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## Mad scientists bend the frame of biobank governance in British Columbia

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# Mad scientists bend the frame of biobank governance in British Columbia

## Abstract

The tools and rhetoric of deliberative democracy are increasingly popular with governments, organizations, and researchers working to enhance 'public engagement with science'. Deliberative fora such as citizen juries have also been heavily critiqued by social and political scientists – for positively and narrowly framing contentious new technologies to secure public support, and for privileging consensus over 'difference'. This paper takes such critiques seriously. Drawing from ethnographic participant-observation and analysis of a deliberative public consultation on biobanking in British Columbia (BC), Canada, it argues for careful attention to deliberative event design. A multi-disciplinary approach, multiple media, and imagination-focused tasks were used in BC to produce inclusive deliberations in which members of the public were able to directly challenge expert assumptions. Ethnographic attention to narrative during analysis of the deliberation reveals the extent to which participants insistently questioned the framing of the event. Drawing from personal experiences, analogies, news stories and fictional events, the deliberants developed and embellished the figure of a 'mad scientist' to challenge certainties promised by scientific, legal, and ethical expertise. This paper argues that such questioning enhanced the accountability of the deliberation and participant trust in the event. It also argues that ethnographic attention to storytelling is a valuable and under-utilized pursuit in the field of deliberative democracy – a pursuit that can enable deliberative events to 'listen'.

## Keywords

deliberative democracy, ethnography, biobank governance, public engagement with science, storytelling

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### **A narrative introductory frame: from fish genes to the origins of HIV**

*JERRY: Well, there's a big debate about the HIV virus, whether it was created by two competing doctors who were trying to find the polio – or not polio, I think it was the polio vaccine in the fifties, and one of the doctors used chimpanzee tissue and inoculated a bunch of people from the Congo and that's where the HIV virus is ground zero. And he denies it but all his assistants have evidence like on paper saying that he did. So.*

As the facilitator of a small group discussion during a deliberative public consultation about biobanking in the Canadian province of British Columbia (BC) during April 2007, I was somewhat taken aback by this 'argument'. There were eight participants in the room. This was their second day of a four-day deliberation at the Morris J. Wosk Centre for Dialogue in downtown Vancouver and their first real opportunity to deliberate as a group. The day before, I had learned several things about this particular participant, Jerry. He was so touched by one woman's story of the suspected euthanasia of her infant that he ran out to buy her flowers during the coffee break. He was on disability benefit. He worked as a volunteer at a men's drop-in centre. He asked challenging questions. He did not have access to a computer and worried that he wouldn't be reimbursed for his bus fare to our event.

I understood his personal concern with the origins of the HIV virus, thanks to a fortuitous conversation at dinner in the Vancouver Art Gallery the night before. Less immediately apparent was how his statement addressed the questions at hand. I had asked the group to share their greatest hopes and concerns for biobanking in BC. The conversation had flown from concerns about military use of DNA, to crossing species boundaries, to fish genes in tomatoes, to this example of the debate about the origins of HIV/AIDS. Bombarded with heavily weighted images and stories, I did not know how to translate them into the 'reasons', 'agreements', 'disagreements', and 'trade-offs' that I was required to list on flip-chart sheets.

Another participant came to Jerry's (and my) rescue at this juncture, neatly articulating his vivid narrative as a documentable 'reason': *"I think the second point was that whatever rules are made, how do we know they're going to comply and what do you do if they don't?"* Relieved, I scribbled 'compliance' on the chart in a red marker. "How about somebody else?" I challenged the group – reasserting the facilitator's authority as expert listener and translator, eager to

move the conversation away from this contentious and deeply personal statement on HIV/AIDS.

This image of the rogue scientist - the trusted white doctor on a mission to eradicate polio from Africa, injecting chimp tissue into the bodies of unsuspecting black natives, letting loose a virus that would ravage the continent and spread throughout the world – did not leave the room, however. It became a central theme of the day's deliberation. The rogue scientist – sometimes 'mad', sometimes 'bad', sometimes well-intentioned but always with disastrous impact – re-emerged again and again throughout the day in a variety of guises. The participants told stories from personal experiences. They drew upon shared references to fictional characters and media reports. They argued through analogy to similar occurrences in different times and contexts, embellishing this multidimensional figure. They used the rogue scientist to question and think through many different hopes and concerns for biobanking in British Columbia. They also used him to repeatedly and insistently challenge the way we had 'framed' the entire deliberative event.

### **The challenge of framing deliberative public engagement with science**

The twenty-first century has seen increasing calls for 'public engagement', 'public participation', and a 'democratization' of science – by governments, as well as civil society groups and scholars working in ethics and the social sciences (Fukuyama and Furger 2007, HMSO 2000). A plethora of large public consultations have been launched around the globe in response, such as the 2001 *Canadian Public Consultation on Xenotransplantation*, the 2002 *UK GM Nation*, a 2005 Citizen Jury assessment of transgenic crops run by the Danish Board of Technology,<sup>1</sup> the UK government's *Nanotechnology Engagement Group*,<sup>2</sup> and the 2007 *Who gets born? Pre-birth testing* deliberative dialogue run by the New Zealand Bioethics Council.<sup>3</sup>

Increasingly, such consultations are borrowing the tools and rhetoric of deliberative democracy. In the United States, organizations such as Everyday Democracy (formerly the Study Circles Resource Centre),<sup>4</sup> *AmericaSpeaks*<sup>5</sup> and

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<http://www.tekno.dk/subpage.php3?article=1136&language=uk&category=11&toppic=kategori11>

2

<http://www.involve.org.uk/index.cfm?fuseaction=main.viewSection&intSectionID=213&intParentID=2>

<sup>3</sup> <http://www.bioethics.org.nz/about-bioethics/issues-in-focus/prebirth-testing/index.html>

<sup>4</sup> <http://www.everyday-democracy.org>

<sup>5</sup> [www.americaspeaks.org](http://www.americaspeaks.org)

National Issues Forums<sup>6</sup> have been facilitating community engagement with political issues for years. Newcomers to the public participation game see these organizations as offering a wealth of experience and resources from which to draw. They are awed by high profile events – such as the recent *CaliforniaSpeaks* event which gathered 3,500 Californians across eight cities to discuss healthcare reform (*CaliforniaSpeaks* 2007). They are compelled by practice drawing from a procedural model of politics in which political norms gain legitimacy through free argument between all affected parties (Roberts and Crossley 2004), participants put themselves in the shoes of all affected parties (Habermas 1996), symbolic claims are dissipated (Niemeyer 2004) and the quality of decisions is enhanced (Pellizzoni 2001).

This fashion for public engagement with science, for deliberative public consultation, has also been subject to fairly insistent critique from within both social and political science. Notably, the *framing* of such events has been taken to task. In its most general sense, framing refers to the ways in which problems, arguments, information and positions are defined, constructed, and presented (Friedman 2007:3). Framing includes the contexts placed around information and the metaphors used to advance values (Lakoff 2004), and can be deliberate or not. Frames have been defined as highlighting some bits of information about an item, elevating them in salience (Entman 1993). Critiques of framing effects within public consultations expand this definition from communication studies, to include framing inherent within research and institutional processes, and within wider culture, as well as the transfer of information.

Joanna Goven has argued that if public participation is to address the problems of expert competence and legitimacy, it must facilitate a reframing of the issues at hand and a problematization of expert assumptions – something that the 1996 New Zealand consensus conference on plant biotechnology failed to achieve (Goven 2003). Other critics have used empirical data to reveal the tendency of public consultations to focus on technological developments too far downstream (MacNaghten, Kearnes, and Wynne 2005), to act as positively framed ‘bolt-on’ activities to secure public support for contentious developments (Petersen 2005), to be framed by narrow questions (Irwin 2001), to reinforce technocratic frames and the lay-expert divide (Kerr, Cunningham-Burley, and Tutton 2007), and to frame ‘science’ and ‘democracy’ as distinct domains rather than recognizing their co-construction (Reardon 2007).

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<sup>6</sup> [www.nifi.org](http://www.nifi.org)

Within political science, the practice of deliberative democracy has also been criticized, by those characterized as ‘difference theorists’ (Dryzek 2000) - for replicating structural inequalities in society, suppressing minority perspectives, and excluding impassioned talk (Sanders 1997), privileging the communication strategies of elites (Kohn 2000), failing to challenge the social structures and hegemonic discourses framing events (Young 2001), over-emphasizing consensus and denying the antagonism that is the necessary lifeblood of democracy (Mouffe 2002). These are critiques of ‘framing’ on the grandest of scales. They challenge the framing that occurs when deliberative democracy encourages ‘rational’ argument, the framing involved in self-selection and other recruitment processes for deliberation, the framing involved in the choice and definition of topics that are suitable for deliberation in the first place, and unconscious framings inherent within cultures themselves.

This paper takes such critiques seriously. Rather than discount deliberative public engagement on the basis of its potential to exclude, or because isolated instances of practice have failed to allow participants to question hegemonic assumptions, this paper reads such critiques as a productive challenge. Friedman (2007) argues that framing should not necessarily be perceived as negative, that framing can – to a certain extent – be used to strengthen rather than weaken the democratic process. He argues that *non-partisan framing-for-deliberation* should be distinguished from *partisan framing for persuasion* and can be used to clarify and illustrate the *range* of perspectives surrounding an issue. He cites non-partisan organizations such as Public Agenda, Study Circles and *AmericaSpeaks* as examples of those who deliberately frame issues for deliberation, by “creating non-partisan guides to the policy debate that begin with the public’s values” and providing “an overview of the range of approaches and solutions that exist and the tradeoffs among them” (2007:4).

Developing Friedman’s concept, I argue that *framing-for-deliberation* can be further extended to address the critiques of the ‘difference theorists’ (Dryzek 2000). *Framing-for-difference* can enable more than a non-partisan presentation of diverse approaches to an issue; it can enable pluralism of perspectives, narrative styles and forms of argument and can also encourage challenges to hegemonic cultural discourses. Using an ethnographic<sup>7</sup> approach, I draw from the experience of participation in, and reflexive analysis of, the design and facilitation of a deliberative public consultation on biobanking during 2007. I describe our

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<sup>7</sup> Ethnography is the foundational research methodology of anthropology as a discipline, an approach that has gained in popularity within sociology and associated social science disciplines in recent decades. Ethnography involves simultaneous participation in the culture or process of study and observation of it – combining the insights of involvement and detachment.

attempts, as a team working at the University of British Columbia, to frame for both deliberation and difference. We deliberately designed and framed an inclusive event, an event that introduced the widest possible range of perspectives and understandings of the issue at hand. We also designed an event open to expression of difference, an event with porous frames.

Drawing from work on storytelling within anthropology, this paper then focuses analytic attention upon the stories that participants told during the deliberation itself. I focus on the first day of deliberation within the small group that I facilitated, in order to analyze the conversation in detail from a participant-observer perspective. Reading the ethnographic work of Michael Taussig (2004) and of Kathleen Stewart (1996) and the stories they share from the ruins of West Virginia's coal camps and the rainforests of Colombia's Pacific Coast, drawing from the insights of Walter Benjamin (1970, 1982, 1999), helps to expose the insistent critical questions of our own participants pushing against the frame of this deliberative event.

Ultimately, this paper argues for the capacity of public participants to challenge whatever limiting frames may exist around a citizen consultation and its topic, if the event is designed and facilitated in an open manner. It also argues for ethnographic analysis – a research methodology little used within political science and rarely seen in analysis of deliberative events<sup>8</sup> - to reveal the extent and form of such challenges. But before the framing of biobanking can be analyzed, the issue must be introduced in all of its complexities. I begin then with a brief explanation of the phenomena of biobanking, an overview of recent developments in the field, and a description of the institutional context in which the idea for a deliberative public consultation on biobanking in BC germinated.

### **What are biobanks? Why deliberate?**

The term 'biobank' can refer to many different collections of biological materials and information – from plant seed banks, collections of mouse tissue and police DNA databases, to collections of cancer biopsy samples in hospitals. Here we are concerned specifically with *human* biobanks, defining them as *collections of human tissue and related information that are used for research purposes*. Such collections vary in size, contents and purpose (Maschke 2005) – from tumor collections in hospital pathology departments, to small research collections for study of the genetic basis of disease, to national disease-based registries such as the Norwegian Multiple Sclerosis (MS) registry (Myhr et al.

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<sup>8</sup> Recent work by Kerr et al. (2007) is a notable exception, and a valuable contribution to the literature.

2006). The latter was established in 1998, had 50 to 60 percent of all MS patients in Norway registered by 2006 and aims to make cerebrospinal fluid, DNA and tissue samples available for research into MS.

Biobanking is not new. Human tissue has been collected for at least 100 years. But the sequencing of the human genome, the emergence of the new sciences of pharmacogenomics and nutrigenomics, and advances in computational biology have fuelled a new level of demand for human blood, tissue, urine, DNA and information. These are now highly valuable materials for geneticists and epidemiologists researching the causes, risks and workings of many diseases. 'Biobanking' as a word was coined in response to this demand, appearing in *PubMed* for the first time in 1996 (Loft and Poulsen 1996). This word is increasingly taken to refer to large population-level biobanks and international networks of biobanks.

The Estonian Genome Project, Biobank Japan, Icelandic Health Sector Database, UK Biobank, Sweden's Medical Biobank and the Singapore Tissue Network – these are all examples of population-level biobanks sprouting around the globe. The European GenomEUtwin Project - a study of twins from Denmark, Finland, Italy, Holland, Sweden, the UK, France, Australia, Germany, Lithuania, Poland, and the Russian Federation – is an example of a large international collaboration. Many of these biobanks are being built as research or technology platforms for the future. Rather than focus on any one disease, they aim to facilitate research into complex gene interactions involved in many multi-factoral diseases and gene-gene and gene-environment interactions at the population level. They solicit blood samples and health and lifestyle information from a range of sick and healthy individuals. Their future research uses are largely unknown. As such, they are often referred to as 'prospective' collections.

The ever-expanding scale of these projects, along with new levels of commercial involvement and the need to recruit volunteers from the general population, has increased the public visibility of biobanking. The reception has not always been positive. The Human Genome Diversity Project (HGDP) proposed an international study of 722 anthropologically unique human populations in 1991. It generated an outcry from scholars and indigenous activists (Harry, Howard, and Shelton 2000a, Reardon 2005). When the Icelandic Parliament authorized a subsidiary of deCODE Genetics to construct a biobank of genetic samples from the Icelandic population (Sigurdsson 2001, Sigurdsson 2003) in 2000, giving them a 12-year exclusive commercial license to use the country's medical records in return for an annual 70 million kronur, there was similar protest (Abbot 2003, Merz, McGee, and Sankar 2000, Potts 2002). Several



hundred articles appeared in newspapers (Palsson and Rabinow 2001), many of them referring to the sale of the ‘genetic heritage’ of the nation. A grass-roots lobby group, Mannvernd, emerged to fight the project (Mannvernd 2004).

Transparent public consultation at the stage of project design is becoming an increasingly essential requirement for new biobanking projects. Public uproar and media frenzy are risks that those launching population biobanks no longer wish to take. At the same time, advocacy groups and the ‘public’ are becoming increasingly concerned about the nature of such consultation. The UK Biobank is now recruiting 500,000 donors. It engaged in a lengthy consultation process with primary health care professionals, stakeholders, and the public prior to launch (Hapgood, Shickle, and Kent 2001, Ltd 2002, Research 2003). The project has still been criticized for invoking insufficient debate (Barbour 2003), for using ‘consultation’ simply to ‘educate’ the public and to facilitate participation (Kerr 2003), and for excluding valuable expertise from the consultation process (Wallace 2005).

### **Biobanking in BC: a deliberative public consultation**

There is no population biobank for the Canadian province of British Columbia. Nor are there public plans for creating a new prospective collection. Biobanking in the province occurs in a somewhat haphazard manner. Research access to tissue samples depends often on personal networks, resources available for donor recruitment, and connections to pathologists overseeing clinical samples. In 2006, however, a team of BC-based research scientists began working up a scientific, business and strategic plan to the Michael Smith Foundation for Health Research<sup>9</sup> Technology/Methodology Platforms Award Program for a proposed BC Biolibrary.<sup>10</sup> The aim: “to establish an integrated, comprehensive, standardised, human biological materials accrual, management and use engine,”<sup>11</sup> allowing easier access to patient specimens and data by researchers from across Canada.

This BC Biolibrary business plan listed a harmonized ethics and privacy framework as a key goal. The team was concerned that biobanking in Canada is ripe for, “a major crisis if public trust is challenged.” Tissue scandals in the UK loomed in the background, alongside the Icelandic and HGDP biobank controversies. When the routine storage of deceased children’s organs for research

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<sup>9</sup> MSFHR is British Columbia’s provincially mandated health research organisation. More information is available at <http://www.mschr.org>

<sup>10</sup> The BC Biolibrary was awarded an MSFHR grant in March 2007.

<sup>11</sup> Quoted with permission from the BC Biolibrary Business Plan submitted to MSFHR.

without parental consent was revealed at Alder Hey Hospital and Bristol Royal Infirmary in the UK in 2001, public outcry led to a near moratorium on tissue banking and research. An expensive system of accreditation of specimen collections by the newly-formed Human Tissues Authority followed. To avoid a similar scenario in Canada, the BC Biolibrary plan declared that, “the development of the BC BioLibrary in conjunction with a process of public engagement will ensure that public trust is maintained.”

Chance connections and common needs led to a partnership between the BC Biolibrary team and an interdisciplinary team of researchers at the Centre for Applied Ethics at the University of British Columbia (UBC). As a visiting doctoral researcher from CESAGen in the UK, I was working within the team. Funded by Genome Canada and Genome BC to research public perspectives and decision-making on genomics research and biotechnology,<sup>12</sup> we were exploring the potential of methods of deliberative democracy. The concrete BC Biolibrary proposal offered an added incentive to take up the gauntlet thrown by John Gastil and Peter Levine in *The Deliberative Democracy Handbook* (2005) – a call for more academics to organize, experiment with, and learn from, practical deliberative events.

From September 2006 until April 2007, our team worked up the design and implementation of *Biobanking in BC: a deliberative public consultation*. We developed the event design and participant information materials through participation in two graduate courses in interdisciplinary studies at UBC. A straw model was presented to an expert workshop of deliberative democracy practitioners and theorists in November 2006, and developed through critique into a final design. The deliberative event took place over two weekends in April and May 2007, separated by a two-week break (Burgess and O'Doherty 2007). Twenty-one random-digit-dialed and demographically stratified BC residents took part.

### **Framing deliberation for ‘difference’**

Inclusion and difference remained high on the agenda during the design and implementation of this deliberative event. As a team we tried to frame the event as widely as possible, to produce background information that introduced the widest diversity of issues pertaining to biobanking, to recruit a diverse group of participants, to allow the articulation of reasons across various media and in

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<sup>12</sup> See <http://gels.ethics.ubc.ca:8213/ge3ls-arch>

varying styles, and to structure the deliberation in a way that encouraged the articulation of persistent disagreements as well as consensus.

Iris Marion Young (2001) offers three paths towards the redemption of the oft-exclusive processes of deliberative democracy. She argues that deliberative democrats need to *withdraw* from the immediacy of the policy trajectory and “create inclusive deliberative settings in which basic social and economic structures can be examined”(2001:684), that deliberative theory should understand itself as *critical* theory, and that deliberation should become more *rowdy*, aiming to rupture complacency. Chantal Mouffe (2002) adds another urgent recommendation: to relinquish the illusions of a consensual model of politics. Our event design followed the advice of these theorists oft-characterised as ‘difference theorists’ (Dryzek 2000:57) – we worked on *framing-for-deliberation* (Friedman 2007) but also *framing-for-difference*.

This framing for deliberation and difference was attempted in four key ways. First, we took a multidisciplinary approach to the issue of biobanking, and combined extensive literature reviews with ethnographic methods at the research stage. Much of the bioethics literature has tended to focus on informed consent or the inadequacy of the concept (Merz, McGee, and Sankar 2000, O’Neill 2001, Williams and Schroeder 2004). Alternatively, it has focused on the challenges of community consultation (Chadwick 2001, Kaye 2004) and international harmonization of regulations and practice (Joly and Knoppers 2006). We drew from a wider literature that challenges hegemonic assumptions underpinning genomics research itself, including critiques of racial typology used in biobanking (Lee, Mountain, and Koenig 2001, Lock 2005, Rabinow and Rose 2006), the ‘medical’ and ‘enhancement’ models of health used by proponents of genomics (Wolbring 2005), and the individualist and sometimes bio-colonial practice of biomedical research (Harry, Howard, and Shelton 2000b, RAFI 1997). We drew from literature on benefit-sharing and from Science and Technology Studies, as well as the ethical, legal and scientific literature.

This wide review informed the structure of the event, the information we provided to participants, and the experts we invited to participate. I also carried out face-to-face and telephone interviews (with biobankers and genomics researchers, indigenous peoples, and disability activists), attended BC Biolibrary team meetings, and made site visits to observe the biobanking process in pathology labs at both St Paul’s Hospital and Vancouver General Hospital in Vancouver. Another team member carried out a series of interviews with patient advocates. The principal investigator on the project, Mike Burgess, consulted a variety of stakeholders in the process of recruiting expert presenters. Insights

gained from these interviews, visits, and informal consultations fed into the design of our participant information and event structure.

Second, we embraced the potential of multiple media and aimed to facilitate dialogue rather than one-way dissemination of information. The team produced a participant information booklet containing: an introduction to biobanking; an overview of scientific, indigenous, race, disability and religious perspectives; an introduction to the regulatory context, informed consent and property rights; and a glossary of technical terms. This was mailed to participants prior to the event. It was also available on the project website <http://biobanktalk.ca>. An annotated bibliography of useful and easily-digestible further information – academic papers and journalistic pieces – was made available on the website and at the event itself. One team member produced a model biobank out of Lego© - to illustrate the biobanking process visually and contextually. I created a private participant blog (and the public website) using Wordpress, to allow participants to raise new issues and questions during and between weekends, and after the event. As a team we also selected five experts to speak on the first day of the deliberative event – a biobanker, a disability spokeswoman, an indigenous spokeswoman, a bioethicist, and a legal specialist.

Third, we developed a recruitment strategy that enabled diversity of participation from around BC. After extensive thought, we elected to recruit participants from each of the BC health regions, and from among those typically absent from consultative events (for example, members of First Nations, the disability community and the unemployed) (Longstaff and Burgess 2007). BC residents were subject to random digit dialing, and recruited to fill stratification for ethnicity, religion, occupational group and gender. The final 22 participants included: members of the Chinese, Ukranian, Indian, German, and Filipino communities; those with Sikh, Catholic, Muslim, Christian, Buddhist and Atheist affiliations; those with and without high school education; four individuals reporting chronic disability and eight who reported risks of inherited diseases; those who worked in business, engineering, trades, the public sector, and those who were retired or unable to work.

Finally, the event was structured to explore the issue of biobanking in depth, to draw from the widest range of perspectives and personal experiences, to facilitate genuine deliberation, and to encourage disagreement as well as consensus. The first weekend was designed as an information sharing phase. Introductions and expert presentations filled the first day. On the second day, participants were asked to explore and listen to each others' 'hopes and concerns for biobanking in BC'. They were divided into three small groups of seven or

eight for the majority of the deliberation, to promote participation and respectful engagement. A 12-day break between weekends encouraged people to talk to friends and family and reconsider biobanking in the context of their own lives. On the second weekend, the small groups were each asked to ‘design a BC biobank’. This task encouraged creativity beyond constraints of the existing regulatory context. Throughout the event, we encouraged challenge to the most fundamental givens within biomedicine and allowed space for the response that biobanking should be abandoned, as well as space for concrete design solutions.

How successful were these attempts to frame for deliberation and difference? The remainder of this paper will tackle this question through a focus on the deliberations in one of the three small groups – the one that I facilitated – during the second day of the first weekend. Drawing from ethnographic observation and analysis of audio recording transcripts<sup>13</sup>, paying particular attention to narrative, I argue that participants insistently questioned the framing of the event. Drawing from personal experiences, analogies, news stories, and fictional events, the deliberants developed and embellished the figure of a ‘mad scientist’ to challenge certainties promised by scientific, legal, and ethical expertise. Not only did they raise questions that we as a team anticipated, the participants also questioned assumptions embedded within our own framing of this event. They challenged the assumption that science can be governed. They challenged the assumption that citizens care what happens to their tissue and personal information and that they are interested in democratizing science. They challenged the assumption that provincial governance is of any use at all.

### **The emergent character of the mad scientist**

The second day of this event was intended to elicit participants’ key hopes and concerns for biobanking in BC. In each group, participants were asked to write down as many hopes and concerns they could think of, each one on a different post-it note. They were then asked to read out their top hope and their top concern and to stick them on the wall. The rest of the day was spent deliberating over these hopes and concerns, one by one, as a group. The day was also intended as an opportunity for the ‘forming, norming and storming’ (Tuckman 1965) stages of group development (prior to ‘performing’) within the small groups.<sup>14</sup> As Young (1996) has argued, greeting, rhetoric and storytelling

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<sup>13</sup> All participant names have been replaced with pseudonyms. The facilitator’s name has not been replaced and is distinguished by bold text.

<sup>14</sup> Tuckman (1965) proposed a four-stage model of small group development: ‘forming’ (comprised of orientation and testing of boundaries), ‘storming’ (characterised by conflict and

can contribute to political discussion. As a facilitator, I encouraged participants to draw from their own experiences to explain their hopes and concerns. I did not arrest or divert conversation when it moved seemingly off the topic of biobanks, as a wealth of previous research has illustrated the critical potency of seemingly tangential narratives to issues as diverse as nuclear power in Britain (Wynne 2008), life in the Yukon (Cruikshank 2000), and global warming (Cruikshank 2005).

Participants' initial hopes included: the availability of medical breakthroughs to poorer countries", "that biobanks move towards universal biolibrary concepts", "what I can get out of it health-wise", "ideas that make consent benefit researchers and protect donors", "to inform other people", "potential medical advances and breakthroughs, new cures, new medicines and new procedures", "sharing info between different biobanks for research purposes" and "science and research advancement". Their top concerns were: "mad scientists", "information access for personal gain", "how it can hurt me", "privacy issues", "genetic modification", and "the waiver of consent for different research".

The idea of the 'mad scientist' was introduced in the first hour of deliberation by one participant. Shortly into the discussion around the first hope (that consent could benefit both researchers and donors), two participants raised concerns about military and other researchers overstepping whatever limits or regulations are introduced. When asked to explain the second topic for discussion – a concern about genetic modification – another participant explained this as a fear of scientists doing to humans what they have already done to genetically modified (GM) crops:

AMAR: I think now that should be a problem for everybody. In essence they're kind of playing God. They take the best of everything, splice it together, and you have a superhuman or whatever.

RUTH: And cloning.

AMAR: Yeah, well, I'm sure they've already tried cloning. There was that one scientist, I don't know what his name was, but he said he was going to have – he was going to clone a

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polarisation around interpersonal issues), 'norming' (in which resistance is overcome, new roles and standards are adopted and intimate personal opinions are expressed), and 'performing' (when structural issues have been resolved and group energy can be channelled into a task). This model remains popular amongst trainers and facilitators working in corporate team building, and various forms of participatory, dialogue-based, and deliberative projects.

human by a certain time, and some say he's already done it and some say he hasn't, and there's a big ethics and moral issue about that right now. So I do see that happening in the future.

When deliberating about the fourth topic – a hope for science and research advancement – participants soon moved from hopes of new drugs to concerns about the advancement of science. These included concerns about designer babies “getting away from nature”, prolonging life without quality of care, discrimination, and science out of control:

SUSAN: Another thing too is for the science, what if they created a new disease?

**HEATHER:** Right.

SUSAN: Then it gets out.

From the beginning, members of this group saw their role as a questioning one. When asked how they would contribute, one participant replied “by asking searching questions”, another challenged the pro-biobanking focus of the day, and another declared that she intended to “ask intelligent questions”. As deliberation progressed, they drew attention to the world of unforeseen consequences, to future unknowns, to the potential for dodgy dealing, to the limits of governance and regulation. They posed repeated challenges to the certainties promised by science, law, and ethics.

The character of the mad scientist was fundamental to this questioning. From the beginning when the mad scientist was introduced as a concern penned on a post-it note, through to the end of the day when the group performed their discussion to the large group through a role-play, the deviant scientist was a central character. The character was taken up and embellished by everyone in the group during the day. They used the mad scientist to think through and challenge the limits of hopes and concerns for biobanking. They elaborated on this character through stories – stories of personal experience, stories of past news events, analogous stories, and stories from fictional events.

One participant told a story about GM grain in India to explain a concern that human variety could be similarly diminished by genetic research. Another participant talked about the production of infertile bananas. Seemingly off-topic bananas and grain served as analogies, providing evidence to critique the idea that scientific advancements, and therefore research using biobanks, will necessarily have positive consequences:

LISA: Well, that's just it. I guess when they genetically modify us are they going to – you know, modify super-humans who aren't able to reproduce and are just used for the Olympics, or you know, or whatever, right?

Sometimes this questioning acknowledged that even the best-intentioned science could have unforeseen negative effects. The most revered and respected of scientific figures have participated in a chain of development with tragic consequences:

CHRISTINA: But even then, good science can go bad.

LISA: Oh, totally.

CHRISTINA: So - Einstein, atom bomb.

Other times, media references were used to argue for the 'mad scientist' as a figure with devilish intentions:

JERRY: They'll hold the world hostage like Dr. Strangelove or something. Or what's that guy? Goldfinger.

LISA: Dr. Evil.

JERRY: Yeah, Dr. Evil. Or withholding cures. We invented this and unless you give us a ton of money or what we want....

Other times, participants created possible future scenarios to argue for the potential of error in research using biobanks:

KLAAS: But then I think a bigger problem is going to be some kind of pandemic that hits the – you know, if somebody makes a mistake and drops a few vials in the wrong place and...

While facilitating this discussion, I was aware that the conversation leapt beyond all boundaries we had instituted. It felt like however concretely we explained biobanking, the participants responded with fiction and fantasy, with crazy and creative ideas and scenarios, with deeply personal stories, humor, and shocking images. One participant spoke about her experience of abortion as an immigrant to Canada, another about her son's rare hip disease, another about her two sisters with epilepsy. Another participant created a scenario in which he had been run over by a car and had a badly damaged leg – to argue his point. Rereading the transcripts these vivid images of infertile super humans, of deadly viruses, of designer babies, clones, and evil scientists holding the world to



ransom, the stories of family illness and vulnerability, they flash on and on, insistently, throughout the deliberation - a surreal montage.

For Walter Benjamin (1982), montage was the key to cultural critique and to a critical form of writing. Juxtaposed side by side, objects, images and narratives spark new understandings, “combining shock with critical distance” (Taussig 2004). There is a thin but powerful strand of anthropology that views Benjamin as a pioneering ethnographer, offering “an alternative track for anthropology ... storytelling with a modernist curve” (Taussig 2004:313-314). It is a track that anthropologists such as Michael Taussig have trodden with great effect. In *My Cocaine Museum*, Taussig presents an ethnography of gold mining and cocaine production in the rainforest of Colombia’s Pacific Coast – structured as a montage of artifacts in an imaginary Cocaine Museum. His museum parodies the existing Gold Museum in Colombia’s Central Bank, a museum that makes no reference to the African slaves who worked the gold mines for around 400 years (Taussig 2004).

This alternative track for anthropology is ripe with potential for the analysis of deliberation. Read alongside the montage of participants’ recollections, fictions, and fantasy scenarios - the vivid images of infertile super humans, of deadly viruses, of designer babies, clones and evil scientists I have just outlined – Taussig’s montage alerts us to their potential to enact a similar critique. The artifacts Taussig places in his imaginary ‘museum’ work to expose the fetishes, transgression, and injustice that official Columbian history erases. So the deliberants’ stories of GM grain, infertile bananas and the atom bomb expose the past failures of scientific ‘progress’ unmentioned by those promoting the benefits of biobanks and health research. Images of past failures, stories of ‘good’ science going ‘bad’: they enable a vivid, visual questioning of the consequences of biobanking for humanity.

Drawing upon the works of Benjamin and Taussig, Kathleen Stewart (1996:3) writes about a very ‘Other’ America, a place in the coal-mining region of southwestern West Virginia that does not fit within the common story of America – the “story of the West versus the rest, of capitalism and modernization, of individualism, materialism, education, reason, democracy”. Stewart’s ethnography, *A Space on the Side of the Road*, also points to the possibility for narrative itself to “fashion a gap in the order of things – a gap in which there is ‘room for manoeuvre’” (1996:3). For Stewart, it is not merely a matter of using the technique of montage to perform critique in ethnographic writing like Taussig does. She detects this critique in her ‘informants’ narratives too. Stewart describes a place in which the residents often tell stories to “bear witness” rather than to

explain, in which local culture is a constant process of storytelling and questioning. She describes a place in which residents roam the hills, stumbling upon objects that stimulate rich stories of past events – stories that enact a direct critique of progress and of the irrational laws of the state.

These images thrown out insistently by our deliberating participants, perhaps they function something like Benjamin's dialectical image: arresting "the progress of ideology with a defamiliarising shock of disjuncture" (Stewart 1996:26) and drawing strange comparisons to challenge the narrative of science as progress? These are stories of science betraying its promise – of bananas that cannot reproduce, of unsustainable GM grain cultivation, of Lisa's son whose hip disease is too rare to generate interest or funding, of the potential origin of AIDS, of the atom bomb. Just like Benjamin's unfinished Arcades Project, in which, "nineteenth-century objects were to be made visible as the origin of the present, at the same time that every assumption of progress was to be scrupulously rejected" (Buck-Morss 1991:218), these stories provide testimony of the co-construction, progress if you will, of science and humanity together, through a series of accidents and errors. Just like the tales told by Stewart's (1996) informants as they wander the hills, these stories question that the present is, or that the future will be, any different.

These stories testify to the historical continuity of the salvation narrative of science, and challenge the notion that progress has been achieved. Some of these stories move beyond Benjamin's concern with the past. They tell of fictional potential futures, stories of the 'what if' variety, stories of designer babies, clones and power-hungry scientists. Genomics funding and the research agenda is driven by speculation, by promise, by fictions of anticipated translations of research into clinical applications. This has been characterized as an "economy of hope" in which, "the hope for the innovation that will treat or cure stimulates the circuits of investment" (Rose 2007:27). Critique of science as utopian culture wisely draws tools for combat from the dystopian genre then, from the economy of fear. Participants use imaginings of disaster to crack the dream.

### **Participant challenges to the deliberative frame**

Is the body a legitimate resource for medical research? Will the BC Biobank facilitate access to tissue and data for *all* BC researchers, or privilege those working in certain research disciplines and geographical areas? Who will profit? Does the proposal privilege a certain type of biological material (e.g. those obtained during surgery and autopsy) and how will this impact upon the design and outcomes of subsequent research projects? Will research projects using this

BioLibrary target diseases of the rich or of southern nations? Will genomics research be more effective than similar investment in education or social programmes? These are just some of the questions I listed in draft papers and in fieldwork notes during the design phase of this deliberative event – questions that seemed to be fundamental to genuine deliberation, questions that challenged the frame of biomedicine and traditional solutions of biomedical ethics.

Our attempts to frame-for-difference and to allow challenge to hegemony were reasonably successful. One participant raised the issue of “availability of medical breakthroughs to poorer countries” as an initial post-it concern. A First Nations participant questioned the legitimacy of bodies as resources for research, explaining the concerns of her community elders:

SUSAN: ...their worry is when I do die, my grandkids will be born with a defective heart or something, because I gave away something of me.

Another participant raised a direct challenge to the enhancement model of health, during a discussion about genetic modification:

LISA: ...and I don't think people should have only good DNA.

JERRY: Like Brave New World.

LISA: You know, like, I think that our flaws are what makes us....

Some of the more complex questions – such as the impact of BC Biolibrary design upon outcomes of research projects – were not raised or addressed.

More importantly, many questions that I did *not* list were raised. As a team, we deliberately framed the event in as open a manner as possible and tried to challenge assumptions inherent within the biobanking agenda. But our frames contained embedded assumptions too – as every framing of every event will inevitably do. Attention to the participants' narratives during this event reveals how insistently and radically they used the figure of the mad scientist, and other figures, other images, other stories to challenge our most fundamental assumptions. They challenged the assumption that science can be governed. They challenged the assumption that citizens care what happens to their tissue and personal information and that they are interested in democratizing science. They challenged the assumption that provincial governance is of any use at all.

“Who’s regulating the doctor?” asked Jerry, questioning the notion that individual informed consent will change what kind of research gets done. “But as long as there is a government, like, and I’m sure the States does it and other countries are doing it, and they are going to do that kind of research and it’s going to happen, right?” asked Klaas, challenging the idea that any government would pass or heed legislation that didn’t suit their needs. That’s what gets me kind of confused because we’re setting like, limits supposedly, but there’s always going to be somebody who’s going to do that whether we like it or not,” argued Jerry again. Enter the mad scientist – the ultimate personification of the inability to fully control biobanking through any governance mechanisms.

The issue of how to organize consent so that it benefited both researchers and donors was a recurrent theme throughout the day. At one point, participants began to question the very idea they were working with – that members of the public cared what happened to their biological specimens and data:

AMAR: Like say I’m in a car accident. I lose my limb. Say I lose my leg.

KLAAS: Yeah.

AMAR: It’s all mangled up or whatever.

KLAAS: Yeah.

AMAR: I don’t really care what happens to it. Take my tissues. I’m not going to ask, “Can I have my leg back?”

Others reiterated this, suggesting that people often do not care - because they trust the professionals:

MALIKA: I had an abortion in B.C. Women’s Hospital and that time they asked me to sign a consent for the body tissues to be done. I don’t know what exactly they’re asking because we recently – at that time we were just moved to Canada, I signed it and I don’t know what is going on with my – whatever it is. But I don’t – I don’t care, like they are using it in research or any other purpose. Like it just....

KLAAS: If you’ve just been hit by a truck you’re not going to ask your questions.

LISA: Well, I think you have to sometimes just have faith in...

MALIKA: The profession.

One participant suggested that members of the public are too busy with their lives to care about the ethics of biobanking, or to want to be involved:

AMAR: It's like the general public, like when you sign an organ donor card or whatever and you sign it and go – people are busy. They do whatever they need to do during their day. They're not going to sit and think about the ethics of biobanking. Right?

**HEATHER:** Yeah.

MALIKA: Most of us, yeah, definitely.

AMAR: Yeah. You've got to take your kids to soccer practice or whatever.

When asked why they had all shown up to deliberate, the participants conceded that they had been interested to take part, that the promise of 100 dollars per day was not the sole motivator. They did not argue that public involvement in the governance of biobanking was a bad idea; on the contrary, they agreed later in the deliberation that it was a good idea. They simply challenged and deliberated over the *assumption* that it was necessarily something the average member of the 'public' wanted.

Finally, there were several challenges to the geographical frame of the deliberation. Linked with the Biolibrary proposal for British Columbia, in a country where provincial government plays an important role, we framed this event accordingly and drew participants from each of the health regions in BC. The task they were given during the second weekend: to 'design a BC Biobank'. Implicit within this framing, perhaps, is an assumption that provincial biobank governance is a worthwhile and achievable goal. The participants challenged this early on in their deliberations. A hope that biobanks will lead to cures for disease led to consideration of the value of sharing samples globally:

LISA: If there were experts all over the world with the access, it's going to hopefully provide more and different cures for different things...

The participants asked whether enhancing access to biobank materials within BC was enough. Russia, India and China were cited as nations that may be doing interesting work of benefit to the BC community. And the mad scientist re-emerged again – to question the utility of provincial governance, and even national governance:

AMAR: Who regulates the so-called mad scientists in different countries? Like, say, we have a board of ethics here in North

America and Europe. What about Russia? Pakistan? Afghanistan?

And again:

AMAR: Like I'm just saying they should have governing bodies. For example the nuclear energy or the nuclear --- I mean, it's well known Pakistan sold secrets to North Korea, Iran, Syria. So there are all those mad scientists that can and will sell genetic information and all that stuff to people who want it for malicious purposes.

The solution: a "United Nations for Biobanks", suggested by Amar.

Examples of science that escaped regulation in the past, an imaginary car crash scenario, one woman's story of signing a consent form during an abortion, and analogies with the development of nuclear weapons and the governance model of the United Nations – all served to insistently question the assumptions underlying this deliberative event. The participants raised many insightful questions that we hoped they might raise – questions that challenged the frame of biomedicine and the traditional solutions of biomedical ethics. They also raised many questions that we did not anticipate – questions about whether science can be governed, whether citizens really want to participate in 'democratizing science', and whether provincial biobank governance has much utility. All of these questions challenged the framing of this biobank deliberation.

This participant questioning of the deliberative frame stands, then, in direct opposition to the critiques of deliberative public engagement summarized at the beginning of this paper. Unlike those in the 1996 New Zealand consensus conference on plant biotechnology (Goven 2003), these participants did succeed in problematizing expert assumptions. Narrowly framed questions (Irwin 2001), a positively framed account of technology (MacNaghten, Kearnes, and Wynne 2005), and technocratic frames (Kerr, Cunningham-Burley, and Tutton 2007) did not radically endanger this event – because participants were visibly able to challenge those frames that did exist. Open framing for deliberation and difference enabled the expression of minority perspectives and impassioned talk (Sanders 1997) and challenges to hegemonic discourses (Young 2001).

**Conclusion: how attention to stories can help a deliberative event 'listen'**

For the organizers of this deliberation, given the inevitability of some unreflexive event framing, this early insistent questioning is undeniably positive. The participants' challenges testify to the design of an open task and porous event frame. They reveal genuine deliberation in which diverse individuals brought their own knowledge, life experiences and thought processes to bear upon the subject, and were not overly 'shaped' or 'directed'. They reveal that, contrary to the gloomy predictions of many critics within social and political science, deliberation can enable participants to challenge hegemonic assumptions surrounding the promise of new technologies such as biobanking. These challenges also contributed to the trustworthiness and accountability of the deliberative process.

In her high-profile BBC Reith lectures of 2002, British philosopher and Parliamentarian Onora O'Neill (2002) presented a model of trust as built through *critical interrogation* and of accountability as a process of being *open to question*. Drawing upon this model in their ethnography of preimplantation genetic diagnosis (PGD) in the UK, Sarah Franklin and Celia Roberts (2006) argued that clinicians' acknowledgement of uncertainty, their skepticism towards positive outcomes, and their openness to patient questioning throughout the PGD process actually generated a greater trust and confidence in the process than any assertion of certainty could have done. I argue that the space given for participant questioning of assumptions during this deliberative public consultation had a similar effect. Insistent questioning of the framing of the deliberative process contributed to a more robust and accountable process. It also contributed to participant trust.

The remaining question of course, is how well did this event listen? How well were these questions translated into the outcomes of this deliberation on biobanking in BC? Did they make it out of this one small group room? If not, do they contribute simply to an illusory accountability – enhancing participant trust in a process whose outcomes do not do justice to such trust? Returning to the story of the origin of AIDS that opened this paper, I confess that as a facilitator, I did often find it difficult to capture or translate participants narrative questions into the 'reasons', 'agreements', 'disagreements', and 'trade-offs' I was required to document. The mad scientists, the infertile superhumans, the UN for biobanks all made it onto my flip chart sheets. But they did not feature explicitly within the concise and pragmatic recommendations the small group ultimately suggested and later ratified in the form of a small group report.

On the one hand, it seems important to understand many of these frame-bending questions as part of the process of deliberation, and not as outcomes. The

fact that the enhancement model of health, the individualized framing of informed consent, and the utility of provincial governance were questioned and challenged by participants is essential to the legitimacy and accountability of the deliberative process. This questioning also had a huge influence on the design process during their second weekend of deliberation. Final recommendations from this group for a BC Biobank included research access fees, some of which should be invested in rare diseases, and a governing body with a tiered review system (Burgess and O'Doherty 2007). These directly address the problems of two key questions raised during the first weekend: what research gets funded and how to control deviant scientists. To an extent, many of these questions and concerns simply needed to be raised and their implications for governance worked through. They tended not to over-ride other hopes within the group, such as those for better networking of biobanks and the resulting development of better treatments for disease.

Nonetheless, I also argue that the insistence and sometimes vehemence of this questioning process should not be overlooked. It is important for the legitimacy and accountability of the deliberative process that participant questions to the deliberative frame become part of the *outcomes* as well as the *process* of this and other such events. It is important to record questioning that may have been quelled by the concrete task of the second weekend of this event.<sup>15</sup> Researcher-produced analysis – in forms such as that performed by this paper – is therefore a valuable supplement to participant-produced reports. Ethnographic analysis, combining real-time observation of and participation in the process of deliberation with retrospective analysis of audio transcripts, is a valuable tool for those practicing and researching deliberative democracy. Ethnographic attention to story – to narrative form and strategy, and the dialectical images of Walter Benjamin – can be especially revealing.

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<sup>15</sup> In an ideal world, initial analysis would be carried out between weekends during an event like this. In reality however, the process of transcription, coding, repeated reading of transcripts, and thoughtful analysis in relation to theory is a time-consuming endeavour that cannot be achieved within a two-week time-frame.



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