, given the large data set it was not immediately clear how to prepare a policy report that reflects the group’s overall conclusions. A range of research methodologies offer approaches for the systematisation of qualitative data based on a number of different theoretical approaches. The ongoing analysis of D2B2 has led our research team to draw on several such approaches to understand the dynamics involved in the deliberations about biobanks. For instance, drawing on the principles of discourse analysis and positioning theory,⁵ it is possible to understand how participants position themselves (e.g., as patients, as a mother or as a member of a particular cultural group) to warrant specific claims or arguments they make during deliberations. We recognise, however, the limitations of such analyses with respect to the formulation of policy. In particular, by seeking to understand the factors that underlie particular statements made by participants, we detract from the actual content of these statements. To provide an outline of participants’ deliberations useful for informing policy and to honour the mandate under which participants were recruited, we

conclude it is necessary to differentiate between analytical outputs and deliberative outputs.

According to our conceptualisation, deliberative output is characterised by the following features:

- relies on explicit statement of participants, which are treated at face value
- reflects the language used by participants themselves, which also makes this form of output accessible to participants (in contrast to analytical output, which is likely to be accessible only to social scientists or other experts working in the discipline)
- should not be subject to considerable analytical treatment (e.g., should not require detailed analysis of transcripts)
- should not rely on technical analytical categories imposed by analysts
- should be ratified by participants

In contrast, analytical output is characterised by the following criteria:

- is subject to principles of social scientific inquiry (rather than ratification of participants)
- acknowledges the discursive nature of the processes whereby consensus is negotiated
- treats participants' statements as socio-cultural products, contingent on the discursive context within which they are produced
- is likely to draw on various forms of data, such as audio or video recordings, flip charts, field notes, etc.
- may involve several layers of analysis

Conclusions

In the case of D2B2, we identified the three small group and one large group reports as most congruent with the criteria for deliberative outputs. Because the original design of D2B2 was not geared towards an explicit production of deliberative outputs (we conceptualised this dichotomy subsequently during the process of analysing the event), the synthesis of these four reports involved a degree of analytical intervention that ideally should not have been required. We thus suggest that the value of public engagements can be enriched by incorporating the following design elements:

1. Identifying a clearly formulated task for participants. In cases where the objective is for participants to choose from a number of pre-formulated policy options, identifying the nature of the task is trivial.

However, when the purpose of deliberative engagement is to help formulate policy recommendations from the ground up, identifying a meaningful and practically implementable task may be more challenging (in D2B2 the task given to participants was to formulate the design elements of a biobank in British Columbia).

2. Construction of an operational framework that facilitates the translation of participants' resolution of tasks into concrete actions (e.g., policy recommendations) with only minimal 'analytical intervention.' That is, the precise format of the desired deliberative output should be formulated before the public consultation occurs.

In conclusion, the analysis of qualitative data is complex. Although sophisticated analyses can highlight issues that are important for social scientific inquiry, they may mask participants' concrete statements that are necessary for policy makers if they are to take the spirit of public engagement (and, in particular, deliberative democracy) seriously. We thus suggest that the design of deliberative events incorporate conceptual frameworks that operationalise required deliberative outputs before deliberation occurs in such a way as to facilitate their eventual translation into policy.⁶

Kieran O'Doherty is a Post-Doctoral Research Fellow and Michael M. Burgess is Professor and Chair in Biomedical Ethics at the W. Maurice Young Centre for Applied Ethics, University of British Columbia Vancouver, BC.

1. 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>>.

2. Michael M. 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: University of British Columbia Press, forthcoming).

3. For discussion, see e.g., John Gastil & Peter Levine, eds. *The Deliberative Democracy Handbook: Strategies for Effective Civic Engagement in the Twenty-First Century* (San Francisco: Jossey-Bass, 2005).

4. For details on recruitment, see Holly Longstaff & Michael M. Burgess, "Recruiting for Representation in Public Deliberation on the Ethics of Biobanks" (2007) Electronic Working Papers Series, online: W. Maurice Young Centre for Applied Ethics < <http://gels.ethics.ubc.ca:8213/ge3ls-arch/ge3ls-arch-working-papers>>.

5. Bronwyn Davies & Rom Harré, "Positioning: The Discursive Production of Selves" in Margaret Wetherell, Stephanie Taylor & Simeon J. Yates, eds., *Discourse Theory and Practice: A Reader* (London: Sage Publications Inc., 2001) 261.

6. D2B2 has since been replicated by collaborators at the Mayo Clinic in Rochester, Minnesota, in which templates used to guide the output of deliberations were valuable in simplifying participants' conclusions and presenting them in a way suitable for informing policy.