

DOES “MISINFORMATION” MATTER?  
EXPLORING THE ROLES OF TECHNICAL AND CONCEPTUAL  
INACCURACIES IN A DELIBERATIVE PUBLIC ENGAGEMENT ON  
BIOBANKS

by

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## **Abstract**

Science is increasingly affecting populations across the globe, and individuals and communities are growing more and more aware of the possible benefits and harms created by new technologies and changes in related policies. Prompted by inadequacies in representation, legitimacy, and trust, there is a need to increase public involvement in decisions regarding the development and implementation of science and technology. Due to claims that the public lacks the necessary knowledge to participate in these democratic processes, this thesis explores whether or not the presence of misinformation during deliberation undermines the usefulness of engaging publics for policy advice.

The BC Biobank Deliberation brought together twenty-one individuals from across the province to explore the values and interests that ought to guide the governance of biobanks (repositories of annotated human biological materials often used as resources for research), and to test and evaluate a model for involving diverse publics in policy-making. As information related to biobanks is challenging to capture and disseminate, technical inaccuracies – those resulting from factual scientific or social information related to biobanking – and conceptual inaccuracies – those resulting from information considered to be outside the scope of biobanking, such as linking activities which are not facilitated by the existence of biobanks, to biobanks (e.g. cloning) – arose during deliberations.

The analysis of this misinformation in the BC Biobank Deliberation seems to indicate that technical and conceptual inaccuracies play four main roles in deliberation: 1) no effect; 2) stall; 3) distraction; and 4) development. In general, when an overview of the scientific and social information related to the topic is provided during an engagement activity, participants who had little or no knowledge of the subject prior to being informed were able to deliberate on a variety of issues related to biobank governance. Findings indicate that in certain instances misinformation may help to develop deliberation, moving participants towards decision points related to biobank governance. This helps to show that scientific knowledge is not necessarily a prerequisite to participating in decision-making processes.

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## 1.0 Introduction

The switch from natural to social sciences was a challenging and rewarding transition. I was looking to exit the laboratory and to apply my evolving knowledge to understanding and tackling global, science-based problems. The interdisciplinary path I chose in applied ethics allowed me to combine my training in genetics with expertise in philosophy and political science. Studying public engagement on societal issues arising from genomic applications also provided me with new perspective. Admittedly, I began this program with preconceived ideas about “the public” and its limited understanding of science, wanting to find new ways to communicate complex scientific information to a variety of people. Now, after shedding my scientific shroud, I have joined others who advocate that inexpert publics are capable of being involved in policy formation and, more importantly, are integral to the process.

As a member of the Face-to-Face research team at the W. Maurice Young Centre for Applied Ethics, whose collaborative efforts culminated in the British Columbia (BC) Biobank Deliberation, I have come to recognise the importance of engaging diverse publics in decision-making processes. This eye-opening experience is based on my introduction to interdisciplinary studies, my interactions with colleagues, collaborators, stakeholders, and participants, and my involvement in the BC Biobank Deliberation.

After seven months of preparation, the BC Biobank Deliberation took place over two weekends in April and May 2007 (Burgess, O’Doherty, & Secko, 2008). Twenty-one participants engaged in large and small group deliberations to explore the values and interests that ought to guide the governance of biobanks,<sup>1</sup> and to test a model for public involvement in

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<sup>1</sup> Biobanks are herein described as repositories of annotated human biological materials often used as resources for research. Biobank research refers to studies that draw on these resources by using samples stored in one or more biobanks. Biobanking combines these definitions to refer to the collection, storage, and study of samples and associated information. Biobanks are discussed further in section 2.2.

policy-making. As with many topics, the technical and social information related to biobanking is difficult to capture and disseminate, as well as to understand and deliberate. These challenges may cause information that appears technically or conceptually inaccurate to arise during deliberations and it is unclear how this “misinformation” affects public engagement processes and outcomes. Does the presence of misinformation undermine the usefulness of deliberative public engagement for policy advice? Drawing from evidence from the BC Biobank Deliberation and from my involvement in the design, preparation, execution, and analysis of this event, I identify and assess four potential roles of misinformation to help answer this research question.

Technical inaccuracies – those resulting from factual scientific or social information related to biobanking – and conceptual inaccuracies – those resulting from information considered to be outside the scope of biobanking, such as linking activities which are not facilitated by the existence of biobanks, to biobanks (e.g. cloning) – seemed to play four main roles in deliberation. Technical inaccuracies that were not discussed by participants seemed to have little or no effect on deliberation. Technical and conceptual inaccuracies that were discussed by participants seemed to stall, distract, or help develop deliberation. Stalls occurred when participants lacked, and occasionally requested, information necessary to continue deliberation on a particular issue, and deliberation on that issue ceased. Distractions occurred when misinformation prompted further inaccuracies instead of raising issues related to biobank governance, and caused deliberation to move away from decision points. Developments occurred when misinformation was corrected via deliberation or when, regardless of its inaccuracy, misinformation enabled participants to illustrate key reasons for their preferences in regard to biobank governance.



Before examining these results and their significance, Chapter 2 provides an overview of the literature in five areas relevant to this discussion: information, biobanking, public understanding of science, deliberative democracy, and public engagement. Chapter 3 describes the BC Biobank Deliberation, the source of the data that inspired me to ask about the effects of misinformation on deliberation, and the methods used to answer this question. Chapter 4 presents and analyses the data, and Chapter 5 discusses the findings and their implications. Chapter 6 extrapolates the results to other topics of public engagement and concludes with possible areas for future research.

## 2.0 Literature review

With the quickening pace of scientific and technological advancement over the past century, emerging risks with unknown variables are becoming increasingly complicated and are rapidly outpacing regulations set to manage them. At the same time, the ability to instantaneously transfer information via a growing network of communication pathways has led to an overwhelming amount of available information on nearly any topic. Combined, the unidentifiable future outcomes, elapsing timelines, and glut of information have contributed to the complexities of decisions and their associated decision-making processes.

These complexities are further compounded by problems with democratic decision-making processes. Important issues cross borders and populations grow and disperse, but they continue to be artificially bound by fixed territoriality and subject to decisions that are largely influenced by market and interest group pressures as opposed to individual preferences (Urbinati & Warren, 2008). Voting, the main existing mechanism for people to express their opinions, has shown a continued decline in Canada's turnout since 1988 (Johnston, Matthews, & Bittner, 2006), and criticisms of "first past the post" (FPTP) electoral systems in Canada and the United States characterise the FPTP system as undemocratic (Milner, 2005). Lastly, although decision-makers are increasingly seeking public opinion, it tends to be trumped by expert knowledge which is regarded as having greater authority (Young & Matthews, 2007). Real and perceived insufficiencies in representation and other aspects of democratic decision-making processes lead to decreased trust and legitimacy. These failings may cause costly controversy in many areas including science and technology, examples of which are discussed later and include crises related to bovine spongiform encephalopathy (BSE) and genetically-modified (GM) foods. These problems call for justifiable mechanisms to help inform and involve individuals and

communities before, during, and after the development and implementation of new technologies and policies. These mechanisms help to minimise conflict and maximise acceptance of decisions by understanding and accounting for divergent public perspectives in the development and implementation of science and technology. These mechanisms also help to increase the legitimacy of, and to promote public trust in, decision-making processes and their outcomes. Deliberative public engagement is one of these mechanisms.

This chapter reviews literature from five areas: 2.1) information; 2.2) biobanking; 2.3) public understanding of science; 2.4) deliberative democracy; and 2.5) public engagement and participation methodologies. Exploring these topics helps to illustrate how the different theories and practical approaches of public engagement draw from multiple disciplines, and provides a background from which to assess the roles of misinformation in deliberation. The amount of literature and subject matter for each area is significant; this chapter summarises the most important aspects of the relevant areas and provides references in which more in-depth discussions of the issues can be found.

## **2.1 Information**

Data, information, and knowledge are three of several related concepts. Data refers to “a set of discrete, objective facts about events,” has no context, meaning, or purpose, and can generally be stored in hardcopy or softcopy using some form of technology (Davenport & Prusak, 1998, pp. 2-3). Information is defined as a message between a sender and receiver that has meaning, and functions to influence the receiver’s perception, judgment, or behaviour. Knowledge is more broadly described as “a fluid mix of framed experience, values, contextual information, and expert insight that provides a framework for evaluating and incorporating new experiences and information” (Davenport & Prusak, 1998, p. 5). Knowledge helps to convert data into

information and information into knowledge; it is an exercise in judgment and interpretation based on experience (Alvesson, 2004, p. 43). The remainder of this section focuses on information and sets up the later analysis of misinformation and its roles in deliberative public engagement activities. The application and acquisition of knowledge in these activities is discussed in relation to deliberative democracy in section 2.4.

Information can be analysed in terms of how, what, and why information is sent. ‘How’ refers to the medium by which information is exchanged. Information can be passed from person to person (Horlick-Jones, Rowe, & Walls, 2007) and is carried by mediums including “pictures, drawings, photographs, plans, blueprints and graphs, spoken and written languages, gestures, hand signals and other non-verbal behavior, genes and DNA, electro-magnetic and sound waves, mechanical and electro-mechanical devices, records, tapes, films, holographs and video-disks” (Fox, 1983, p. 7). ‘What’ refers to the content of the information, and ‘why’ refers to the purpose. The content and purpose of information are important in this discussion. The content can be analysed in terms of its technical accuracy according to currently accepted factual scientific and social information, and of its conceptual accuracy according to the scope of the information being exchanged. The content is therefore important in distinguishing information and its corollary, “misinformation,” where the latter’s content is herein characterised by technical or conceptual inaccuracy. The purpose directs or causes the action following the exchange of information, and can be analysed in terms of its outcome or function. The analysis of the content and purpose is therefore important in distinguishing information from “misinformation” and in understanding the roles misinformation plays in deliberative public engagement activities.

The purpose of information is influenced by several factors. An important factor is the orientation, or the intention, of the information. Jonathan Potter (1996) presents two orientations

of descriptions, one that influences factuality and another that causes action. First, the epistemological orientation of description considers how descriptions can be made to appear factual through the process of fact construction. Fact construction refers to “the process by which description is built up into accepted fact” (Potter, 1996, p. 121), where individuals draw on a variety of resources to discredit or support the factuality of descriptions. For example, descriptions can be discredited through “lies, delusions, mistakes, flattery, deceptions and misrepresentations”, and established through elements such as subject positioning, corroboration, and the provision of details (Potter, 1996, pp. 112-118). The action-orientation, on the other hand, considers how descriptions can be used to serve different functions, such as to perform actions. Information may be used for a certain purpose or to make a particular point during a discussion. This demonstrates how information, regardless of its accuracy, can be analysed in terms of the purpose it serves.

Potter (1996) draws from the work of John Austin (1962) who describes two types of utterances. The first type of utterance is that which states something and can be analysed in terms of its truth or falsity. For example, ‘One of the world’s largest biobanks is in Iceland’ is true, whereas ‘There are no biobanks in Canada’ is false since, based out of l’Université de Montréal in Quebec, CARTaGENE is a resource for populations genomic research. The second type of utterance is that which does something and can be assessed for its action rather than its accuracy (Potter, 1996, pp. 202-203). For example, a statement such as ‘Biobanks will be used to create biological weapons’ may function to relay fear related to the unknown. This example gives voice to an uncertainty associated with biobanking and acts to move the discussion in a particular direction. Potter (1996, p. 204) indicates that when a statement is used to convey a certain meaning, participants are more concerned with addressing the meaning, or “what is being

done with [the statement],” rather than the accuracy of the statement. By favouring the purpose, the action performed by the information may at times be more important than the accuracy of the information itself.

These concepts can be illustrated using an example from O’Doherty and LeCouteur (2007). In their examination of descriptions of people seeking to enter Australia as refugees, their analysis of the social categorisation of refugees using labels such as “illegal immigrants”, “asylum-seekers”, and “boat people” draws from both orientations of description. From the epistemological orientation, they indicate that while each term might appear factual, none of these labels are a complete description of the subject population, thereby making each description inaccurate. For example, “‘boat people’ would seemingly refer to anyone... who arrived by boat, but not to those who arrived by plane” (p. 5). From the action orientation, which examines the purpose of discourse and how it is achieved, they indicate how, for example, the term “illegal immigrants” emphasises the viewpoint that these individuals should be deported since “people who are in a place illegally have, by definition, no legal right to be there” (p. 6). In this way, although a statement may be inaccurate based on facts, completeness, or context, the statement may still serve a purpose, such as to emphasise a particular viewpoint.

These distinctions allow the content of information to be analysed in terms of accuracy, and the purpose in terms of the action information performs. The content and purpose are therefore important in the analysis of the roles of misinformation in deliberative public engagement activities. The following section looks at some of the information used in the BC Biobank Deliberation, providing an overview of biobanking and the ethical issues that must be addressed through the governance of biobanks.

## **2.2 Biobanking**

Biobanks are repositories of annotated human biological materials. Often used as resources for medical research, these collections can be used to discover genetic, lifestyle, and environmental causes of health conditions, as well as to develop new and improved treatments for and forms of prevention against them. Samples may be stored for short or long terms, depending on the type of sample and the specifications of the research projects. Over time, advancements in biotechnology and medicine may call for new, initially unspecified research on stored samples. While the potential benefits may be high, the possible ethical, legal, and social problems associated with biobanking and the secondary use of biological materials, discussed below, may result in negative outcomes for individuals and communities. People who may be affected by biobanks ought to therefore be engaged in decision-making processes related to the development of biobanks. This section overviews biobanks, the governance of biobanks, and the potential ethical issues governance must address.

Human biological samples have been gathered into repositories at least since the use of tissues and cadavers in research and training was established by the medical profession (Nelkin & Andrews, 1998, as cited in Burgess & Tansey, 2008). Certain national institutions have extensive DNA databases built for specific purposes other than research. For example, the United States military includes DNA information in service personnel files, and the Canadian police created the National DNA Data Bank, which consists of genetic data from crime scenes and particular classes of convicted offenders (Burgess & Tansey, 2008). These DNA databases have distinct uses compared with developing disease- and population-based biobanks, which contain biological samples and data related to specific medical disorders, or from an array of individuals in a given population, respectively.

Several existing and emerging biobank projects are underway across Canada. The Canadian Lifelong Health Initiative is being established by the Canadian Institutes of Health Research (CIHR) to facilitate longitudinal cohort studies across the country, such as the Canadian Longitudinal Study on Aging (<http://www.cihr-irsc.gc.ca/e/18542.html>). In Quebec, the publicly-funded CARTaGENE project aims to improve the health of Quebec residents by creating a provincial resource of data and DNA to help advance genetic research (<http://www.cartagene.qc.ca/accueil/index.asp?l=e>). Based in Newfoundland and Labrador, Newfoundland Genomics is a research and development company currently conducting four province-wide studies of complex genetic disease with donor volunteers (<http://www.newfoundgenomics.com/index.html>). In British Columbia, the BC BioLibrary facilitates access to biological samples stored in biobanks in an effort to improve access to these samples for research (<http://www.bcbioblibrary.icapture.ubc.ca/>). Many examples can also be found internationally, from large, national, population-based biobanks including deCODE's Icelandic Health Sector Database Project (<http://www.decode.com/>), the UK Biobank (<http://www.ukbiobank.ac.uk/>), and the Western Australia Genome Health Project (<http://www.genepi.org.au/projects/waghp.html>) to smaller, specialised collections in various countries.

In Canada, a patchwork of overarching federal and provincial legislation and regulation, such as the 'Privacy Act' and the 'Personal Information Protection and Electronic Documents Act' (PIPEDA), currently applies indirectly to biobanks.<sup>2,3</sup> At the local level, research ethics boards (REBs) provide primary governance and oversight, ensuring the ethical conduct of research involving humans (McDonald, 2001). At the individual level, informed consent allows each

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<sup>2</sup> For the governance context of Canadian biobanks, see Sheremeta (2003), Section 4.F, Table 16; For details of Canadian legislation applicable to biobanks, see Caulfield & Ries (2004).

<sup>3</sup> For examples of laws governing biobanks in other countries, see Maschke (2005); Kaye, Helgason, Nõmper, Sild, & Wendel (2004).



person to control the collection, storage, and study of his or her samples and information.

However, these poorly coordinated controls fail to completely address the ethical issues and implications of biobanks. Described below, these issues are related to information and consent procedures, privacy and confidentiality, communication of results, ownership and intellectual property, and benefit-sharing.

Information and consent procedures pose several problems for researchers and research participants. With historical significance acknowledged in the ‘Nuremberg Code’ and the ‘Declaration of Helsinki’, informed consent has long been respected as an ethical necessity in research involving human subjects (Boulton & Parker, 2007). Informed consent aims to enable research participants to be fully informed and to freely determine the extent of their involvement in research projects. Yet while informed consent promotes individual, autonomous choice, it also “ignores the cultural context within which the process of consent takes place” (Corrigan, 2003, p. 770). Certain views of autonomy increasingly acknowledge that “individuals only exist in interaction with and in relation to others” (Held, 2006), prompting a shift toward relational autonomy. Relational autonomy places individuals within their personal experiences and relationships and indicates how these factors alter individual capacities for autonomous action (Sherwin, 1998). Informed consent must therefore respect individual choice and collective decisions, where applicable

Biobanking also presents several unique challenges for information and consent procedures. First, biobanks, especially population-based biobanks, are predicated on the use of samples for research projects that are unknown and are therefore unable to be specified during initial informed consent procedures (Hansson, 2009). Similarly, samples that are collected for specific projects may be reused in projects that were not originally specified (Hansson, 2009). Broad or

general consent for biomedical research might therefore be more appropriate for biobanking, although some argue that this violates traditional, information-specific models of consent (Hansson, 2009). Second, biobanking may have implications for individuals, such as biological relatives, and communities, such as specific ethnic groups, who were not directly involved in biobanking (Capron, Mauron, Elger, Boggio, Ganguli-Mitra, & Biller-Andorno, 2009). In these situations, collective or group consent has been suggested in addition to individual informed consent.

Biobanking also raises ethical issues related to privacy, confidentiality, and security. Samples may contain or be directly associated with personal information (identified), be linked to personal information via a single or double code (identifiable), have been irreversibly unlinked (anonymised), or have been collected without associated personal information (anonymous) (Hansson, 2009). Identified and identifiable samples are of greatest use to biobanking since personal information, such as medical records and place of residence, can be tracked over time (Maschke, 2005). According to Hansson (2009, p. 10), “[t]he greatest potential of a biobank lies in the possibility to link genetic and biologic data to medical and personal information, and to re-contact donors in order to update this information.” If samples are identified or identifiable, it is important to safeguard the personal and medical information that is collected. Privacy, confidentiality, and security are important since genetic predisposition discovered through biobanking may cause difficulties with respect to gaining employment, or life and medical insurance, and may also provide a basis for stigmatization if research results are applicable to a particular population (Mehlman, 2004).

The communication of research results to participants is another concern. Public consultation related to the Quebec CARTaGENE project revealed that potential participants might be more

willing to donate samples for research if they would receive feedback on the findings (Godard, Marshall, & Laberge, 2007). At the same time, significant resources are required to communicate results to participants in terms of resources to re-contact participants and counsel them and their families regarding the results. Even with necessary resources, results may be open to misinterpretation which might cause undue psychological, social, and economic harm, especially if methods of treatment and prevention are not available (Helgesson, Dillner, Carlson, Bartram, & Hansson, 2007, as cited in Hansson, 2009). Whether or not research results ought to be communicated to participants remains a topic of debate.

Ownership and intellectual property issues also arise in regard to biobanks. It is generally acknowledged that property rights do not apply to the human body. At the same time, biobanks will likely result in techniques and products with commercial value and it is important to understand how these will be managed. This leads to a final ethical issue associated with biobanking, that of benefit-sharing. A wide range of benefits and services have been suggested in exchange for donating samples to biobanks or specific research projects. These include free tests and medications derived from research, a percentage of the profits, or resources for community training and development. An international study by Capron and colleagues (2009) of 42 individuals working directly with or at the policy level of biobanks demonstrated a general preference to share benefits within collectives who contributed to the research and to allow each collective to determine the nature of its benefit. At the same time, knowledge gained from biobanking is intended to benefit the wider population (Hansson, 2009), and offering benefits in exchange for participation raises concerns of exploitation (Capron et al., 2009). The following examples help to illustrate the ethical issues described above.

From 1982 to 1985, Richard H. Ward, a researcher at the University of British Columbia, collected blood samples from aboriginal peoples of the Nuu-chah-nulth First Nations of Vancouver Island, BC. Participants consented to having their samples screened for arthritis biomarkers, contributing to Health Canada-funded research into the genetics of rheumatic disease in this highly-afflicted population (Schmidt, 2001, p. A216). Unable to produce conclusive results, Ward left Canada and, without informing or obtaining further consent from the original participants, used the samples in genetic anthropology studies, researching genetic diversity and the dispersion of aboriginal peoples across the North American continent. This was of particular concern as the results could have challenged aboriginal identities and land-claim rights, due to the Beringia land bridge theory<sup>4</sup> (Wiwchar, 2005, p. 13). Additionally, Ward sent the samples to other researchers working on a variety of potentially controversial topics, particularly in aboriginal communities, including alcoholism and HIV/AIDS, again without appropriate consent (Wiwchar, 2005, p. 13).

On Canada's East coast in 1998, a team of researchers from Baylor College of Medicine spent a weekend in St. John's, Newfoundland, collecting blood from residents to study ARVC, a congenital cardiovascular disease. Instead of providing genetic counselling or treatment, relating results about risk, or allowing access to the data, these "Texas vampires" or "helicopter scientists" sent only brief 'thank-you' notes (though Baylor University eventually issued a qualified apology) (Staples, 2000). The small, genetically-isolated population of Newfoundland and Labrador makes it ideal for medical genetic research, which has occasionally occurred in the past without the knowledge, and therefore the consent, of its residents (Longtin, 2004, p. 1567).

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<sup>4</sup> The Beringia land bridge theory claims that aboriginal peoples descended from Siberian ancestors who migrated across the Bering Strait to Alaska between 15,000-33,000 years ago.

Outside of Canada, there are several examples of research using human biological materials performed without consent. In the UK and Scotland, the Bristol, Alder Hey, and McLean inquiries revealed that body parts and tissue removed from children during post mortem examinations had been retained for later examinations without consulting the parents (Skene, 2002, p. 145). In Japan, a court “auctioned off a human cell collection that a scientific society had used as collateral on a loan” in 2001 (Kaiser, 2002), raising concerns that, without regulation, a biobank could be sold to almost anybody in the advent of bankruptcy (Hansson, 2004, p. 323).

The above examples help to illustrate the ethical issues and implications associated with biobanking, including the inadequacies of current governance mechanisms such as REBs and informed consent. While additional regulations may address these concerns, they may also create barriers that restrict research. Additional regulations may also be counter-productive and remove opportunities for trusting relationships (Pettit, 1995, p. 225). Mats G. Hansson (2005, p. 415) argues that trust is essential for the success of biobank research because biobanking is dependent “upon the trust of patients and healthy persons donating blood and tissue samples.” It has been suggested that governance mechanisms which help to increase public trust in biobanks and their governance would facilitate biobanking while protecting research participants and other individuals and communities. In addition to public trust, it is equally important to increase public representation in decision-making related to biobanks. Each of these components – public trust and representation – helps to increase the legitimacy of decision-making processes and outcomes. Public trust and representation may be increased through governance supported by public engagement activities. This is discussed further in the following sections.

The ethical issues associated with biobanking help to demonstrate the need for additional mechanisms, such as deliberative public engagement activities, to facilitate the governance of biobanks. The BC Biobank Deliberation, discussed in detail in section 3.1, is one example of a deliberative public engagement that sought to understand the values that should guide biobanking. The remaining sections in this chapter explore the historical, practical, and theoretical bases for deliberative public engagement through a review of public understanding of science, deliberative democracy, and public engagement and participation methodologies.

### **2.3 Public understanding of science**

Science is increasingly affecting populations across the globe, and individuals and communities are growing more and more aware of the possible benefits and harms created by developments in technologies and changes in related policies. Experts, who are considered the primary source of information which helps to guide decision-making, are hesitant to involve a public “ignorant of science” (Levitt, 2003) in decision-making activities. As described below in reference to Shen (1975) and Miller (1996), comprehension of scientific information has long been considered an essential condition of an individual’s ability to participate in policy-making. This section examines the historical focus on scientific literacy and public understanding of science (PUS) that linked increased education with improved public attitudes towards science and technology, and arguments against this ‘deficit model’ that prompted the shift from public education to public engagement in the areas of science and technology.

Since the 1950s, the need to involve the public in decision-making in a society increasingly permeated by science and technology has been tempered by the view that the public lacks the necessary knowledge to participate in these democratic processes. This apparent incompatibility prompted the start of systematic measurements of public understanding of science in an effort to

gauge the level of scientific knowledge and the dominant attitudes towards science and technology among the general population. In 1957, the National Association of Science Writers (NASW) and the Rockefeller Foundation sponsored a survey of 1900 adults to assess American attitudes towards science (Miller, 1992). It proved of little use in measuring public understanding of science over time, since the substantive knowledge questions pertained only to four time-sensitive topics – polio vaccination, fluoridation of drinking water, radioactivity, and space satellites (Withey, 1959; Miller, 1992, 1998). The focus on public attitudes continued with early issues of the biennial ‘Science Indicators’ (later the ‘Science and Engineering Indicators’), first released in 1972 as status reports on American science and technology (Miller, 1992). Studies that informed these reports were significantly expanded in 1979 “to focus more attention on attitudes, knowledge measures, and expected participation measures for specific issues and controversies” (Miller, 1992, p. 24). Results indicated that a more attentive and therefore presumably more knowledgeable public was more likely to participate (National Science Board 1983, as cited in Miller, 1992).

This period from the 1960s to mid-1980s was dominated by a focus on scientific literacy (Bauer, Allum, & Miller, 2007). Emerging from the concept of literacy itself – the “ability to read and write” – scientific literacy refers to the ability to comprehend basic scientific vocabulary, to understand the basis for, and processes or methods of, scientific discovery, and to recognise how science and technology affect society (Miller, 1996, 1998). Based on these three criteria, the results of a 1992 study of 2,001 American adults found that approximately only 7% qualified as scientifically literate, mainly due to difficulties understanding scientific methods (Miller, 1996, p. 193).

Referenced by Miller (1998), an earlier three-pronged approach to scientific literacy was introduced by Benjamin Shen in 1975, who divided the concept into practical, cultural, and civic science literacy (Shen, 1975, pp. 46-49). Practical science literacy, which refers to the possession of scientific knowledge, is necessary to solve practical problems, and cultural science literacy, which refers to the presence of or accessibility to science in everyday life, is needed to generate interest in, and opinions about, science, and to help differentiate between scientific ideas and non-scientific beliefs. Civic science literacy, “a cornerstone of informed public policy,” focuses on how scientific understanding enables citizens to “participate more fully in the democratic processes of an increasingly technological society.” This idea is echoed by Miller (1996, p. 186):

“As new energy and biological technologies move toward the marketplace, there will be important public policy issues to be decided, and some of these issues may erupt into full-scale public controversies. The preservation of the democratic process demands that there be a sufficient number of citizens able to understand the issues, deliberate the alternatives, and adopt public policy.”

On one hand, this view supports involving the public in decision-making processes. It was believed that leaving decisions on science-related issues to experts was insufficient “if for no other reason than that experts are not popularly elected” (Shen, 1975, p. 48). It was also recognised that “how a technical project is implemented is mainly a job for experts, but the more basic decision of whether or not the project is to be undertaken must rest with citizens and their representatives” (Shen, 1975, p. 48). On the other hand, the position described above emphasises prerequisite scientific knowledge. This fuelled the attitude among experts that “a de facto ignorant public is disqualified from participating in science policy decisions” (Bauer et al.,



2007, p. 80), and called for an increase in formal science education to improve scientific literacy and enable public participation in policy-making (Bauer et al., 2007; Miller, 1996).

In 1985, the Royal Society of London released a report on the public understanding of science (PUS) in the United Kingdom. The report indicated that “[t]here are few, if any, public issues... that do not have a scientific or technical component” and that “[c]onversely, issues that appear to be largely scientific or technical in nature mostly have major social and political implications” (p. 9). The Bodmer report stressed the importance of PUS, where “understanding includes not just the facts of science, but also the method and its limitations as well as an appreciation of the practical and social implications” (p. 6), repeating the themes relevant to scientific literacy as described above. Overall, it emphasised PUS as a “major element in promoting national prosperity, in raising the quality of public and private decision-making and in enriching the life of the individual” (p. 9), suggesting that added scientific understanding would result in greater prosperity and personal successes based on an overall improvement in the quality of individual decision-making (Irwin & Wynne, 1996). Among other things, the report called for more research into measuring public understanding of science and technology, for increased science education during and following formal schooling, and for greater efforts from the government, mass media, industry, and scientific community to communicate among themselves and to the general public about science.

The report on PUS heralded a new focus on public attitudes towards science and technology. At the time, the report described the public as “guardedly supportive of science while being wary of some of its applications” (p. 14). The report recommended monitoring public attitudes towards science and using the information to help improve public understanding. It indicated that major scientific findings influence how individuals view themselves, as well as shape their

societies and cultures, and warned that “an uninformed public is very vulnerable to misleading ideas” (p. 10). According to other summaries, the report indicated concern that negative, “anti-science” attitudes might erupt in public controversy and threaten scientific developments (Bauer et al., 2007, p. 82), and suggests “that a more ‘scientifically literate’ public would be more supportive of scientific research programs and more enthusiastic about technological innovations” (Sturgis & Allum, 2004, p. 55).

The idea that negative public attitudes towards science and technology are due to a lack of scientific knowledge became known and critiqued as the “deficit model” of public understanding of science. The deficit model suggests that “the public’s doubts about the value of scientific progress or fears about new or unfamiliar innovations... are due to ignorance of the science behind them,” and that this lack of understanding causes people to “fall back on mystical beliefs and irrational fears of the unknown” (Sturgis & Allum, 2004, p. 57). In this way, the public was deemed “deficient” in terms of scientific understanding (Gross, 1994, as cited in Sturgis & Allum, 2004, p. 57), and this lack of scientific knowledge was blamed for negative public attitudes and distrust towards science. It was thought that improving public understanding of science would improve public attitudes and increase the acceptance of rapidly developing science and technology. While some empirical evidence supported this idea, PUS was widely criticised as summarised below.

One criticism of the deficit model challenged the separation of science from the context of individuals’ everyday lives. Surveys used to measure public understanding focused on factual scientific information, asking multiple choice and true or false questions such as “the earth moves around the sun” or “tomatoes have genes.” This division imposed the scientists’ views of science on the public, effectively disregarding how science is embedded in society. In this way,

the deficit model was criticised for misunderstanding science, the public, and how the public understands science. Researchers including social scientists and others involved in science and technology studies (STS) began to recognise that “‘science’ is not a well-bounded, coherent thing, capable of being more or less ‘understood’” and “that what counts as science is sometimes defined very differently by different people – or even by the same people under different circumstances” (Ziman, 1991, p. 100). Researchers realised that the public had different understandings of science; people interpreted science in different ways based on their personal experience and situational interests. In this way, researchers had an inadequate grasp of the diverse individuals and communities that comprise society’s many dynamic “publics.” Citing John Dewey (1927), Edna Einsiedel (2000, p. 206) describes “publics” as:

“...each consisting of individuals who, together, are affected by a particular action or idea. Thus each public will not normally consist of the same individuals who make up any other particular public, although every individual will, at any given time, be a member of many other publics.”

In light of these new understandings of science and publics, the importance of technical understanding gave way to social understanding, focusing on how science was framed and interpreted by various publics to reflect different social interests, assumptions, and contexts (Irwin & Wynne, 1996).

Second, what the deficit model of PUS described as irrational public fear, critics characterised as functional public perception of risk. Opponents of the deficit model argued that fears of science and technology were not based on a lack of scientific understanding, but were instead an expression of core societal beliefs and values (Sturgis & Allum, 2004). When expressing their concerns, publics were expressing the important elements of their communities and cultures. In

this way, decisions based solely on factual information miss the importance of cultural contexts to public acceptance of decisions.

Last, trust, rather than knowledge, more strongly influences public attitudes towards science and technology. Govier (1993, p. 17) has simply defined trust as “an attitude based on beliefs and expectations about what others are likely to do.” Trust in science is dependent on perception of science and the scientific community, and is influenced by beliefs, values, and experience as opposed to solely by technical information. Similarly distrust, or the “fear that others may act in ways that are immoral or harmful to us” (Govier, 1992, p. 17) is expressed as a negative attitude based on fearing unknown, unfortunate outcomes rather than lacking information. Many analysts now believe that trust plays a greater role than scientific knowledge in individuals’ perceptions of risks and therefore their acceptance of science and technology (Priest, 2001 as cited in Sturgis & Allum, 2004; Siegrist et al., 2000 as cited in Sturgis & Allum, 2004; Irwin & Wynne, 1996, p. 42).

Despite these counterarguments, it is important to recognise that, to varying degrees, the idea that a lack of scientific knowledge causes public fear of and negative attitudes towards science and technology persists and is weakly confirmed by some empirical evidence (Sturgis & Allum, 2004). The perception that the public is unaware or misinformed is a common and sometimes valid complaint among scientists. Sturgis and Allum (2004, p. 58) argue that though “culture, economic factors, social and political values, trust, risk perception, and worldviews are all important to influencing the public’s attitude towards science,” it is important not to dismiss the role of scientific knowledge in influencing their attitudes and affecting their actions, including making decisions. Yet the question remains as to whether or not a lack of scientific knowledge resulting in misinformation undermines public involvement in decision-making? The following

section provides an overview of deliberative democracy as a basis for the continued discussion of public engagement and participation methodologies in section 2.5, and for a response to this research question.

## **2.4 Deliberative democracy**

Deliberative democracy aims to increase the legitimacy of collective decisions by providing opportunities for individuals and communities from affected publics to become informed and to deliberate on important societal issues. Deliberation helps to identify the underlying reasons and values for different positions through a process of reasoning that helps to broaden participant perspectives. From classical democracy's roots of equality, liberty, and respect for the law and justice (Held, 2001, p. 13), deliberative democracy responds to the need for increased understanding, representation, trust, and legitimacy in decision-making processes. This section overviews how deliberative democracy theoretically and practically responds to these needs. Deliberative democracy aims to enhance effective participation, improve information-sharing, broaden participant perspectives, and increase the quality and legitimacy of decision-making processes and their outcomes.

Deliberative democracy has been described in several ways. Although previously theorized, practiced, and championed, deliberative democracy was not explicitly named until 1980 when Joseph M. Bessette indicated that the overall purpose of the individuals who framed the American Constitution in 1776 was “to restrain popular majorities but also to effectuate majority rule”; to establish a “deliberative democracy” (Bessette, 1980, p. 104). James Bohman (1998, p. 401), broadly defines deliberative democracy as “any one of a family of views according to which the public deliberation of free and equal citizens is the core of legitimate political decision-making and self-governance.” Contrasting deliberative with aggregative forms of

democracy, John Dryzek (2000, p. v) echoes that “democratic legitimacy should be sought... in the ability of all individuals subject to a collective decision to engage in authentic deliberation about that decision” instead of through “devices such as voting and representation.” Amy Gutmann and Dennis Thompson (2004, p. 7) more precisely define deliberative democracy as:

“a form of government in which free and equal citizens (and their representatives), justify decisions in a process in which they give one another reasons that are mutually acceptable and generally accessible, with the aim of reaching conclusions that are binding in the present on all citizens but open to challenge in the future.”

This definition helps to explain deliberation as a process in which participants exchange reasons for their positions in an effort to understand the values underlying these positions. Through deliberation, deliberative democracy aims to transform private preferences into positions that are supported by diverse publics, thereby enhancing decision-making processes and outcomes (Held, 2006).

According to Gutmann and Thompson (2004), deliberative democracy is characterised by four main features. First, deliberation must involve the exchange of reasons. This “reason-giving requirement” is widely accepted as “the core of all theories of deliberative democracy” (Thompson, 2008, p. 498). Giving reasons helps participants understand the underlying motives and values for particular positions, thereby increasing participant awareness and broadening participant perspectives. Second, deliberation must be publicly accessible. This indicates that the opportunity to deliberate must be available to all members of affected publics. It also indicates that the information and reasons that are exchanged during deliberation must be comprehensible to all participants. These points are elaborated during the discussion of effective participation and information-sharing below. Third, points raised and decisions made during

deliberation must be reflected in the final outcome. This idea of “linking talk to action” has become increasingly important to ensure that deliberation helps to make legitimate decisions, not to legitimise decisions that have already been made. Fourth, decisions must be reflected upon, and revisited if they fail to meet the needs of the affected publics over time.

The above characteristics relate to the objectives of deliberative democracy to improve information-sharing, to broaden perspectives, to promote mutual respect during the decision-making process, and to increase the legitimacy of decision-making processes and outcomes (Gutmann & Thompson, 2004). First, deliberative democracy provides participants with the opportunity to share information in the form of reasons and to expand personal and collective knowledge. Through deliberation, errors that arise may also be corrected from sharing information. Second, exchanging information may introduce elements of an issue that had not previously been considered by participants. Deliberation helps participants apply their knowledge to the interpretation of new information, and in turn helps them to acquire knowledge and broaden their perspectives. Third, deliberation promotes mutually respectful decision-making processes by helping participants understand and acknowledge the moral basis of valid opposing claims (Gutmann & Thompson, 2004, p. 11). Many disagreements during decision-making processes result from embedded moral positions as opposed to expressed superficial differences. Deliberative democracy aims to address moral disagreement during decision-making processes and reach mutually acceptable outcomes (Gutmann & Thompson, 2004), while allowing individuals to maintain different reasons for agreeing to a collective choice (Dryzek, 2000, p. 72). While not all affected individuals and communities will achieve their desired outcome, a reasoned process of decision-making will achieve a more legitimate and therefore more acceptable outcome for all who are affected by the decision – the fourth objective of

deliberative democracy (Gutmann & Thompson, 2004). Given limited resources, it is generally impossible to satisfy conflicting wants and needs of diverse publics. Deliberation helps to account for the various perspectives and their underlying motives and to express these in the outcome. Once decisions have been implemented, deliberative democracy also encourages reflection and allows for decisions to be challenged and changed. These characteristics and objectives of deliberative democracy contribute to the acceptance and legitimacy of decision-making processes and outcomes.

Deliberative public engagement based upon deliberative democracy responds to deficits in understanding, representation, trust, and legitimacy. First, deliberative public engagement aims to inform all participants – both experts and publics – through the exchange of comprehensive information and reasons underlying personal preferences, allowing participants to broaden their perspectives and change their viewpoints without undue influence. Second, deliberative public engagement encourages effective participation, promoting involvement of diverse individuals and communities and helping to ensure inclusiveness. Third, the overarching objective of deliberative public engagement, and one of the main aims of deliberative democracy, is to increase the quality and legitimacy of decision-making processes and outcomes, thereby promoting trust. These three elements are discussed below.

Information-sharing and knowledge acquisition, which help to broaden self- and collective understanding, are important elements of deliberative democracy. As discussed in Section 2.1, information can be shared through a variety of formal methods, such as written material and audio-visual presentations. Participants themselves are also important sources of information who bring personal as opposed to technical expertise to decision-making processes. Deliberation involves the exchange of information in the form of reasons, followed by the application of



knowledge to interpret and learn new information, enabling participants to acquire new knowledge. In this way, deliberation helps participants to become more aware, to understand, and to consider the different dimensions of a collective decision (Dryzek, 2000). This “deliberation-induced awareness” therefore helps to broaden participants’ perspectives and self- and collective understanding during decision-making processes. The following description helps to illustrate how information and knowledge are respectively shared and acquired during deliberative public engagement activities based on theories related to deliberative democracy and knowledge transmission.

Knowledge is difficult to explicitly define and is more commonly described in terms of application or acquisition. According to traditional transmission models of education, “there is a fixed body of already existing knowledge that needs to be taught and learned” (Nola & Irzik, 2005). This theory does not account for individual interpretation of information based on experience. Social constructionist theory describes knowledge as influenced by human action and interaction; “not something people possess somewhere in their heads, but rather something people do together” (Gergen, 1985). As opposed to simply sharing, knowledge is acquired through “processes of learning, re-framing, and understanding” (Horlick-Jones et al., 2007, p.261). Deliberative public engagement similarly entails several phases. During the initial “forming” stage, participants come together as a group while learning about each other and about the topic. The main characteristic of the second, “storming,” phase is deliberation. Participants share reasons for their views in an effort to understand the moral values underlying them. The reasons themselves are information, but the capacity to reason and to deliberate involves the application and expansion of knowledge. Here, participants broaden their perspectives through the acquisition of new knowledge, aided by deliberation. In the final, “norming,” phase,

participants reach collective understanding of the differing points of view, which must then be expressed in the final accepted outcome. This outcome may be reasoned agreement, persistent disagreement, or a combination of the two. This process and the above discussion help to illustrate that deliberation relies on individual knowledge in terms of each participant's capacity to interpret information and to reason based on personal and not necessarily professional experience. It shows that different types of information are important during deliberation, but that prior scientific knowledge and technical expertise are not necessary to deliberate.

Deliberation also helps to clarify and to correct misunderstood, inaccurate, or irrelevant information that may arise during a discussion. James Surowiecki's book, 'The Wisdom of Crowds' focuses on how together, people are often more successful at generating accurate information than are individuals alone. He indicates that "if you can assemble a diverse group of people who possess varying degrees of knowledge and insight, you're better off entrusting it with major decisions rather than leaving them in the hands of one or two people, no matter how smart those people are" (Surowiecki, 2004, p. 31). Deliberative democracy aims to improve information-sharing and broaden participant perspectives through the exchange of reasons and the application and acquisition of knowledge. This implies that complete understanding of the issue prior to deliberation is both unnecessary and unlikely because deliberation is a means of sharing and acquiring knowledge to better understand and reach decisions on particular issues.

Effective participation is based on the democratic value of equality and is comprised of representation, inclusiveness, and involvement. Part of ensuring "effective participation," one of the standards Robert Dahl (1998, pp. 37-38) indicates must be met to achieve political equality, is to provide equal and adequate opportunities for all citizens to share their perspectives with others. The conception of representativeness in deliberative democracy does not necessarily

refer to statistical or electoral representativeness, but rather to democratic representativeness where the social characteristics and viewpoints expressed in society are adequately represented (Goodin & Dryzek, 1996). The idea of deliberating mini-publics, “groups small enough to be genuinely deliberative, and representative enough to be genuinely democratic,” has been suggested to help achieve representativeness (Goodin & Dryzek, 1996, p. 220). Recruitment and stratification strategies for public engagement activities therefore play a part in representativeness, and must be developed and adjusted accordingly.

Inclusiveness and involvement are two additional aspects of effective participation. Inclusiveness relates to representativeness and the importance of including diverse publics with differing perspectives who would not normally associate with one another in decision-making processes. Of particular importance is recognising the perspectives of historically-oppressed segments of the population when they comprise any proportion of the affected public (Dryzek, 2000, p. 57). Inclusiveness also refers to the accessibility of opportunities to deliberate and of resources required to deliberate, including information. Allowing and enabling various means of communication, including story-telling and testimony, greeting, and the use of rhetoric (Dryzek, 2000, pp. 67-71), help include various individuals in deliberation. These and other forms of communication which evoke emotional responses are more powerful ways for participants to establish particular viewpoints and should not be excluded from deliberation (Dryzek, 2000, p. 53). Involvement refers to the active participation of individuals in deliberation. Held (2001, p. 232) emphasises the importance of “enhancing the nature and form of political participation, not just increasing it for its own sake”. Dryzek (2000, p. 58) also emphasises the need to provide structured and safe decision-making processes while evoking important viewpoints. Richardson (2002, p. 85) points out that since people differ in their reasoning and persuasive abilities, it is

important to ensure a fair or equal chance for each participant to influence the decision, satisfying the need for “qualitative equality”. In these ways, deliberative democracy enables individuals and communities to participate however they are most capable and most willing to be involved.

A final element of deliberative democracy is its focus on increasing the quality and legitimacy of decision-making processes and their outcomes. Increased quality and legitimacy are achieved in part through promoting equality by enhancing effective participation through representativeness, inclusiveness, and involvement of participants, and by aiding the process of sharing information and broadening participant perspectives through deliberation. Legitimacy also results when experts, stakeholders, and publics together reach accepted outcomes and identify persistent disagreements that require further consideration, and when actions that demonstrate these results are taken after the decision is made.

Through giving reasons, broadening perspectives, promoting mutual respect, and allowing reflection, deliberative democracy helps participants and decision-makers to share information, acquire knowledge, and understand differing perspectives, which can then be considered during decision-making processes and reflected in their outcomes. Through its characteristics and objectives, deliberative democracy provides a theoretical basis for public engagement and participation methodologies, discussed in the following section.

## **2.5 Public engagement and participation methodologies**

Proponents of PUS focused on increasing public understanding through formal education and one-way communication from experts to “the public” to improve public attitudes in science and technology and peoples’ abilities to participate in policy-making. The focus on factual scientific information neglected the diversity of “the public” and therefore publics’ understandings of

science. Accounting for only the facts disregarded how science is contextualised by individual values and experiences, how fears express important cultural values as opposed to ignorance, and how trust in science and the scientific community influences individual attitudes towards science and technology to a greater extent than scientific knowledge. Deliberative democracy attempted to improve on inadequate representation of diverse citizenry, overrepresentation of organised interest groups and key financial players, and insufficiencies in expert consultations which considered expert opinion above public perspectives. Bringing these issues to light, public controversies that stalled initiatives and strained economies overwhelmingly demonstrated the need for increased public engagement in decisions that affected communities and individuals. As discussed below, public engagement brings experts and publics together to collectively understand and address issues. Public engagement activities draw from the aims of deliberative democracy to enhance effective participation, to help share information and broaden perspectives, and to increase the quality and legitimacy of decision-making processes and their resulting decisions. This section explores public engagement and public participation methodologies and the various criteria that help to evaluate these activities.

There is widespread recognition that public engagement in regard to science and technology is on the rise. Rowe and Frewer (2000, p. 5) attribute the increase in public engagement activities to either “a recognition of basic human rights regarding democracy and procedural justice,” referring to the democratic principles of freedom and equality that entitle all individuals to have a say in matters that may affect their lives, “or simply [to] a practical recognition that implementing unpopular policies may result in widespread protest and reduced trust in governing bodies.” This latter reason responds to public controversies such as the “mad cow crisis” in the United Kingdom (UK) that erupted following an admission from the government in March 1996,

after a decade of false reassurances, that the consumption of beef contaminated with bovine spongiform encephalopathy (BSE) was the likely cause of Creutzfeld-Jakob disease (CJD) (Butler, 1997). This revelation caused consumption of beef in the European Union (EU) to drop by 11% from 1995 to 1996, and cost billions in subsidies to the beef industry (Butler, 1997). In the late 1990s, the UK public also protested against genetically-modified (GM) organisms due to safety concerns for human and environmental health. This led to a moratorium on GM crop cultivation, the destruction of GM trial crops, and the withdrawal of GM products from the marketplace (Horlick-Jones, Walls, Rowe, Pidgeon, Poortinga, & O’riordan, 2006). Recognising the need to involve the public, the British government sponsored the ‘GM Nation?’ public debate from 2002 to 2003 when reopening the issue of GM crop cultivation and commercialisation in the UK. Since then, varying types and degrees of public participation have been used to address issues and to discuss ideas that may affect the public.

The growing importance of public engagement is evident in other areas including electoral reform, environmental assessment, and urban planning. For example, in 2004 the British Columbia’s Citizens’ Assembly brought together 160 randomly selected participants to assess if and how the province’s “first-past-the-post” (FPTP) electoral system should be changed. After several months of deliberation, this unique process empowered “ordinary citizens” to propose the adoption of “single transferable voting” (STV), which, as expressed to the Assembly by presenter Nick Loenen, would likely never have been advocated for by any political party (Milner, 2005). Examples of public engagements related to BC’s environment are Simon Fraser University’s ‘Speaking for the Salmon’ series that focused on wild salmon conservation, and the related deliberative public engagement hosted by the University of British Columbia in November 2008 that explored the hopes and concerns related to sequencing the salmon genome

(O’Doherty, Longstaff, & Burgess, under review). Provincial and municipal organisations, such as BChydro, coordinate public engagement activities to involve various publics in urban planning and development. Elsewhere in Canada, the ‘imagineCALGARY’ project (<http://www.imaginecalgary.ca/>), which took place over 18-months starting in January 2005, gathered input from over 18,000 Calgarians to produce a 100-year vision for their city in one of “the largest community visioning [processes] of its kind anywhere in the world.” These and other examples show that provincially, nationally, and internationally, public engagement is taking place and is growing in importance in science and technology and other areas.

Bidirectional communication that provides information to and gathers input from affected populations in order to incorporate their feedback into decision-making processes distinguishes public engagement activities from other communication strategies which focus predominantly on informing and educating (Rowe & Frewer, 2000). Public participation methodologies range from small-scale focus groups, which generally involve up to twelve people, to large-scale referenda, which are open to an entire population (Rowe & Frewer, 2000). Other methods, described elsewhere (Abelson, Forest, Eyles, Smith, Martin, & Gauvin, 2003; Rowe & Frewer, 2000), include surveys, public hearings, citizens’ panels, and consensus conferences. Certain methods, such as citizens’ juries and deliberative polls, rely on deliberation while others do not necessarily incorporate this form of reasoning. As the practice of engaging the public continues to grow, it becomes increasingly important to understand the elements that contribute to effective public participation procedures and outcomes. Evaluation of these activities is therefore crucial to continued and improved public engagement on issues and ideas that impact society.

Many researchers have indicated a need for a comprehensive framework to evaluate the effectiveness of public engagement and participation methodologies. Responding to this need,

Rowe and Frewer (2000) describe two sets of criteria necessary to constitute effective evaluation of these activities. “Acceptance criteria” describe components of public engagement activities that may be used to evaluate the acceptance of the outcome. These include the criteria of representativeness, independence, early involvement, influence, and transparency. “Process criteria” describe the components of public engagement activities that may be used to evaluate the acceptance of the procedure itself. These include the criteria of resource accessibility, task definition, structured decision-making, and cost-effectiveness. Below, these and other criteria described in the literature are applied to the broader evaluation of participation, information-sharing, and legitimacy, three elements deliberative democracy aims to increase, discussed in the previous section. Particular attention is paid to the evaluation of information-sharing based on task definition, resource accessibility, translation quality, and structured decision-making, which contribute to broadening participant perspectives in deliberative public engagement activities.

Participation can be evaluated based on representativeness, inclusiveness, and involvement. Representativeness indicates that the sample of participants should broadly represent the affected public. The majority of public participation methodologies are unable to accommodate statistically significant numbers of participants due to size, cost and other limitations. One exception is deliberative polling, developed by James Fishkin. Deliberative polling recruits large, random samples to generate findings considered more applicable to and representative of the larger population (Fishkin, Luskin, & Jowell, 2000). Where statistical representativeness is not achievable, representativeness focuses on the composition of the participant sample as opposed to the number of participants (Burgess, 2004). In this way, recruitment and stratification strategies that target and filter for individuals who represent the diversity of the affected population are required to achieve representativeness. It is important to be aware of the



limitations of recruitment strategies since the mode of participant selection may contribute to over- or under-representation of certain segments of the population (Dalton, Cain, & Scarrow, 2003, as cited in Warren, 2008) and methods may need to be adjusted accordingly. For example, in the BC Citizens' Assembly, one man and one woman of aboriginal ancestry were added for representativeness when the process of random selection<sup>5</sup> and stratification based on the most recent Census data did not generate any aboriginal participants (Ratner, 2004). Effective participation is also proportionately influenced by participant inclusiveness and involvement. Public engagement activities which more effectively include and involve diverse individuals who differ particularly in how they share information and acquire knowledge may be considered more effective based on these criteria. These are discussed below in relation to information-sharing.

Deliberation may be criticised as uninformed when it includes inaccurate information, which may cast doubt on the legitimacy of the deliberative process and its usefulness in providing policy advice. Informing participants of the basic scientific and social information about the topic under discussion, in order to provide a foundation to build upon during deliberation, is therefore of extreme importance. Information-sharing and the effectiveness of public engagement activities to broaden participant perspectives can be evaluated by the criteria of task definition, resource accessibility, translation quality, and structured decision-making. Task definition gives participants a clear understanding of their role, the procedure, and the expected outcome of the engagement activity, yet is not restrictive if participants or procedures request or require change based on new information or disputes that arise. For example, the organisers of the 'GM Nation?' public debate "expressed a commitment that the public should be allowed to determine how the issues around GM were to be discussed during the debate" (Horlick-Jones et

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<sup>5</sup> The recruitment process for the BC Citizens' Assembly involved several steps. See Ratner (2004) for an overview.

al., 2007). This element of task definition also contributes to the independence and transparency of the procedure and therefore the legitimacy of the activity, as discussed later.

Resource accessibility is an important component of information-sharing. Resources include information resources such as facts, human resources or individuals with different types of expertise, material resources such as flipcharts and other decision-making tools, and time resources in terms of sufficient time to make decisions (Rowe & Frewer, 2000). Resources are generally determined by the task and budget of each activity (Rowe & Frewer, 2000).

Information and human resources are particularly important in terms of sharing information and broadening participant perspectives. First, it is necessary to achieve a balance between providing the minimum amount of information required to make a decision and avoiding “information overload” which may “lead to stress and confusion” (Rowe & Frewer, 2000, p. 16). Another balance is needed between established factual information and value-based considerations (Horlick-Jones et al., 2007). These considerations include the overall amount of information presented as well as the level and type of language, and the mode and timing of dissemination. In these ways, it is necessary to use, and enable participants to use, a variety of forms of communication, to help participants share and learn information.

Related to information-sharing and broadening participant perspectives, “translation quality” is an additional criterion to evaluate the effectiveness of public engagement activities (Horlick-Jones et al., 2007). Translation quality evaluates how effectively different sources of knowledge are captured, integrated, and used in public engagement processes. It is measured on whether participants were suitably informed by stimulus materials, and whether organisers appropriately collected participant views (Horlick-Jones et al., 2007, p. 268) and accurately represented them

in the outcome of the activity. Improved translation of information during public engagement processes increases information-sharing and helps to broaden participant perspectives.

Structured decision-making is a key criterion of public engagement activities. Deliberation is one mechanism to structure and display the decision-making process and is specifically important in terms of sharing information, in the form of reasons, and broadening participant perspectives through the application and acquisition of knowledge. As described in Section 2.4, deliberation helps to access the reasons underlying different points of view in an effort to base decisions on these values or needs. In these ways and those described above, public engagements which are more effective at sharing information through task definition, resource accessibility, translation quality, and structured decision-making may be considered more successful.

The legitimacy of public engagement procedures and outcomes can be evaluated in terms of cost-effectiveness, independence, transparency, early involvement, and genuine influence. First, the choice between alternative methodologies is generally based on available funding and time. It is also important that the activity reflect the size or potential impact of the decision to be made. In these ways, cost-effectiveness, or the efficient use of money and time, contributes to the legitimacy and therefore the effectiveness of public engagement activities. Second, legitimate public engagement activities must be independent and unbiased both in actuality and as viewed by others. Independence is achieved through the involvement of neutral parties in the organisation or oversight of the activity, through disclosure by organisations and individuals, including participants, of any affiliations, and through the use of a respected facilitator (Rowe & Frewer, 2000, p. 13). Third, public engagement must be transparent so that individuals who are not directly involved in the process are able to see and understand how decisions are being made.

Fourth, public engagement activities must take place early, or “upstream,” in the development or implementation of new policies and technologies. Rowe and Frewer (2000, p. 14) indicate that while “it may not be sensible to have public participation in making decisions about highly technical issues,... when value judgments become important... the public should be consulted.” If public engagement takes place “downstream,” or late in the process, it is more difficult and expensive to incorporate public feedback which in turn may be disregarded. Fourth, public engagement must have a genuine influence. There is increasing focus on “linking talk to action” in regard to public engagement activities. In certain situations, participants are seen to merely give advice which may not influence the outcome (Warren, 2008), and in others, public engagement activities have been criticised as aiming only to legitimise decisions that have already been made. In these “participation without power” situations, citizens may be less satisfied, and regard their involvement, and subsequent engagements, as pointless (Abelson & Eyles, 2002; Irvin & Stansbury, 2004). The evaluation of the legitimacy of public engagement activities can be assessed through cost-effectiveness, independence, transparency, early involvement, and genuine influence.

Public engagements which enhance participation through representativeness, inclusiveness, and involvement may be considered more effective. These activities improve information-sharing by clearly defining the task and scope of each exercise, by providing access to resources, by increasing the translation quality, and by structuring decision-making processes to promote two-way communication and to enable deliberation to access the reasons underlying different positions. Last, they increase legitimacy by being cost-effective, independent, and transparent, by taking place upstream when value-based judgments become important, and by following through on decisions in order that the genuine impacts of public engagements can be realised

immediately and reflected upon in the future. These criteria are important to evaluate public participation methodologies in order for increasingly successful engagements to continue to gather public perspective and improve decision-making processes and their outcomes.

Deliberative public engagement activities involve the exchange of information in the form of reasons and help participants to acquire knowledge and broaden their perspectives in an effort to understand underlying motives and reach an outcome accepted by affected publics. Information, shared in stimulus materials and by the participants themselves, is an important element of deliberative public engagement activities. In addition to sharing information and acquiring knowledge, deliberation helps to correct mistakes that arise during the decision-making process by drawing on collective knowledge. Through examining the contents and purposes of inaccurate statements, I explore the roles of “misinformation” in the BC Biobank Deliberation. The next chapter provides an in-depth guide to the BC Biobank Deliberation and the methods used to examine if and how misinformation mattered in this event.

### **3.0 Methods**

The preceding chapter overviewed literature related to information, biobanking, public understanding of science, deliberative democracy, and public engagement and participation methodologies. It described how additional, supportive mechanisms may be required to address insufficiencies in understanding, representation, trust, and legitimacy, and how public engagement activities based upon the characteristics and objectives of deliberative democracy in terms of increasing information sharing, effective participation, and legitimacy respond to these needs. This chapter describes the BC Biobank Deliberation, which provided data for this thesis and other papers (Appendix A), and the qualitative methodology used to analyse the roles of misinformation in this event.

#### **3.1 The British Columbia Biobank Deliberation**

The creation of biobanks has outpaced the development of a comprehensive governance framework to address the practical and ethical issues associated with biobanking, as discussed in section 2.2. As public unease regarding established and emerging biobanks in Europe was reported (Rose, 2006), and researchers in British Columbia endeavoured to facilitate biobanking through the formation of the BC BioLibrary,<sup>6</sup> biobanking presented itself as an ideal topic for a public engagement event that would help to guide the governance of biobanking in the province.

Preparation for the BC Biobank Deliberation began in September 2006 with the development of a preliminary model of public engagement based on background literature and available resources. Collaborators in relevant areas of research provided input on the model at a workshop

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<sup>6</sup> <http://www.bcbiolibrary.icapture.ubc.ca/>

in November 2006,<sup>7</sup> and the model was refined and finalised in the months remaining before the event (Figure 1). One research objective of the event was to test and evaluate the model of public engagement in terms of involving politically diverse publics in the formation of legitimate public policy in BC.

Recruitment began in March 2007. Due to limited resources, it was not possible to recruit a statistically representative sample of the provincial population. Instead, recruitment aimed to be representative of diversity. Drawing from the five provincial health regions, participants were recruited by random-digit dialling to fill stratification for ethnicity, religion, occupational group, gender, and level of education based on numbers from the 2001 Canadian Census for BC (Table 1; Figure 2). Initially, an oversample of thirty-four participants was recruited for the event. Twenty-three participants registered on the first day, and twenty-one participants completed the event.<sup>8</sup>

The BC Biobank Deliberation was held in Vancouver over two weekends separated by a twelve-day interim period in April and May 2007. One large, professionally-moderated group was divided into three small groups (A, B, C) of six to eight participants, each facilitated by a graduate student. The overall goals of the two weekends were to explore the values and interests that ought to guide the governance of biobanks and to test a model for public involvement in policy-making. The first weekend focused on sharing information with participants and on enabling participants to express their hopes and concerns regarding biobanking. The second weekend aimed to address these hopes and concerns with design recommendations for a hypothetical BC biobank. Strong support was suggested for the existence of biobanks in general,

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<sup>7</sup> Deliberative Democracy and Biobanks Workshop, November 10-11, 2006. Vancouver, B.C. Invited participants: Susan Dodds, Archon Fung, John Gastil, Barbara Koenig, Simon Niemeyer, Mark Warren, Peter Watson, Richard Hegele, Janet McManus, Angela Brooks-Wilson, Nola Ries, and Janet Joy.

<sup>8</sup> See Longstaff & Burgess (forthcoming) for a detailed description of recruitment.

for the standardisation of sample collection and annotation procedures to facilitate research, and for governing bodies independent of funders and researchers seeking access to biobanks.<sup>9</sup>

Participants were informed of the scientific and social perspectives related to biobanking through various stimulus materials and media (Figure 3). Shortly before the first weekend, participants were provided with an information booklet written specifically for the event. This was supplemented with a collection of optional readings accompanied by an annotated bibliography available at the event. On the first afternoon, following an illustration of biobanking using a physical model made of Lego<sup>®</sup>, five expert and stakeholder presentations took place. These experts and stakeholders attended the event to give presentations and to answer questions. They were explicitly excluded from the large or small group deliberations to avoid the possibility that they might have too much influence on the deliberations.<sup>10</sup> A private website providing access to event details, electronic versions of the information booklet and supplementary readings, and discussion forums was also available. Participants were able to pose questions either directly to members of the research team or via the website, and answers were provided after consultation with experts and stakeholders. All discussions were summarised and presented to participants, and were available in hardcopy during the second weekend of the event.

### **3.2 Misinformation**

As indicated above, understanding the scientific and social information related to biobanking may be challenging for participants, and deliberation helps to facilitate knowledge acquisition. During this process, it is possible for apparently inaccurate information to arise. The presence of

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<sup>9</sup> See Burgess et al. (2008) for a detailed discussion of the event and results.

<sup>10</sup> See MacLean & Burgess (forthcoming) for additional information on expert and stakeholder involvement in the BC Biobank Deliberation.



misinformation may be used to discredit the legitimacy of public engagement activities based on the extent to which they are, or are not, informed. It is therefore important to understand how this misinformation affects public engagement processes and outcomes to assess the involvement of publics in decision-making activities.

The information provided and presented to participants as stimulus materials and media was considered factually correct and representative at the time of the event. Deliberation helped participants share this and other information, acquire knowledge, and broaden perspectives. From the theories described in section 2.1, my analysis of the roles of apparently inaccurate statements – or misinformation – in deliberation looks first at the content of informative statements to identify instances of misinformation, and second, drawing from the action orientation of description, at the action following misinformation to characterise its roles in deliberation. The analysis ultimately serves to explore how and why information, independent of its accuracy, may alter the course of discussions during deliberation and how technically and conceptually inaccurate information may sometimes enhance deliberation as opposed to discredit it.

### **3.3 Methodologies**

The BC Biobank Deliberation was analysed using both quantitative and qualitative methods.

The main quantitative instrument was a pre/post survey based on the principles of Q-methodology, designed to identify shifts in participant perspectives following deliberation.<sup>11</sup>

Other aspects of the analysis relied mainly on qualitative methods. The methods I used to identify and assess the roles of misinformation are described below.

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<sup>11</sup> See Corr (2001) for a discussion of Q-methodology; See Secko, Preto, Niemeyer, & Burgess (2009) for an example of how it was used to analyse perspectives related to informed consent in the BC Biobank Deliberation.

The data set from the BC Biobank Deliberation consists of audio-recordings, transcripts, notes from observers, note-takers and flip charts, surveys, and small and large group reports. Content analysis of the large and small group transcripts was used to answer various research questions, including this one related to the roles of misinformation. The first step in the analysis was to develop a list of the main themes that arose during deliberation and use these themes to code the data. Approximately forty codes based on group reports and researcher input were developed and applied to the transcripts from the large and small groups using ATLAS.ti software and verified for inter-researcher reliability. To analyse the roles of misinformation, I independently analysed the large and small group transcripts for instances of apparently inaccurate information and coded these as 'misinformation'. Participant discourse from before and after each instance of misinformation was analysed to characterise its action or role. Transcripts from the large group were not analysed because opportunities for deliberation in the large group were limited, as discussed in section 3.4.

An additional step in the analysis involved assessing the frequency of words associated with unethical outcomes and comparing this with the frequency of words associated with biobank governance in the small group transcripts. The 'word count' function in Microsoft Word was used to determine the frequency of words. The list of words and their frequencies are identified in Table 2 and are compared in Figure 4 and Figure 5.

### **3.4 Assumptions and limitations**

It is important to identify several assumptions and limitations of this analysis. Given that biobanking is a relatively unknown subject amongst the majority of publics and involves significant scientific information, I assumed that many instances of technical inaccuracy in regard to scientific information would occur in both the large and small groups. The analysis

revealed that little scientific information was discussed and that participants predominantly deliberated the social issues of biobanking. In addition, participants raised what they perceived to be unethical outcomes of biobanking, such as human cloning and bioterrorism. Since these negative consequences are not dependent on, nor are they an aim of, biobanking, I considered them to be outside the scope of the deliberation on biobanking and therefore classified them as misinformation based on conceptual inaccuracies. During the analysis, I therefore expanded the definition of misinformation to include apparent technical and conceptual inaccuracies related to the scientific and social elements of biobanking. Discovering that participants focused predominantly on social issues related to biobanking, despite technical and conceptual inaccuracies, was key to assessing the importance of public understanding in public engagement activities. Why the focus on social as opposed to scientific information is important is discussed further in Chapter 5.

One limitation was that the roles of misinformation were analysed using data from only the small groups and from only a single deliberative event. The focus of the large group was on presenting and clarifying the main points of discussion from each small group, identifying areas of similarity between the small groups, and discussing these areas of similarity in further detail. The number of discussion points from each of the small groups and insufficient time to address each one increased the need for facilitation and limited the opportunities for deliberation. Additionally, little misinformation arose; while certain terms were defined differently by each small group, the varying definitions were not considered inaccurate. For example, during the final large group session, participants from different small groups presented different definitions for 'standards' when discussing the issue of standardisation. One participant indicated that standards referred to "ethical people," while another thought it referred to "the motivation... the

purpose behind the research project.” Several other participants described the standardisation of the collection, annotation, and storage of samples and data “for the purpose of sharing among different biobanks,” the definition that was agreed upon after facilitated discussion. For these reasons, data from the large group was not used to analyse the roles of misinformation in the BC Biobank Deliberation.

The following section presents and analyses the data to characterise the roles of misinformation in the BC Biobank Deliberation.

## **4.0 Data & Analysis**

This section presents data excerpts from the small group transcripts that seem to represent the roles of misinformation in the BC Biobank Deliberation. Section 4.1 provides an overview of the two types of misinformation – technical and conceptual inaccuracies – and indicates their four roles in deliberation. Section 4.2 illustrates these four roles using data from the small group transcripts. Data in section 4.3 represents the range of participants’ comments regarding their knowledge about biobanking and their involvement in the BC Biobank Deliberation. The data in relation to deliberative public participation and engagement activities is discussed in Chapter 5.

### **4.1 Types of misinformation**

Information that appears inaccurate in regard to the scientific and social aspects of biobanking is herein referred to as misinformation. Analysis of the data revealed two types of misinformation that contributed to its roles: 1) technical inaccuracy; and 2) conceptual inaccuracy.

Instances of technical inaccuracy were identified when the content of the information contributed by participants did not correspond with scientific or social information and practices accepted at the time of the BC Biobank Deliberation. When technically inaccurate information was mentioned, but not discussed by participants, it generally had little or no effect. This occurred most often in regard to factual, scientific information. When technically inaccurate information was discussed by participants, it either stalled or developed deliberation. Stalls occurred when participants decided they could not deliberate further due to a lack of information that required expert clarification. This happened most often in regard to intellectual property issues such as ownership of tissues and patenting, for example, participants indicated that they would need additional information on patents to continue deliberations on that topic. At other times, participants recognised and discussed technical misinformation resulting from insufficient

information and were able to reach a decision point and leave the technical details to the experts, thus developing deliberation. Technical inaccuracies also helped to develop deliberation when errors were recognised and corrected by participants.

Inaccuracies due to incorrect conceptual information were generally related to what participants perceived to be unethical outcomes of biobanking, such as human cloning and bioterrorism. These unethical outcomes were considered inaccurate since they are not dependent on, nor are they an aim of biobanking, and are therefore conceptually outside the scope of biobanking. While participants often recognised this information as inaccurate, they continued to raise information related to these unethical outcomes during deliberation, though far less frequently than they discussed aspects of biobank governance. Based on word count frequencies, Table 2, Figure 4, and Figure 5 indicate that consent was the most frequently raised topic related to biobank governance, while discussions related to cloning and bioterrorism occurred far less frequently. At times, inaccurate conceptual information distracted deliberation and led to less relevant points of discussion. In other instances, inaccurate conceptual information developed deliberation by helping participants to illustrate reasons for their points of view on biobank governance. Examples of each role in Section 4.2 help to illustrate the above descriptions.

Technical and conceptual inaccuracies, whether or not recognised by participants, resulted in four roles of misinformation in deliberation: 1) no effect; 2) stall; 3) distraction; and 4) development. These are illustrated below using excerpts from the small group transcripts.

#### **4.2 Roles of misinformation**

Analysis of the data indicates four main roles of misinformation in deliberation, illustrated in the following subsections:

- No effect – technical inaccuracies, most often in scientific as opposed to social information, that were not discussed by participants most often had little or no effect on deliberations.
- Stall – technical inaccuracies that were discussed by participants sometimes ended deliberations when additional information was requested or topics were considered too sensitive to continue.
- Distraction – conceptual inaccuracies, most often related to perceived unethical outcomes of biobanking, that were discussed by participants sometimes moved deliberations away from a discussion or decision point.
- Development – technical and conceptual inaccuracies that were discussed by participants often helped continue deliberations or move them towards decision points; these inaccuracies were either corrected through deliberation, disregarded as unnecessary, or used to help participants illustrate reasons for their preferences by raising important issues regarding biobank governance.

### **Transcription conventions**

Letters (a, b, c, d...) are used to identify the start of each excerpt. The large group (LG) or small group (SG A, B, C), and the day (1, 2, 3, 4) and time (morning/afternoon) are indicated at the end of each excerpt.

<b>NAME</b>	Participant name that has been replaced by a pseudonym
<b>NAME</b>	Facilitator name that has been replaced by a pseudonym (RYAN – Small Group A; CLAIRE – Small Group B; MICHELLE – Small Group C; JACK – Large Group)
...	Dialogue immediately preceding excerpt has been removed
--	Pause (when found within a line of dialogue); Interruption (when found at the end of a line of dialogue)

#### 4.2.1 No effect

Technical inaccuracy in scientific information that was not discussed by participants often had little or no effect on deliberations as shown by the following excerpt. In this excerpt from the second day of the event, small group A is discussing the issues of privacy and discrimination in conjunction with defining the term ‘community’. Julia, a participant from small group A, refers to foetal alcohol syndrome (FAS), a condition caused by alcohol consumption during pregnancy, in the same manner as BRCA-1, one of the genes associated with hereditary breast and ovarian cancer.

- a. JULIA: ...we have people who come to our place and... they get tested and then some of them don't want to know the results because then they can't answer honestly on insurance companies that they don't know. If it says, "Do you have any genetic conditions?" they have to write either "FAS" or "BRCA-1" and then they'll be judged on that.... And some people want to know it so they can help themselves or get screening earlier or whatever, or take treatment for FAS because they know they have it...

Small group A – Day 2

The above statement is technically inaccurate since FAS is not an inherited condition. The discussion of FAS in this statement demonstrates concern about stigmatizing labels for symptomatic conditions as it pertains to small group A’s discussion of potential discrimination caused by biobanking. As an example of how inaccurate technical information may be mentioned during deliberation, this excerpt demonstrates how the inaccurate part of the example does not become the topic of deliberation and therefore does not have an effect on the course of deliberation beyond its use as an example of stigmatizing labels.



#### 4.2.2 Stall

Technical inaccuracies caused by insufficient information were often discussed by participants. A stall is characterised by misinformation resulting from insufficient information that causes participants to stop deliberating, generally acknowledging that they require additional information to continue. The following excerpt illustrates how participants from small group C inaccurately estimated the duration of patents and expressed the need for more information, which stalled deliberation on issues related to intellectual property.

b. ZOÉ: That's how they come up with generic medication, right? By following --

CHRIS: Exactly.

JOAN: Yeah.

CHRIS: Or they wait for the patent to expire, it's like 15 years.

JOAN: Yeah.

ZOÉ: Yeah.

CHRIS: Not huge, really.

KEN: Yeah. Ten, now.

CHRIS: Ten now?

KEN: Yeah.

...

**MICHELLE:** ...I don't know anything about patents.

JOAN: We need to know a lot more about that.

Small group C – Day 3

The participants briefly continued to discuss patents before tabling the issue and indicating to the facilitator that if patents are an important piece of the discussion on biobank governance, an expert on the topic of patents would need to be consulted for additional information. The

participants then began to talk about presenting their discussion to the larger group before breaking for the day.

---

Misinformation about patenting and generic medicine also arose in small groups A and B, as shown by the following two excerpts:

c. MARGARET: ...they have a patent for a hundred years and then it's --

BETTY: I don't know.

DENNIS: Well, that's the way the drug companies work now. They've got a proprietary patent for -- what is it? How many years?

MARGARET: Twenty.

DENNIS: Twenty? And then they say because that --

MARGARET: And then it can be shared with everybody?

DENNIS: Well, it's not shared. By that time, I think after about the first two weeks, other drug companies have got it analyzed and they know how to make generics. But that just keeps the generics off -- well, it won't even keep them off the market because I don't know what 12 percent you've got to modify it or -- something before it, so.

JULIA: It's different enough to be called something else?

DENNIS: Yeah, exactly right.

Small group A – Day 2

Following this excerpt, the facilitator recapped the points of their discussion and the participants began deliberating how profits generated by biobanks and their associated activities should be shared to benefit society as a whole.

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d. AMAR: Well, once a drug is made, like say -- do all drug companies have patents on their products, or are there some products that are just the combination of different types of drugs?

LISA: There's some kind of rule on it, I don't know what it is, that once a product has been on the shelf for X number of years, then it can be made in a generic form.

AMAR: Yeah.

LISA: But I don't know what --

MALIKA: But it depends upon each individual company.

AMAR: Yeah.

MALIKA: Sometime has like five years, sometime have ten years, fifteen years.

Small group B – Day 2

This excerpt shows that technical inaccuracies related to patents also arose in small group B.

This discussion jumped to the topic of cloning without participants coming to any conclusions on patenting.

---

According to the Patent Act (1985), patents expire twenty years following the date of filing, at which time generic drugs may be produced. The above three excerpts show how insufficient information regarding intellectual property generated misinformation which at times caused deliberations to stall on the topic of patenting since additional information was required to continue deliberation. Stalls also occurred when participants recognised insufficient information on other complex or sensitive topics. The following excerpt shows how deliberation in small group C stalled because participants were unwilling to deliberate further on the topic of race-based research. Participants seemed to have insufficient information to formulate reasons for their points of view and, since it was also perceived to be a sensitive topic, did not continue deliberating.

e. JOAN: The arguments are very complicated on it. That it's not biologically sound to make those kinds of distinctions, that it leads to great stigmatization and discrimination, like, potential for...

**MICHELLE:** Very contested.

JOAN: It is, it's very highly contested.

ZOÉ: And I so disagree. I'm totally on the other side, I think it's really important in the field of nutrition to do research based on races and genetics.

...

JOAN: They are making a distinction, most of the researchers, between race and ethnicity. And they were saying that ethnicity was a more valid and useful component to identify and to study. And, like, with nutrition, they used that in several articles as an example.

...

**MICHELLE:** And it's so contested within the field that some people say, "You absolutely must study by race", "You absolutely must not study by race", you must look -- it's just -- there --

ZOÉ: It's very touchy.

Small group C – Day 3

Following this exchange, the facilitator acknowledged that the participants did not want to discuss race-based research. Small group C instead began to discuss the various motivations of researchers and other parties accessing the biobank and how access to biobanks might be managed.

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Conceptual inaccuracies also caused deliberation to stall. In the following excerpt, participants from small group C are discussing whether or not biological warfare, one of the perceived unethical outcomes of biobanking, is a possible consequence of biobanking.

Deliberation stalls when participants decide they would like to ask an expert since they have insufficient information to continue.

f. STAN: And I think that bioweapon is not based on DNA, it's on chemicals for killing people, and that is -- I don't see any connection between biobanking and bioweapons, because --

JOAN: But they might need -- at some point, they might develop something that they need, you know, biobank material to use. I can see that --

**MICHELLE:** Biological.

JOAN: Yeah.

**MICHELLE:** I am hearing that type of question for an expert. That's something that you can ask them and say, --

JOAN: Yeah. Yeah, for sure.

**MICHELLE:** -- "What about this?" Like, we're concerned.

JOAN: What is the likelihood that materials stored at a biobank could be accessed for research into --

ASHA: Biological warfare --

JOAN: -- biological warfare, or any kind of military purposes. Any kind of military -- yeah.

ZOÉ: Terrorist groups.

Small group C – Day 2

This is an example of a stall because participants requested information on the topic under discussion – access to materials stored in biobanks for unethical purposes – and began to deliberate on a new issue – the security of information stored at biobanks. Participants received a response to their question during the twelve-day interim period from Peter Watson, the expert presenter on biobanks. He indicated that the creation of bioweapons using samples stored in biobanks was extremely unlikely and unfeasible, as shown in the response below.

### **Can bioweapons be made from biobank samples? Has this ever occurred?**

Not to my knowledge. Biobanks I work with all process samples into a frozen or fixed form that could not generate a live cell or tool and therefore would have no conceivable application. Some banks (not mine currently) do store samples in a form that can retrieve live cells. These have research value of course and I can't think of a bioweapon value. Bioweapons would mostly be infectious agents that can infect live humans and biobanks would not be a good source of these human pathogens. I'll think about it some more but no one has ever raised this as a risk for tumour banks for sure. (Peter Watson – April 26)

Despite his response, misinformation regarding perceived potential unethical outcomes of biobanking continued to be raised during deliberation. The other roles of conceptual inaccuracy are discussed below.

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This subsection illustrated how technical and conceptual inaccuracies may be recognised by participants who are unable to deliberate further and who may request additional information. A second role of misinformation is therefore to stall deliberation.

#### **4.2.3 Distraction**

Misinformation may also distract deliberation. Distractions occurred when misinformation raised issues unrelated to the governance of biobanks and moved deliberation away from a topic or a decision point. This occurred most often when conceptual inaccuracies related to perceived potential unethical outcomes were discussed.

The following two excerpts from small groups B and C show evidence of how misinformation may distract deliberation.

g. AMAR: My concern is genetic modification... If they can modify plants and animals, they can obviously splice DNA in humans and mix and match and do anything pretty much they want.

**CLAIRE:** So what concerns you about that in relation to your values and -- your values and interests? What's the next sort of step in the sense of why is that a problem?

AMAR: I think now that 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 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.

...

JERRY: I saw this documentary about India, the grain, they have the grain bank, and the big companies are trying to promote the genetically modified grains, but they don't want them because the viruses will -- they'll have only one type of grain, and if one virus kills that type of grain, everybody will starve.

...

ALINA: Well, it's the same problem with bananas.

**CLAIRE:** Okay, good. What about bananas?

ALINA: That it's naturally got a seed, and [inaudible] there's no way now to reproduce because there are no seeds. So where do they go now?

Small group B – Day 2

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h. LI: ...because of the easy access to the information. It makes it easy for them to create bio-weapons...

**MICHELLE:** ...How -- what information would they be getting from a biobank that would help them create a weapon?

LI: Well, right now I can't really think of any, but say, I'm targeting the population of B.C. there with -- on this kind of disease. So I'm just trying to look for this disease and --

**MICHELLE:** Oh, I see. So they're looking for weakness.

LI: Yeah.

CHRIS: People with genetic dispositions for, like, a particular race or --

LI: Yeah, so I just target B.C. people, rather than the whole world.

ZOÉ: Yeah, what if you find that a specific race is genetically weak to --

KEN: Certain things.

ZOÉ: -- a certain disease, and then you tweak that disease into biological warfare.

CHRIS: Yeah.

ZOÉ: So a certain race --

CHRIS: Yeah, make an epidemic, sort of like European diseases coming over to North America to the native Indians. They were -- you know.

**MICHELLE:** Oh, right.

JOAN: Smallpox. Here we come.

CHRIS: Exactly.

**MICHELLE:** Smallpox and First Nations people as an example of that.

...

STAN: But the point is that your government is not going to use this weapon against you.

ASHA: Just everybody else. [LAUGHTER]

JOAN: No, but I don't want them -- I don't want them creating it with my tax money to use against anybody else.

Small group C – Day 2



The above excerpts are evidence of distraction during deliberation, the third role of misinformation. Distractions were characterised by longer periods of discussion which generally arose from inaccurate conceptual information and failed to raise issues related to biobank governance. While distractions may have moved deliberations away from decision points, the perspectives expressed during these discussions often described valid public concerns which may have otherwise been lost during deliberation.

#### **4.2.4 Development**

Technical and conceptual inaccuracies that were discussed by participants often helped develop deliberations or move them towards decision points. These inaccuracies were corrected through deliberation or were used to help participants illustrate reasons for their preferences by raising important issues regarding biobank governance, as shown by the excerpts below.

The first excerpt illustrates a technical inaccuracy discussed in small group C that was corrected by other participants during deliberation, thereby helping to clarify this point during the deliberation.

i. KEN: ...I mean, why should the male worry about the breast cancer, type of thing? You know. Not that, you know, people have wives and daughters and what-have-you...

KADRI: Men get breast cancer too. Men get breast cancer too.

KEN: Well, I don't know about that. I don't know, is there anything racial to it, and we have prostate kind of problems, you know. Same thing, you know.

KADRI: Women don't get that. [LAUGHTER]

KEN: You don't have prostate problems? You're right.

KADRI: No, unfortunately, and it must be a stigma, men do get breast cancer --

JOAN: Yeah, they do. Yeah.

KADRI: And I wish they would call it chest cancer or something --

JOAN: Yeah.

Small group C – Day 2

The above excerpt is an example of how deliberation helps to correct inaccuracies by drawing on the collective knowledge of the group. Correcting misinformation helps deliberation continue on a particular topic.

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The following excerpt shows how, even with a lack of technical expertise acknowledged by participants, misinformation helps to develop deliberation and enable participants to reach a decision point.

j. KLAAS: ...how does the biobank actually function, in terms of what's the facilities that are required in terms of what kind of funding you need in order to fulfill the facilities. I mean, you know, you're going to need refrigeration, you're going to need transportation, there would be limits on how long samples can be kept and also --

**CLAIRE:** Are you guys able -- are you guys able to decide?

LISA: Well, we don't really have the technical knowledge to make those decisions.

KLAAS: Well, we don't have any technical knowledge about any of this stuff. I mean, it's all guesswork, I mean, as far as that goes. It's no -- it's no more technical than any of these other issues.

...

**CLAIRE:** I think the thing is, there's no way you could possibly go into details about that because you don't have technical knowledge, but what you can do is talk about setting up a system of quality control.

KLAAS: Because when we put the large bank together, I mean, how often are we going to have the experts in the room? It can -- and that will be part of the dialogue with them, I think. It's -- you know --

AMAR: We can just write down "standards need to be met for quality control."

**CLAIRE:** Yeah. Right.

**AMAR:** Leave it open.

Small group B – Day 4

In the above excerpt, the participants acknowledge that they lack technical knowledge related to the collection and storage of biobank samples, such as transportation and storage conditions.

The moderator, Claire, helps to refocus the participants and they are able to reach a decision at a higher level of abstraction, concluding that appropriate standards of quality control need to be met as part of their biobank governance structure.

---

In certain instances, conceptual inaccuracies helped to develop deliberation by enabling participants to illustrate reasons for their perspectives on biobank governance. This role of misinformation is illustrated in the following three excerpts from each of the small groups. The first excerpt from small group A shows how certain concerns could be mitigated through legislation and consent. Although the concerns are conceptually inaccurate, they help to generate deliberation on regulatory elements of biobank governance.

k. **MARGARET:** ...we were just talking about, like clones, cloning, military and designer babies, that's not legal but it's not illegal either. So you would have to --

**CHARLES:** Because there -- so far, perhaps there isn't any federal law against those.

**MARGARET:** Yeah, that's what I'm saying, so we would --

**CHARLES:** There's no law against using your samples to create bio-weapons --

**MARGARET:** Yeah.

**CHARLES:** -- to create cloning or super-baby, designer baby.

**MARGARET:** Yeah. I mean if --

**CHARLES:** So we have -- some of these concerns cannot be addressed by us putting those into the agreements.

MARGARET: No, I agree.

...

CHARLES: There should be certain federal -- there should be certain provincial-level legislation and regulations governing all biobanks. And there should be certain individual choices that would be incorporated in the consent form --

JULIA: Consent forms.

CHARLES: -- or the agreements, whatever we call that.

Small group A – Day 3

---

The following excerpt from small group B shows how participants also began to discuss regulatory enforcement and the oversight of biobanks after misinformation on the perceived potential unethical outcomes of biobanking was raised, thus helping to develop deliberation on biobank governance.

I. AMAR: ...there's a lot of classified information and, you know -- you know, the public doesn't have access to it because it's over the -- just anything military, right? I'm sure they were -- they've already done stuff that the public isn't aware of and that we'll never be aware of.

JERRY: 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.

KLAAS: Yeah, so that brought me back to my original question which is about -- Ken brought it up this morning, is how do we guarantee that the ethics boards have enough power so that they can actually not only make regulations but they can actually make sure they're enforced?

Small group B – Day 2

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The following excerpt from small group C illustrates how misinformation related to unethical outcomes helped one participant make her point about the importance of consent in biobank governance.

m. KADRI: Well, if we give blanket consent, we don't know what's going to come down in the future.

ZOÉ: Yeah, but that's --

KADRI: And there may be something that you disagreed with, that you hadn't even perceived at the time that you gave the consent.

...

KADRI: I don't think we're aware of what is going to be in the future. And to consent to something in future that you're not aware of, I don't think is -- you may have a problem with that, when it arises.

Small group C – Day 3

Participants were discussing blanket consent, where one instance of informed consent would give permission for secondary research. She uses the idea that unethical practices may result from biobank research – a conceptual inaccuracy – to help make the point that she is not comfortable with blanket consent since there are many outcomes which people may not be aware of at the time the consent is given.

---

The examples above illustrate that misinformation plays a fourth role to help develop deliberation. Misinformation may either be corrected, deemed unnecessary and disregarded, or used to argue for a particular point of view in regard to biobank governance. Analysis of these excerpts shows how misinformation may have little or no effect, stall, distract, or develop deliberation. What these roles mean to public participation and engagement activities are

discussed in section 5. The following section reviews comments regarding public involvement and information in the BC Biobank Deliberation.

### **4.3 Participants' comments regarding public involvement and information**

It is not only the experts who have doubts about involving the public in policy formation.

Initially, several participants expressed scepticism regarding their abilities to meaningfully contribute to the discussion on biobanks. At the start of the event, participants also questioned the format and usefulness of the engagement as shown in the following two excerpts:

- n. DENNIS: ...the topic got so extensive that when you hear two minutes left for the speaker and/or one or two questions that we had time for, you just wonder how much more information might have been curtailed by that. But I can understand the need for organizing it, which makes you wonder, is it too broad a subject to be put into two two-day sessions? I don't know.

Large group (Participant from SG A) – Day 2

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- o. STAN: What I just want to say, that I was surprised that there is a really need for consultation regarding biobanks. When we can help to develop new medicine and cure some diseases, that's just for me the green light, they should go ahead and there is no doubt about existence of biobanks, and we should discuss some question about those kind of -- the ethics, and something like this, but I was surprised that you needed even the consultation with the public regarding this. That's what I think.

Large group (Participant from SG C) – Day 2

---

Yet as the days and weekends progressed, participants indicated that despite their initial reservations they enjoyed the process and were able to generate ideas and input important to biobanking in BC:

- p. ZOÉ: ...I guess what stood out is that it can feel empowering for an individual to see that their opinions are taken into account. There's a large segment of the population that's very bitter and cynical about all the research and all that stuff and doing all the complaining in the background and nobody really cares what we think. To consider that what they have to say might be taken into consideration, that's very positive.

Large group (Participant from SG C) – Day 2

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- q. KLAAS: ...we were talking about how amazing it actually is that here we are, people who know absolutely nothing about the subject and we haven't really been told very much but we're still able to generate a lot of ideas which are probably quite relevant to what we're talking about.

...

KLAAS: So what it means is somewhere there's a translation of -- this translation which comes from other areas that we have experienced, and it's dealing into this lot.

Small group B – Day 2

This excerpt shows that participants felt they were able to contribute by drawing on their personal expertise and feel as though they were making a relevant contribution to the discussion.

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However, the overwhelming amount of information and limited time to absorb it led some participants to express feelings of frustration:

- r. JULIA: It's so hard to make these design choices when you don't have all the answers.

Small group A – Day 3

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Yet even in the small groups, participants recognized the value of the engagement process and the ways in which deliberation helps to broaden personal perspectives.

s. HARSHAD: That makes the job easier when there are no two people understanding the same --

JULIA: Exactly, because then you get better viewpoints.

HARSHAD: Then you get better -- you save and it's --

JULIA: Or different viewpoints. More different viewpoints.

HARSHAD: You are talking from different angles.

JULIA: Right, just like we are all here today.

Small group A – Day 3

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Through participation and deliberation, participants felt informed and empowered by their involvement in the BC Biobank Deliberation.

t. JOAN: I was challenged by trying to fill some significant deficits in my education in two weeks and come up to speed, particularly in the biology but learning so much. And I was also challenged by having to accept the fact that I couldn't possibly do that. So then I had to sort of try to make decisions about how I felt based on less than adequate information. It was challenging but I really enjoyed that process as well. Learning so much was fascinating, and of course meeting everybody here has been great.

Large group (Participant from SG C) – Day 4

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u. ZOÉ: I usually don't like expressing my opinion about something unless I feel like I know what I'm talking about or have a grasp of whatever was behind. But I did some research



and some reading, and I trust that I could contribute something without having to be an expert.

Large group (Participant from SG C) – Day 4

Overall, a number of participants indicated a need for increased education and information about biobanks and voiced support for continued public involvement in the governance of biobanks.

The following chapter discusses these findings in further detail.

## 5.0 Discussion

Science and technology help to shape society. New discoveries and developments influence ideas and values and begin to change societal norms. As these areas continue to advance, they outpace the creation of comprehensive governance frameworks to prevent potential issues and manage existing problems. At the same time, decision-making regarding the development and implementation of new initiatives and technologies and any associated policies often neglect public perspectives in favour of expert and stakeholder input. As public funding is invested into science and technology, as publics recognise and exercise their right to participate in democratic processes, and as developments raise controversial concerns, it becomes increasingly important to engage diverse publics in decision-making processes in order to reach collective decisions that are amenable to all those who may be affected by any changes that take place.

While involving the public in decision-making activities has long been considered important, scientific literacy, or the ability to understand scientific terms and the premises of scientific inquiry, has been considered a requirement to participate. This posed a problem when surveys completed in several countries starting in the late-1950s measured low levels of public understanding of science. This apparent lack of scientific knowledge was addressed through increasing formal scientific education. Increasing public education and communication was also the response to improving poor attitudes towards science and technology that were considered an impediment to scientific progress in the 1980s. This deficit model of public understanding, in which negative public views and fears of science and technology are attributed to a lack of knowledge in these areas, prompted critics to argue that social knowledge was more important than scientific knowledge, and that involving publics in decision-making activities should be

given a high priority. Public engagement has since gained support across a variety of areas and it is important to understand the elements and functions of these activities.

This thesis research helps to show that the presence of misinformation does not necessarily undermine the legitimacy of deliberative decision-making processes. Provided with basic information on the topic of biobanking, participants were able to deliberate issues related to biobank governance. The BC Biobank Deliberation was attentive to the elements of deliberative public engagement activities that help to enhance participation, information-sharing, and legitimacy. Recruitment and stratified sampling helped to bring together a small sample of participants who, though not statistically representative, reflected a significant range of the diversity of the provincial population. Information related to the scientific and social perspectives of biobanking as communicated to participants through a number of different stimulus materials that incorporated visual and auditory methods of communication, including an information booklet and supplementary readings, presentations by a variety of experts and stakeholders, a Lego<sup>®</sup> model of biobanking, and a website developed specifically for the event. Deliberation also helped participants to share reasons underlying their perspectives and to understand the views of others and acquire new knowledge. Held upstream of the development of biobanks in BC, it also aimed to genuinely influence any endeavours to facilitate such practices in the province. Lastly, participants were encouraged to offer input and to provide feedback throughout the process.

Participants were able to deliberate on several issues important to biobanking and its governance, including consent, privacy and confidentiality, security, oversight, ownership, and benefit-sharing. At times, inaccurate technical and conceptual information arose during the BC Biobank Deliberation. Technical misinformation involved inaccurate factual scientific or social

information and conceptual misinformation involved references to ideas considered to be outside the scope of biobanking. Conceptual misinformation was most often related to unethical potential outcomes that were unlikely to be or unfeasibly facilitated by biobanking. Based on the data illustrated in Chapter 4, the four roles of misinformation were categorised as 1) no effect; 2) stall; 3) distraction; and 4) development. Characterisation of these four roles helped to show that although misinformation at times stalled and distracted deliberation, it generally had little or no effect and at times helped to develop deliberation.

Misinformation caused stalls and distractions that suspended and changed the topic of deliberation, respectively. For example, small group C decided they were unable to deliberate further and therefore requested additional information and ceased deliberation on the topic of patenting. In another instance, small group C also stopped deliberating the topic of race-based research due to its sensitive nature and insufficient knowledge to help argue their views. In other instances, the small groups were distracted by conceptual misinformation related to perceived unethical potential outcomes of biobanking, even when participants acknowledged the unlikelihood of these outcomes.

This study also shows that in certain instances, misinformation helps to develop deliberation. As illustrated in section 4.2.4, misinformation was at times corrected by participants. In other instances, misinformation helped participants recognise that they lacked technical expertise, but that at the same time, technical expertise was not necessary for general decision-making on issues related to biobank governance. For example, participants in small group B were able to express that standardisation of sample collection and annotation is important to facilitate research without needing to understand precisely how standardisation would be carried out. Participants were able to continue deliberation and reach a decision point based on the information that had

been provided to them and based on the importance they placed on facilitating research.

Additionally, inaccuracies did not undermine the usefulness of examples participants used to express particular viewpoints and the reasons underlying their preferences. This is evidenced by the excerpts in section 4.2.4 in which conceptually inaccurate information regarding unethical potential outcomes of biobanking was used to illustrate concerns over regulations and their enforcement, oversight, and consent.

Technical and social information related to a particular topic can be provided to participants in stimulus materials, but knowledge gained through experiences and based on values is not as readily conveyed. Equally, while technical decisions and their implementation may best be left to individuals with technical expertise, the initial decision as to whether or not a scientific development ought to be pursued merits public understanding and input. Uninformed publics ought to be involved and to help with decision-making through the process of deliberative public engagement, thereby improving understanding, representativeness, trust, and legitimacy in decision-making processes and their associated decisions.

This study recognises that information is an important component of deliberative public engagement activities, but assesses how inaccuracies affect these processes and their outcomes in an effort to respond to claims that uninformed publics are unfit to provide input in decision-making processes. In general, when an overview of the scientific and social information related to the topic is provided during an engagement activity, participants who had little or no knowledge of the subject prior to being informed were able to deliberate on a variety of issues related to biobank governance. Instances of misinformation did not necessarily undermine the legitimacy of deliberations and decisions. While technical and conceptual inaccuracies may at times have stalled or distracted deliberations, these situations reflect valid participant

perspectives that might have been missed had misinformation been disregarded. Misinformation was also shown to have little or no effect and, more importantly, to help develop deliberation through clarifying elements of discussions and by allowing participants to make particular points related to biobank governance. Follow-up studies would help to further characterise the roles of misinformation in deliberative public engagement. Additional studies to better understand expert and public attitudes towards the involvement of publics in decision-making activities in order to design approaches that account for these attitudes would also be useful.

## **6.0 Conclusion**

Biobanks and activities to facilitate biobanking are increasing throughout the world. While biobanks may support research to understand and improve health, they also pose potential ethical issues related to information and consent procedures, privacy and confidentiality, ownership and intellectual property, the communication of results, and benefit-sharing. These issues affect individuals and communities who are directly and indirectly involved in biobanking. Biobanks may also involve significant amounts of public funding, reflecting lost opportunities elsewhere. Further, research based on biobanks has the potential to shape the future, and citizens are entitled to be involved in decision-making related to their futures. It is therefore important to understand public values and priorities, through activities such as deliberative public engagements, and to account for these perspectives in the governance of science and technology.

Misinformation that arises during deliberation among publics does not necessarily undermine the usefulness or credibility of engagement activities. On the contrary, while misinformation may stall or distract deliberation in certain instances, it often has little or no effect and more importantly, may also help to develop deliberation by enabling participants to make particular points that emphasise the reasons for their perspectives. In the BC Biobank Deliberation, despite several instances of technical and conceptual inaccuracies, deliberative public engagement was able to respond to the ethical challenges of biobanks. Participants were able to reach agreement on several aspects of biobank governance, including general support for biobanking, the need to standardise collection and annotation of samples to facilitate research, and independent oversight of biobanks.

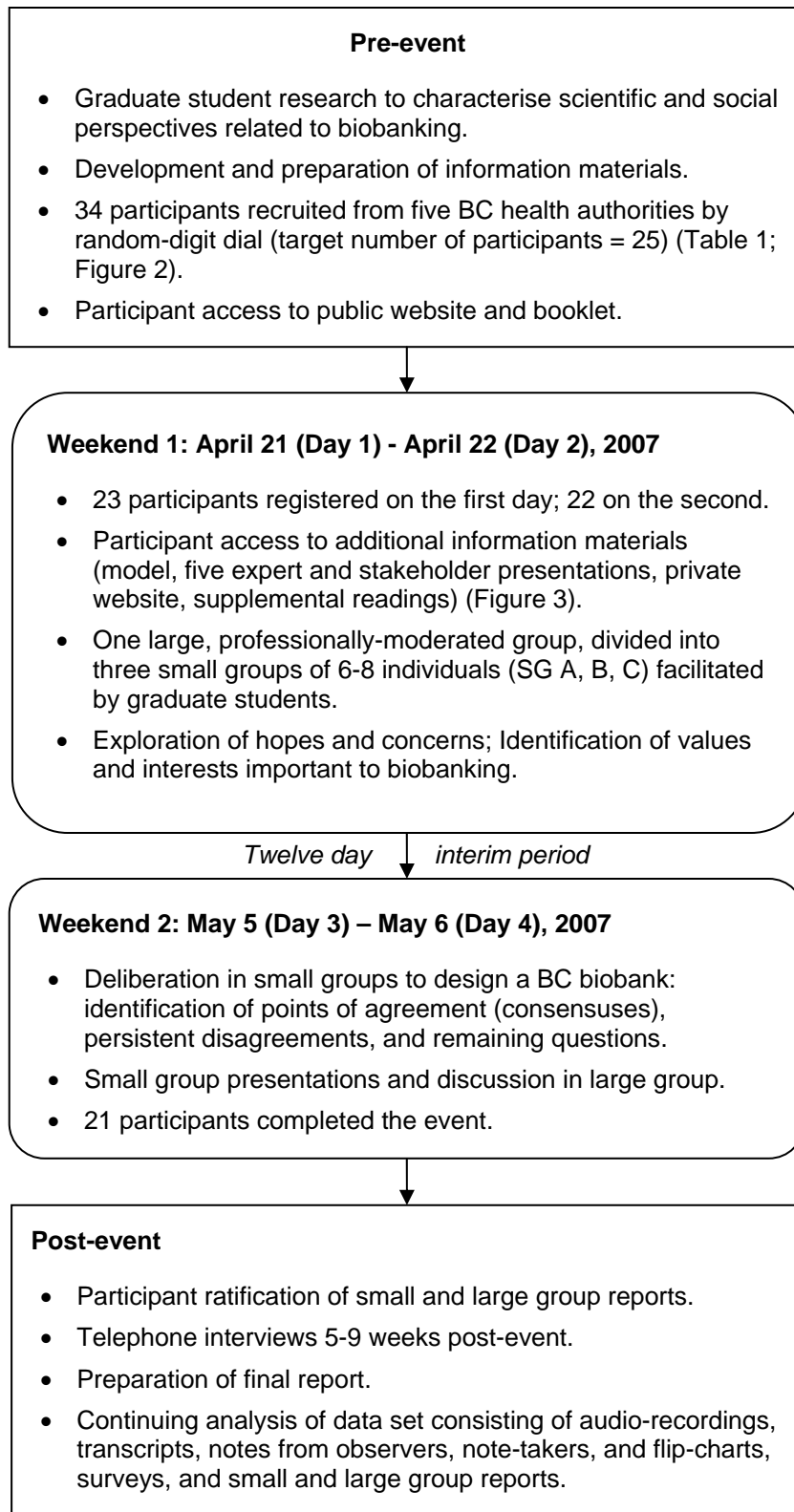
Biobanking may seem a relatively easy topic on which to hold such an event, since publics are generally unaware of biobanks and have yet to form strong opinions on them. Still, the presence

of misinformation might affect the processes and outcomes of deliberative public engagements on more politicised topics, such as sequencing the salmon genome in British Columbia, health care reform in the United States, or stem cell research across North America and in other parts of the world? A process of structured decision-making which incorporates deliberation and therefore focuses on sharing information and broadening participant perspectives helps all involved, including experts, stakeholders, and publics, understand diverse views and the reasons underlying them. As demonstrated in the analysis of the BC Biobank Deliberation, misinformation may even help to argue particular points.

This experience has taught me several valuable lessons. Above all, it has instilled in me the importance of engaging affected publics in decision-making processes. Publics represent different groups of individuals. These groups may overlap and, similarly, individuals may be members of more than one group. From citizens and residents of a country, to employees of an organisation, and to members of a family or a relationship, individuals who may be affected by a decision ought to be informed and be given the opportunity to share their views. Accounting for various perspectives during decision-making processes improves the quality and legitimacy of, and trust in, these processes and their outcomes. Technical expertise is not the only necessary expertise. Publics understand the most important aspects of their cultures and their societies, and draw on their values to express their perspectives. Understanding these underlying values and reasons helps to make more legitimate and ultimately more acceptable decisions.



## Figures & tables

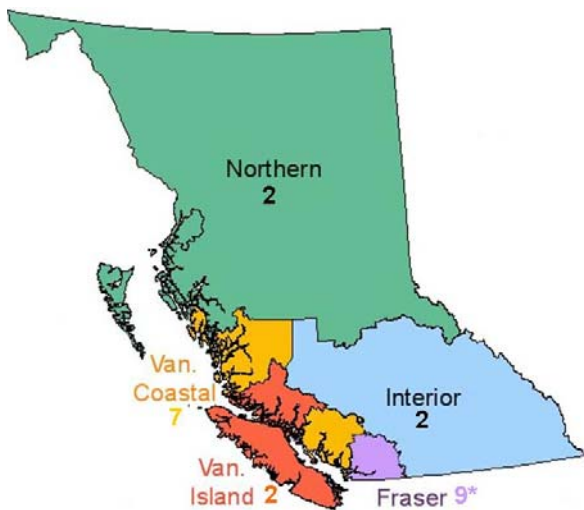


**Figure 1:** Flowchart of the BC Biobank Deliberation model.

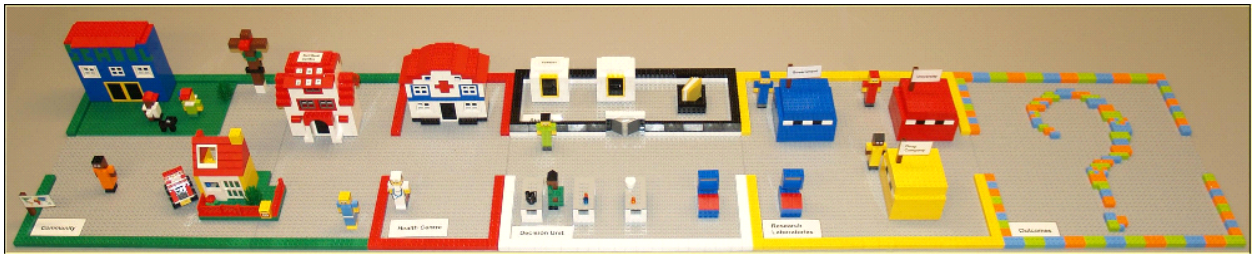
<b>Gender</b>	Female	12*	<b>Income</b> (21 responses)	Less than \$25,000	1	
	Male	10		\$25,000-\$49,999	3	
<b>Health Region</b>	Fraser	7		\$50,000-\$74,999	3	
	Interior	2		\$75,000-\$99,999	1	
	Northern	2		\$100,000-\$149,999	3	
	Vancouver Coastal	9*		\$150,000 and over	0	
	Vancouver Island	2		Undisclosed	10	
<b>Employment</b> (20 responses)	Business - Finance - Administration	3*		<b>Chronic illness/disability</b>	Yes	4
	Chemical Engineering	1			No	18*
	Social - Education - Gov't - Religion – Health	4		<b>Risk of inherited disease</b>	Yes	8
	Trades - Transportation - Equipment	3			No	14*
	Unable to work	2		<b>Religion</b>	Atheist	1
	Looking for work	1			Buddhist	1
	Retired	5			Catholic	4*
Other	1	Christian			6	
<b>Ethno-cultural</b>	Caucasian	2			Muslim	1
	Chinese	3			Protestant	1
	Pakistan	1			Sikh	2
	Indian	3		Theist, no religion	1	
	Anglo	1		None or other	5	
	Ukrainian	1		<b>Number of children</b> (17 responses)	none	6
	First nations	2	1		4	
	German	1	2		3	
	Filipino	1*	More than 2		4	
<b>Education</b>	Other	7	<b>Age</b> (18 responses)	Under 30	3	
	More than high school	20*		30 – 45	5	
	Less than high school	2		45 – 60	4	
				Over - 60	6	

\* Includes one person who only participated in the first weekend's deliberation

**Table 1:** Participant demographics.



**Figure 2:** Map of British Columbia indicating the number of participants recruited from each of the five health authorities.



(a)

**Expert and stakeholder presentations**

Peter Watson – Director, Tumour Tissue Repository, BC Cancer research Centre; Professor of Pathology, University of British Columbia & University of Victoria. **Why do we need biobanks?**

Nola Ries – Lawyer; School of Health Information Science and Centre for Studies in Religion and Society, University of Victoria. **What are the privacy concerns related to biobanks?**

Barbara Farlow – Mother whose infant daughter with trisomy-13 died unexpectedly while hospitalised. **What are the concerns of people living with disabilities?**

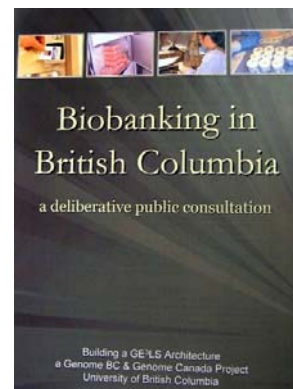
Doris Cook – CIHR Project Manager on Aboriginal Ethics. **What are the concerns of aboriginal peoples?**

Daryl Pullman – Professor of Medical Ethics, Memorial University of Newfoundland. **How can communities be fairly treated?**

(b)



(c)



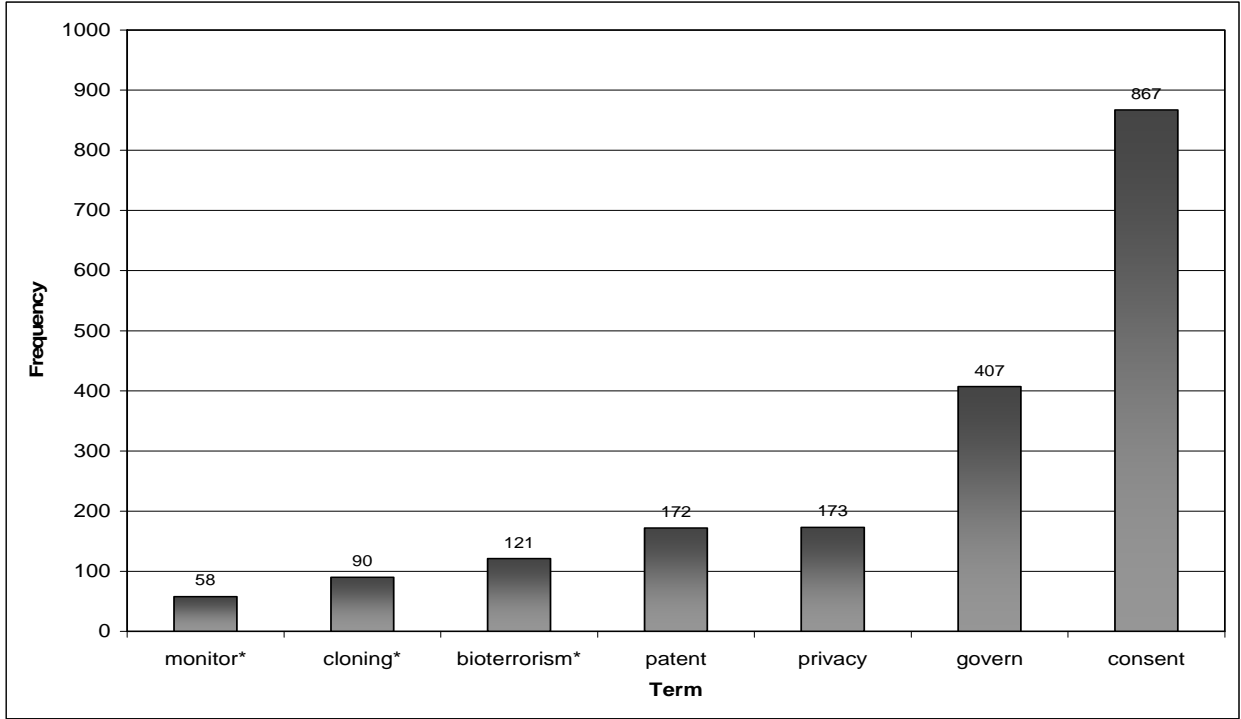
(d)

**Figure 3:** British Columbia Biobank Deliberation participant information materials  
 (a) Lego<sup>®</sup> model – ‘The process of biobanking’;  
 (b) expert and stakeholder presentations;  
 (c) public and private websites;  
 (d) booklet accompanied by (optional) supplemental readings and an annotated bibliography.

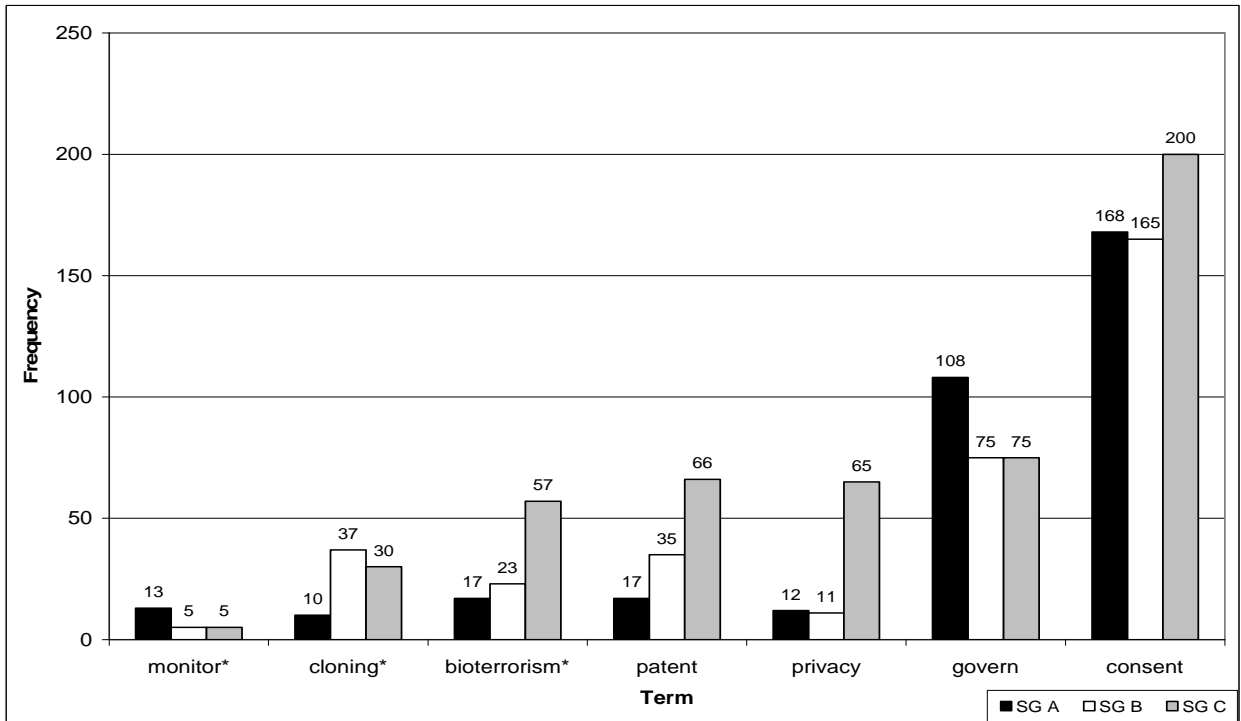
Term	LG (weekend 1)	LG (weekend 2)	SG A	SG B	SG C	Total
<b>bioterrorism</b>						
terror (bioterrorism, terrorise, terrorist)	3	10	7	1	12	33
war*	0	0	1	1	1	3
warfare (biowarfare)	0	0	1	0	12	13
military	2	1	2	13	17	35
weapon (bioweapon)	4	1	1	4	13	23
Iraq	0	0	0	0	2	2
bomb	2	1	2	4	0	9
biochemical	0	0	3	0	0	3
						<b>121</b>
<b>cloning, clone</b>	4	2	6	26	18	56
eugenics	2	0	0	0	6	8
designer babies	0	2	3	2	1	8
modify, modifi (genetically)	1	0	1	9	2	13
Gattaca	2	0	0	0	3	5
						<b>90</b>
consent	130	204	168	165	200	<b>867</b>
govern	39	110	108	75	75	<b>407</b>
privacy	68	17	12	11	65	<b>173</b>
patent	25	29	17	35	66	<b>172</b>
monitor, oversee, oversight	21	14	13	5	5	<b>58</b>

**Table 2:** List and frequencies of the terms used to describe unethical outcomes in comparison with terms used to describe other issues important to biobank governance.

\*indicates document search for whole words only



**Figure 4:** Total small group frequencies of two terms used to describe unethical outcomes in comparison to frequencies of terms to describe five issues important to biobank governance.



**Figure 5:** Comparison of small group frequencies of two terms used to describe unethical outcomes in comparison to frequencies of terms to describe five issues important to biobank governance.

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## **Appendix A – Publications resulting from the BC Biobank Deliberation**

### **F2F publications resulting from the BC Biobank Deliberation**

- Burgess, M., O’Doherty, K., & Secko, D. (2008). Biobanking in British Columbia: discussions of the future of personalized medicine through deliberative public engagement. *Personalized Medicine* 5(3), 285-296. doi:10.2217/17410541.5.3.285
- Longstaff, H., & Burgess, M. (forthcoming). Recruiting for representation in public deliberation on the ethics of biobanks. *Public Understanding of Science*. doi:10.1177/0963662508097626
- Longstaff, H., & Secko, D. Media influence on biobank deliberations. Under review in *Journal of Public Deliberation*.  
Currently available as: Longstaff, H., & Secko, D. (2007). Media influence on biobank deliberations. Electronic Working Papers Series. W. Maurice Young Centre for Applied Ethics, University of British Columbia at [www.gels.ethics.ubc.ca](http://www.gels.ethics.ubc.ca).
- MacLean, S., & Burgess, M. (forthcoming). In the public interest: Assessing expert and stakeholder influence in public deliberation about biobanks. *Public Understanding of Science*. doi:10.1177/0963662509335410
- O’Doherty, K.C., & Davidson, H.J. Subject positioning and deliberative democracy: Understanding social processes underlying deliberation. Under review in *Journal for the Theory of Social Behaviour*.  
Currently available as: O’Doherty, K., & Davidson, H. (2008). Subject positions and self-warranting in a deliberative democracy event on biobanking. Electronic Working Papers Series. W. Maurice Young Centre for Applied Ethics, University of British Columbia at [www.gels.ethics.ubc.ca](http://www.gels.ethics.ubc.ca).
- Secko, D.M., Preto, N.S., Niemeyer, S., & Burgess, M.M. (2009). Informed consent in biobank research: A deliberative approach to the debate. *Social Science and Medicine* 68(4), 781-789. doi:10.1016/j.socscimed.2008.11.020
- Walmsley, H. (forthcoming). Biobanking, public consultation, and the discursive logics of deliberation: Five lessons from British Columbia. *Public Understanding of Science*. doi:10.1177/0963662509335523
- Walmsley, H.L. (2009). Mad scientists bend the frame of biobank governance in British Columbia. *Journal of Public Deliberation* 5(1), Article 6. Retrieved from <http://services.bepress.com/jpd/vol5/iss1/art6>
- Wilcox, E. (2008). A Lego model to help inform participants at the British Columbia Biobank Deliberation. *Health Law Review* 16(4), 9-11. Retrieved from <http://www.law.ualberta.ca/centres/hli/userfiles/wilcox.pdf>
- ### **F2F publications resulting from the 2009 BC BioLibrary Deliberation**
- O’Doherty, K., & Hawkins, A. Making public engagement effective in policy development on human tissue biobanking. Submitted to *Public Health Genomics*.

## Appendix B – Copy of UBC Research Ethics Board's Certificate of Approval



*The University of British Columbia*  
*Office of Research Services*  
**Behavioural Research Ethics Board**  
*Suite 102, 6190 Agronomy Road, Vancouver, B.C. V6T 1Z3*

### CERTIFICATE OF APPROVAL - FULL BOARD AMENDMENT & RENEWAL

<b>PRINCIPAL INVESTIGATOR:</b> Peter A. Danielson	<b>DEPARTMENT:</b> UBC/College for Interdisciplinary Studies/Applied Ethics	<b>UBC BREB NUMBER:</b> H06-80029
<b>INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:</b>		
<small>Institution</small>	<small>Site</small>	
UBC Other locations where the research will be conducted: Morris Wosk Centre for Dialogue, Vancouver	Point Grey Site	
<b>CO-INVESTIGATOR(S):</b> Michael Burgess		
<b>SPONSORING AGENCIES:</b> Genome British Columbia		
<b>PROJECT TITLE:</b> Building a GE3LS Architecture (GE3LS Arc)		

**CERTIFICATE EXPIRY DATE:** April 12, 2008

<b>REB MEETING DATE:</b> April 12, 2007		
<b>AMENDMENT(S):</b>	<b>RENEWAL &amp; AMENDMENT APPROVAL DATE:</b> April 13, 2007	
<small>Document Name</small>	<small>Version</small>	<small>Date</small>
<b>Consent Forms:</b>		
Informed Consent Consultation 2007	4	March 15, 2007
<b>Other Documents:</b>		
Recruit Screener	3	March 15, 2007
Background materials for deliberation	2	March 22, 2007
<b>Other:</b>		
<p>The application for continuing ethical review and the amendment(s) for the above-named project have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.</p>		
<p><b>Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:</b></p>		
<p>_____</p> <p>Dr. Peter Suedfeld, Chair                  Dr. Jim Rupert, Associate Chair                  Dr. Arminee Kazanjian, Associate Chair                  Dr. M. Judith Lynam, Associate Chair                  Dr. Laurie Ford, Associate Chair</p>		