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Structuring Public Engagement for Effective Input in Policy Development on Human Tissue Biobanking

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Abstract

We begin with the premise that human tissue biobanking is associated with ethical ambiguities and regulatory uncertainty, and that public engagement is at least one important element in addressing such challenges. One is then confronted with how to achieve public engagement that is both meaningful and effective. In particular, how can public engagement on the topic of biobanking be implemented such that:

1. It is perceived broadly as legitimate.
2. The results of the engagement are relevant and useful to the institutional and regulatory context.

In this paper we build on previous work that has addressed the former point, and focus primarily on the latter point. We argue that one way to increase the likelihood of results of public engagement being taken up in policy is through framing the issues that are deliberated by members of the public based in part on the practical policy questions for which input is sought. In this approach, we move discussion on the social and ethical implications of biobanking from abstract principles, to their consideration in the context of local biobanking practices. This is illustrated using a practical example involving a public engagement conducted to inform institutional policy for biobanking in British Columbia, Canada.

Keywords

biobanks; deliberative democracy; framing; governance; health research; consent; privacy; policy; public engagement

1. Introduction

There is considerable support in the academic literature that human tissue repositories, or biobanks, have the potential to be of significant benefit to health research (our own empirical work also suggests that lay publics express strong in principle agreement with using biobanks to facilitate health research [1,2]). This expectation, however, is accompanied by the recognition that biobanks are associated with ethical challenges that are not adequately

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addressed by existing research ethics protocols. Recently, there have been several attempts to assist in the resolution of such challenges by conducting public engagements of various forms. Such public engagements are themselves not without criticism, and some efforts have gone into developing theory and practice to help ensure both political and epistemic legitimacy in public engagement on biobanking. These efforts have involved drawing on principles from deliberative democracy to conduct public engagements on the social and ethical challenges posed by biobanks. This paper builds on this work and specifically aims to address the problem of translating the results of public deliberation into biobank policy, which we call the 'deliberation to policy gap'. While this problem has been generally recognised, up until this time, there has been little attention geared towards theoretical and practical resolution of the issue.

We begin with a brief review of human tissue biobanking, the promises it holds for medical research, and some of the social, ethical, and legal complications associated with this kind of research. In our analysis we focus on disease based tissue collections, rather than larger population based banks and cohort studies. Second, we revisit work on public engagement on the topic of biobanking with a particular focus on deliberative democratic methods. Third, we outline some of the problems associated with translating results from public deliberation into policy and biobanking practice. We provide guidelines to consider in the implementation of public engagements to increase the likelihood of uptake in policy and, finally, illustrate our arguments using the practical example of a public deliberation event conducted in British Columbia, Canada, in collaboration with The BC Biolibrary, an institution that acts as a network to integrate and improve access and quality of several provincial biobanks.

2. Biobanks – promises and problems

Biobanks are large collections of human biological tissue that are used for research. Biobanks may also contain varying amounts of other health related data including clinical, medical and personal health history as well as other lifestyle information. Proponents argue that biobank-based research is an important means for further understanding the multifactorial nature of genetic and environmental factors in causing common disease. Researchers hope that the genomic knowledge gleaned from such biobanks will enable a better understanding of the role of genetics in disease [3] as well as lead to a more personalized approach to medicine with safer and more effective drug use by permitting individualized therapy (i.e. pharmacogenomics) [4]. Biobanks can be disease based (smaller collections of samples obtained from individuals with a specific disease) or population based (larger scale collections obtained from individuals with and without a variety of diseases) [5,6]. This differentiation is an important consideration; while the principles discussed in this paper are relevant to both types of biobanks, our example pertains to disease based biobanks.

While biobanks offer great promise to health care research, they have sparked significant controversy due to the ethical, legal, and social implications surrounding utilization of samples and data. These issues include informed consent, ownership, confidentiality, secondary use of samples and data over time, return of results and data sharing, trust, access to samples, and potential commercialization [6,7,8]. Such issues present significant challenges for research ethics boards, many of whom are unsure how to deal with such issues resulting in a lack of consistency in committees’ decisions regarding biobanking [9].

Given these concerns with biobanking and the fact that there is no general agreement as to how best to resolve them, the argument has been made that there is a need for public engagement on the issue [10,11]. To address this call, multiple public engagement techniques have been employed to elicit public opinion including focus groups, individual interviews, community advisory groups, public meetings, surveys and deliberative democracy discussions [12,13,14]. Such engagements are performed in response to a recognition that society, as well as scientists and policymakers need to be included in discussion to counter the potential for loss of trust in science and meet the demand for greater accountability [15]. Public involvement addresses democratic deficits raised by new genomic technologies [16,17,18] and improves social justice in recognizing the Kantian perspective that all people, and their viewpoints, matter [15]. These consultations act to promote public education and engagement in science as well as ensuring that the ethical, legal and social implications of genomic research are discussed, and that societal viewpoints and concerns are considered [13,14,19,20]. Calls for greater public engagement on complex biotechnologies are strengthened by a social science literature that suggests that a lay public can critically process a diverse range of information to develop a sophisticated understanding of the complexities of these issues [21,22].

3. Public engagement and deliberative democracy

If one accepts the argument that policies surrounding human tissue biobanking stand to benefit from public engagement, the obvious question that arises is how to conduct such public engagement and, more importantly, how to do this effectively. When talking about public engagement, we are not referring to unidirectional attempts to increase public awareness of certain aspects of science and technology; nor are we referring to the measurement of ‘public opinion’ on certain controversial issues. Rather, we are concerned with mechanisms whereby there can be meaningful and legitimate public input into policy that involves dialogue between relevant publics with scientists, policy makers, and other stakeholders.

In the context of biobanking, several different avenues for public engagement have been implemented [5]. Here, we focus primarily on methods based on deliberative democratic principles and specifically draw on the design for public deliberation outlined by Burgess, O’Doherty, and Secko [1], as these have proven to be particularly useful for the topic of biobanking (this design has also been used by the Mayo Clinic, Rochester, Minnesota, to inform institutional biobanking policy, and by the Office of Population Health Genomics, Western Australia, to inform a state-wide policy on biobanking). Moreover, the specific implementation of public engagement events on biobanking developed in these studies explicitly takes into account criticisms of previous attempts to engage publics in biobanking activities [23].

Deliberative democracy events are designed to create a forum for learning, debate and discussion in which public opinion on certain topics may be gauged. Deliberative democratic consultations are used as a forum to collect informed and representative views of the public. As Gastil [24] explains, "when people deliberate, they carefully examine a problem and arrive at a well-reasoned solution after a period of inclusive, respectful consideration of diverse points of view."(p. 8) Such techniques seek to avoid manipulation [25] as well as giving a voice to those who may be affected by some issue, but might otherwise not have been consulted [26,27,28]. While some deliberation exercises focus exclusively on achieving consensus, suitably designed and moderated deliberation also allows for the identification of persistent disagreements among members of the public [2].

In implementing a public engagement on biobanking that is based on principles from deliberative democracy, certain foundational problems need to be addressed. As these issues have been dealt with previously, we do not elaborate further on them here, but only give a brief overview. These include:

- How to conceptualise and define 'the public' and how to operationalise this definition in terms of recruitment [29].
- Developing a clear theoretical foundation for dealing with the challenge of using a small sample of individuals to act as representatives for a larger public [30].
- How to provide participants with sufficient information on the topic to be able to come to meaningful conclusions, without biasing discussions from the outset or having them captured by particular views that are dominant in the media or academic literature [31].
- How questions for deliberation should be structured to avoid imposing the views of the researchers on what should be considered important issues [23].
- How to conceptualise and report on the results of such public engagements [2].

While these considerations are critical in constructing legitimate public engagement, they do not in themselves guarantee or even address the issues of actual uptake in policy. This problem manifests in the observation that too many science and technology public engagements have no discernible impact on policy. Thus, while much attention has focused on making public engagement legitimate, less attention has gone to increasing the chances of the results of public engagement being taken up in policy. The rest of this paper is concerned specifically with addressing this 'deliberation to policy gap'.

4. Closing the gap between public engagement and policy uptake

There are many factors that contribute to the eventual uptake, or lack thereof, of the outcomes of public engagement in some form of social action or policy. For instance, the relationship between the hosts of a public engagement and institutional bodies who actually make policy on the issues under consideration clearly has an impact on the mandate of the public forum to influence policy. Whether the public engagement is conducted as an academic experiment, hosted by an interested NGO, or by a provincial or federal government department clearly affects how and if results are reflected in policy (as well as perceived legitimacy of these results). While these issues are important, we are here concerned more with the actual design of public deliberation. In particular, deliberation can be structured in ways that either increase or decrease the facility with which they can be translated into policy. For example, there is a danger that results of deliberation do not take into account practical constraints, such as immovable laws or protocols [32]. If the conclusions reached by participants of a public engagement are not implementable based on constraints that are genuinely outside of the relevant policy makers' control, attention should be given to finding improved ways of structuring deliberation to achieve more practical recommendations. This does not mean that participants should not be given the opportunity to disagree with, for example, current laws, but that such constraints need to be made explicit.

One factor to increase likelihood of policy uptake is therefore the framing of questions for participants to consider. The issue of framing questions and issues for members of the public to consider in deliberations about biobanks has received considerable attention. Both public engagements for specific biobanking projects (e.g., UK Biobank), as well as public engagements more generally have been criticised for framing issues from the outset in such a way that they do not allow for participants to fully express their views and values. In particular, framing of issues in public deliberation has been argued to limit discussion and results and lead to a failure to have complete expression of the publics' underlying values [23,33,34,35]. Though definitions of framing vary, in this context it is generally seen as involving 'selection' and 'salience' of issues [36] and encapsulates the way in which problems, arguments, information and positions are defined, constructed and presented [37]. Framing is influenced by local histories, political dynamics, experts, cultural values and positions and is realized through selective presentation of issues and language [33]. Some discussions of framing focus on emphasis being given to only subset of potentially relevant considerations [38,39], while others focus lesson how a topic is presented, but rather what topics are selected for presentation in the first place [33,35] (see also Potter [40] on ontological gerrymandering).

While these critiques must be taken seriously in the construction and analysis of public engagements, they must be understood in the context of the challenge of attempting to translate results into policy. This translation can falter for a variety of reasons: results are too general; results do not address specific ethical areas; and, as noted, results may not take into account practical limitations such as immovable laws and protocols [32]. Rather than dismissing this as an 'insurmountable challenge' [17] to be avoided, we argue that considered and contextual framing of issues to be presented to members of the public can be a legitimate way to ensure that public engagement leads to practical policy input. In short, it is possible to construct public engagement is such a way that it is both practical and sensitive to critical perspectives.

5. Implementation of the BC Biolibrary Deliberation

Given our arguments above, the practical challenge of implementing a public deliberation on biobanking that is both legitimate and meaningful for policymakers involves 1) structuring the deliberation such that results are practically implementable and 2) making it possible for emergent values to be taken into account in recommendations made by the deliberating public. Below we outline how this was achieved for the case of a public engagement event hosted in Vancouver, British Columbia, in March 2009 (The BC Biolibrary Deliberation).

Please note that owing to space constraints associated with academic publications, it is not possible here to consider the public deliberation in its entirety. Our focus is primarily on the challenge of framing issues for deliberation to increase practical efficacy of results, without diminishing the legitimacy of these results by undermining participants' ability to challenge practical assumptions and restrictions. In this context, we concentrate specifically on particular design elements that are refinements of previous work. Other features of the public engagement design and implementation will be outlined, but can be found in more detail elsewhere [1,29]. Manuscripts pertaining to the analysis and reporting of results of the 2009 BC Biolibrary Deliberation are currently in preparation.

The BC Biolibrary

The BC Biolibrary was established in 2007 to support biobanking and a broad range of health research applications that utilize biospecimens in British Columbia, Canada. The BC Biolibrary is itself not a biobank; rather it functions as a network, complementing existing biobanks by improving quality and access to human biospecimens and enhancing the ability to collect biospecimens via standardized collection and annotation procedures. The BC Biolibrary is therefore concerned with not only the physical availability of sample to researcher but also the protocols whereby tissues are obtained from donors [41].

The BC Biolibrary is in the early stages of setting up governance mechanisms and standard operating procedures for biospecimen collection. In addition, the BC Biolibrary has a commitment to societal input and involvement in the Biolibrary and "seeks ongoing public participation in the design of a sustainable ethics and governance structure, one that reflects the values of the BC public"[1]. Specifically, the Biolibrary has a need for input on disease based biobanks, for which tissues are collected after clinical procedures, and on certain types of regulatory uncertainty.

Recruitment of deliberation participants

The 2009 BC Biolibrary Deliberation is the result of collaboration between the W. Maurice Young Centre for Applied Ethics at the University of British Columbia and the BC Biolibrary. The event aimed to build on previous public engagements on biobanking [1,2] with the specific purpose of informing governance, ethical protocols and certain standard operating procedures of the Biolibrary.

The aim of recruitment was to achieve a sample that represented the diversity of values, life experiences, and discursive styles of the citizens of British Columbia, in the context of a relatively small scale event that allowed for meaningful deliberation and with a limited budget [29]. A further aim was to address perceived democratic deficits [16], by giving voice to individuals and groups that would otherwise not be heard (i.e., special interest groups that

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[1] http://www.bcbiolibrary.ca, accessed July 12, 2009

already are able to lobby and influence policy by virtue of the fact that they constitute organised groups). To this end, a random demographically stratified sample of 25 residents of British Columbia was recruited to the deliberation. Although a small sample cannot be politically (and statistically) representative of a provincial population, it is possible to aim for diversity and to minimize selection bias. Randomisation was achieved through sending out 5000 letters of invitation to random households selected by postal code, which resulted in 224 individuals expressing interest in attending the deliberation. Demographic stratification was achieved by selecting 25 individuals from the 224 respondents to fill stratification for the demographic filters of Health Region, age, and gender (additional demographic variables were measured to insure diversity of the final sample, but were not part of the initial filters). Thresholds were used to achieve approximate proportional representation relative to official Canadian census statistics, with the exception of two groups (First Nations and individuals with genetic or chronic disabilities). These two groups were over represented relative to the general population (minimum of two participants for each category) to ensure that their voices would be present on a topic potentially able to affect them in a disproportionate manner.

Deliberants were not expected to have any prior knowledge of biobanking, and received information through an information booklet, expert/stakeholder presentations representing range in opinions on biobanks, an annotated bibliography and a private website. Deliberation occurred in both small and large group sessions, and was facilitated to promote participation, respectful listening and thorough discussion.

Areas of ethical ambiguity in human tissue biobanking

To focus on the practical efficacy of the public deliberation, the first stage of planning involved a mapping of the Biolibrary's collection, storage and research procedures to identify a comprehensive list of 'areas of ethical ambiguity' to be considered for discussion during the deliberation. By this we mean those precise junctures where, given current accepted best practice principles and generally agreed upon ethical guidelines, managers of the Biolibrary were nevertheless uncertain what the most appropriate course of action should be.

These areas of ethical ambiguity were mapped out over the course of four months in meetings between the authors and key personnel from the BC Biolibrary and categorized into overarching topics. Initially, this process led to the identification of twelve topic areas for which the managers of the BC Biolibrary wanted to have public input to consider in their protocols and governance structure. These twelve topics were later reduced to five that were most pertinent to the procedures, protocols and operations of the Biolibrary, and that could realistically be covered in sufficient depth within the time constraints of a four day deliberative public engagement:

1. **Collection of Biospecimens** (including questions regarding the acceptability of using left over clinical specimens for research, and collecting additional specimens not required for clinical purposes)

2. **Initial contact/Introducing the Biobank** (including questions regarding appropriate avenues for introducing the biobank to potential donors, and how they might be identified by the biobank in the first place)
3. **Linking Samples to Personal Information** (implications of anonymous versus identifiable samples used for research)
4. **Consent** (whether 'blanket consent' is acceptable, considerations of 'community consent', and the appropriate time and place for obtaining consent), and
5. **Governance of Biospecimens and Associated Data**.

All topics and the specific questions within them were cross-referenced against the results of a previous public engagement on biobanking [2] in which no questions were pre-formulated or framed. The reason for this cross-referencing was to attempt to frame issues for discussion in such a way that they were in line with previous knowledge of public discourse on the topic (this is explained in more detail below in the section 'Balancing a priori structure with emerging values').

The five topics and the specific contentious issues within each of them were written up in the form of a workbook that was used by facilitators to structure the deliberation during the actual event. The workbook also served to ensure that the deliberations and the conclusions eventually reached by participants remained within the parameters of recommendations that the Biolibrary was realistically capable of taking into account in their governance structure.

The deliberation workbook

The workbook was divided into five sections, each dedicated to one of the topics identified above. Each section included an introductory paragraph outlining the main characteristics of the problem, and the particular questions that participants were asked to discuss and use to formulate recommendations for the Biolibrary. Each section also included additional information in the form of vignettes, explanations of relevant terminology, examples of recommendations from the previous (unstructured) public engagement on biobanking conducted in BC (The 2007 BC Biobank Deliberation [28]), and recognised pros and cons. (For a more detailed description of the items discussed under each of the five topics and a copy of the complete workbook, see www.biobanktalk.ca.)

The workbook also included blank 'notes' sections so that participants could document their thoughts and questions throughout the deliberative process. Participants were encouraged to record changes in opinion in their individual workbooks, independent of the conclusions of the group as a whole. At the end of the event, workbooks were collected by the research team for further analysis.

Structured deliberation on biobanks

With the exception of the first day of deliberation (of four), which was dedicated primarily to orienting participants and to expert and stakeholder presentations, all deliberations were guided by the structure of the workbook. Each of the five topics was first introduced by the principal moderator, with additional technical information provided by a senior member of the BC Biolibrary. This introduction was based closely on information provided in the workbook; additional information was often provided together with tangible ‘teaching aids’. For instance, the topic of biospecimen collection was introduced with the aid of a plaster model of a piece of colon with a tumour, and mock up dissection slides; the topic of linking samples to personal information was introduced together with screen shots of the database used by the Biolibrary to store and access donor information; the topic of consent was introduced with the aid of copies of actual consent forms currently in use by different biobanks in BC.

After this initial introduction of the topic participants broke into three small groups. Groups were selected at random and participants remained in the same small group throughout the event. Each small group was facilitated by a member of the research team with previous experience and training in qualitative research methods and small group moderation. In these small groups, participants started exploring their views on the particular topic area, clarifying key concepts and terms, and began to focus on the specific questions pertaining to the topic.

In a significant deviation from previous work [1], participants were not guided towards any form of group agreement in these small group discussions. Rather, after 1-1 hours of small group discussion, participants reconvened in the large group to attempt to come to an agreement on specific questions posed for each topic area. Discussion was led by the principal facilitator, and guided by deliberative democratic principles outlined above. Facilitators gave particular attention to ensuring that all voices were heard and no views glossed over in the formulation of final recommendations. In a further significant deviation from previous work, discussion on particular questions was concluded with a vote. Importantly, this vote was not intended to revert to a model of aggregative (rather than deliberative) democracy [42]. Rather, the purpose was 1) to provide a certain closure to discussion on one issue, enabling a shift to the next issue, and 2) to ensure that participants who disagreed with a majority or vocal minority view had an explicit opportunity to express themselves. The practice of calling a vote for each question and recommendation was associated with a clear documentation of divergent views and the identification of reasoning of both majority and minority perspectives. In summary, the purpose of the final large group discussion for each of the five topic areas was to aim for participants to come to agreement about how the BC Biolibrary should structure their protocols on particular issues. Where unanimous agreement was not achieved, the facilitator was instructed to obtain a clear understanding of where there was disagreement and for what reasons. In all cases, a clear articulation of participants’ positions was obtained and documented.

One of the risks of which we were cognisant in structuring deliberation in this way was that there are inevitable order effects in presenting the different topics to participants in a sequential order. For example, would participants respond differently to issues related to privacy depending on whether they were exposed to the question before or after considering the problem of informed consent? Undeniably, the different areas of ethical ambiguity we identified are intimately entwined, and ultimately should not be considered in isolation. However, the constraints of conversation and reasoned debate make simultaneous considerations of these different issues virtually impossible (especially in a group newly exposed to these issues). To deal with potential order effects, therefore, the final half day of deliberation was dedicated towards ratifying the conclusions participants had reached on each of the topics. During this ratification process, all conclusions and recommendations made by participants were revisited and a genuine opportunity was provided to reconsider, change and clarify previous points. In this way, participants had the opportunity to consider in depth each of the issues presented to them, while making their final recommendations based on a more holistic recognition of all the topics they had debated over the full four days.

Balancing a priori structure with emerging values

In this paper we have been focused on some particular design elements we see as important in facilitating the uptake of conclusions of public deliberation on biobanks in policy. In this context we have advocated a relatively tight structuring of deliberation by facilitators, that is informed by the practices and constraints under which biobanks in BC operate. However, as we have outlined above, serious criticisms have been levelled at other public engagement exercises, particularly on biobanks, owing to tight framing of issues. Some consideration is thus required to reconcile these views.

The first point to note is that the framing we advocate here is not based on preconceived ideas of the authors or even the academic literature on the subject. Rather, the framing is based on a systematic analysis of biobanking practice. Several additional steps were taken to ensure that framing did not unduly constrain participants’ expression of views.

In the process of identifying areas of ethical ambiguity and constructing the workbook, the authors undertook a comprehensive cross-referencing of all items against the results of a previous public deliberation on biobanking in which no structure was imposed on deliberations (The (2007) BC Biobank Deliberation [2]). In doing so, it was possible to ensure that emergent themes and values that arose during unstructured deliberations on biobanking were captured and incorporated in the structure imposed on deliberation for this subsequent event. Building on this prior knowledge of informed public discourse on biobanking also enabled us identify unwarranted assumptions on our part and align the framing as much as possible with public values on the subject. It is worth noting that in many contexts it may not be practical to have such a two staged process of deliberation – one unframed and a second framed event. The topic of biobanking has two characteristics that point towards the necessity of this kind of design: complexity and low public awareness. For topics that are less complex, or for which there is a certain level of public knowledge (and some studies of public attitudes are available in the peer-reviewed literature), this degree of effort may not be necessary.

Next, facilitators were instructed to consider the way in which questions were framed for deliberation in the workbook as provisional. The provisional status of questions was conveyed to participants by explaining that they were free to challenge the way a particular issue was presented and suggest alternatives. This meant that if, during deliberations, participants felt that a particular framing of a question did not allow them to accurately express their opinions, the question was amended. This occurred in several instances. For example, the initial version of the consent section in the workbook included questions regarding the acceptability of obtaining of consent during seven specific periods of medical treatment. The deliberants rejected this presentation of the issue and instead argued that the acceptability of approaching a donor for consent should be based on a more subjective consideration of multiple factors such as the donor's state of mind. In this way, the final framing of recommendations reflected both the practicality of being grounded in the practices of the BC Biolibrary as well as the values participants were attempting to express during deliberation.

Finally, issues that participants felt were important, but that fell outside of the scope of the public engagement were included for consideration but bracketed in such a way that they did not detract from dealing with the issues at hand. A risk of tightly structured deliberation is that participants may feel that they are being strategically guided away from specific areas of concern. This is particularly problematic if it leads to cynicism among participants in the sense that they feel that they are being led into simply endorsing existing practices, and prevented from considering controversial issues. An example of one such instance in our deliberation was the issue of population based biobanks. At several points during the deliberation, participants wanted to shift the topic of conversation from disease based biobanks towards population based biobanks, usually collected independent of research on specific diseases. The problem from the perspective of the BC Biolibrary was that any conclusions the participants may have reached on population biobanks were of limited relevance as the Biolibrary is not engaged in these kinds of activities. For participants to spend a significant amount of time talking about this issue thus ran the risk of missing the opportunity to gain important insights from members of the public pertaining to activities in which the Biolibrary is involved, and that Biolibrary managers are able to act upon. Explaining to participants that we were unable to do anything tangible with their recommendations owing to the particular mandate of the public engagement had only limited success (i.e., participants still expressed dissatisfaction about wanting to discuss the issue)[2]. What did seem to be effective in enhancing the legitimacy of the process, however, was to have a 'parking spot' (in the form of a dedicated flip chart page) for issues that participants felt were important to discuss, but that did not fit onto the agenda. The parking spot served to collect these issues and about two hours were dedicated at the end of the final day to discuss them. Conclusions reached by the participants on these issues were also documented with all other recommendations.

In summary, while we advocate a tight framing of deliberation structure in the interest of increasing likelihood of uptake in policy, we are cognisant of criticisms and the risks that can be associated with such framing. These criticisms should not be ignored and appropriate steps need to be taken to ensure that the framing of issues for deliberation is warranted and in line with emergent values of participants in deliberation.

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[2] The fact that participants were able to express this resistance can also be taken as evidence for a form of legitimacy, as the deliberation was sufficiently robust to preclude constraining participants from touching upon issues of evident public concern.

6. Conclusion

The purpose of this paper has been to address the challenging observation that in spite of the numerous public engagements that are conducted in the context of emerging biotechnologies, very little impact of these engagements in actual policy can be discerned. We have argued that one way in which the likelihood of uptake can be increased is through careful framing of questions to be considered during deliberation. In particular, consideration of areas of ethical ambiguity that are evident in routine biobanking activities and protocols has the advantage of ensuring the practical relevance of results of deliberation.

Discussion of the social, ethical, and legal implications of biobanks is extensive but no consensus has emerged regarding best ways to safeguard donors' privacy, how best to secure informed consent for prospective studies, or how to ensure that benefits of biobanking research are distributed in a just manner. We have argued here and elsewhere that public engagement should be at least one factor to be considered in the resolution of these problems.

In our discussion, we have paid close attention to criticisms of framing of issues in public engagements. We largely agree with these criticisms and have therefore argued for the adoption of methods that allow for the pragmatic structuring of deliberation without detracting from the legitimacy of the public consultation. In more general terms, we feel that it is important that any tight framing of issues for discussion in public engagement requires not only careful theoretical and pragmatic justification, but sensitive and active management by facilitators. Although we have not elaborated on this latter point, we feel that appropriate facilitation is a critical aspect of deliberation deserving of further attention. The point of public deliberation is to allow members of the public to express themselves on the issue and to obtain their input for some form of policy. Regardless of the theoretical grounding and practical attention that has gone into framing issues for deliberation on biobanks, flexibility is required to ensure that participants are able to express the values they feel are most relevant to the issue. In imposing structure on deliberation, the event designers may have gotten it wrong, and a degree of willingness to be guided by participants is essential.

We have presented our argument regarding the process of appropriate framing of issues for deliberation as increasing the likelihood of policy uptake, rather than an essential and sufficient ingredient. Given that the kinds of processes we are advocating are not of the type that can feasibly be tested using a true experimental design, care needs to be taken in attributing a definitive causal role in eventual policy uptake. Nevertheless, we do feel confident in claiming that the results of the public deliberation are being taken into account in biobanking policies in BC. Mangers and personnel from the Biolibrary whose responsibility it is to formulate these policies and SOPs attended the deliberation specifically to gain input into the problems they are grappling with in designing appropriate policy. Joint meetings between the authors and Biolibrary personnel were also held subsequent to the public deliberation to provide summaries of results and discuss key findings. Biolibrary personnel reported on many occasions that the public deliberation had given them valuable input for their task of setting up a sustainable governance structure for biobanking in BC. Importantly, one of the participants of the 2007 public engagement event[1,2] was also present to observe the second public deliberation, and now attends meetings as an ongoing member of the Biolibrary's *Governance Oversight Committee*.

Inherent in our argument there is a tension between the general and the particular. One the one hand, we have argued for incorporating detailed local institutional knowledge into the structure of public engagement. On the other, we have attempted to situate our case study in such a way as to suggest generalisable guidelines for increasing the likelihood of uptake of results of public deliberation in policy. These guidelines can be summarised as follows:

1. The causal relationship between conducting a public engagement and eventual policy uptake is complex and involves many factors. One relevant factor is the way in which the issues to be discussed by members of the public are framed.
2. Appropriate framing should take into account the nature of the problem from a policy perspective. In our example, this involved mapping out the areas of ethical ambiguity in the practices of the Biolibrary. However, biobanking is a relatively complex domain and other public engagements may not require this level of effort. Critical items to consider, though, include consideration of how public opinion on a given issue can realistically be acted upon by policy makers and whether appropriate links exist between the hosts of the public deliberation and the individuals or institutions formulating policy.
3. Appropriate framing should take into account the fact that the nature of the problem from a public perspective may not be known. If a topic is simple enough to be represented by only a few multiple choice questions, then a public deliberation may not be warranted in the first place. However, attempts to reduce a topic as complex as human tissue biobanking to just a few questions will likely fail to take into account not only the complexity of the problem, but also the diversity of world views that underlie the expression of public values in different contexts. In short, if it is to be legitimate, public deliberation must take into account the perception of the problem from the perspective of the publics being consulted. In our example this was implemented by basing the original framing of questions in part on the results of a public deliberation where the issues for discussion were not pre-formulated, and through allowing participants to challenge the way in which issues were presented to them and reframe them in ways more in tune with the way they perceived the problem. Again, this level of effort may not be necessary for all forums. What is required, however, is a degree of reflexivity on the part of those formulating the issues to be discussed and a realisation that they do NOT understand the world view of those they are consulting. If they did, consultation would be superfluous.
4. Finally, in spite of our argument for structuring deliberation to increase likelihood of the policy uptake, it is important not to over emphasise the immediate policy relevance of public discussion on a topic. Funders may be more likely to pay for public deliberation designed to produce policy relevant output, but there is a risk that funders are simply paying for the output that they want. Formal policy is an operationalisation of collective social action and, as such, should represent collective values. In some instances, institutionalised

> avenues for policy construction may already be embedded in implicit value systems. A particularly dangerous misuse of public deliberative forums is for them to be conducted to provide justifications for particular policy decisions, without genuinely opening up issues for public debate. Not only is this likely to undermine the particular policy being debated, but it contributes to political alienation and mistrust in existing social structures. Public deliberation should provide both a forum for public hopes and concerns to be heard, as well as providing an effective avenue for incorporating public values into policy.

In conclusion, the link from public engagement to policy relevance is not automatic and stands to benefit from conscious attention at the stage of designing and implementing the engagement. We have focused here on a case study involving institutional policy for biobanking, which is distinct from other forms of policy, such as state or federal policy or laws. In this context, we sought to achieve a degree of structural congruence between the conclusions resulting from public engagement and actual biobanking practices in BC. These results are currently being integrated into the policies and ethical protocols of the BC Biolibrary.

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