

Public Involvement in Decision-Making

Health Innovation for Patients and Populations:
Science, Systems & Structures

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25 February 2009

Accountability for Reasonableness

1. **Publicity:** transparent & public rationales
2. **Relevance:** evidence or principles fair minded parties accept as relevant
3. **Appeals:** challenges, ongoing review, and revision of decisions
4. **Enforcement:** publicly regulated

Daniels and Sabin 1998:57

Deliberative participation unrealistic

- Consumer participation might improve deliberation about some matters, but it is unlikely that we could ever enlist active enough consumer participation to deliberate about limit setting. . . . there is no realistic mechanism for making consumers who participate truly representative of the consumer population as a whole.

Daniels and Sabin 1998:61

Deliberative mini-publics on Biobanks

Public Involvement in Decision-Making

Can publics provide
informed, civic-minded policy advice?

2006 International Workshop Deliberative Democracy & Biobanks

Democracy & engagement

- **Archon Fung**, Kennedy School of Government, Harvard
- **John Gastil**, University of Washington
- **Simon Niemeyer**, Australian National University
- **Mark Warren**, Political Science, UBC
- **Janet Joy**, Vancouver Coastal Health

Genomics & biobanks

- **Angela Brooks-Wilson**, Genome Sciences Centre, BC Cancer Research Centre
- **Peter Watson**, BCCA, TTR, UBC & University of Victoria
- **Richard Hegele**, UBC & iCAPTURE Centre

Ethics & Law

- **Susan Dodds**, University of Wollongong, Australia
- **Barbara Koenig**, Mayo Clinic (Minnesota)
- **Nola Ries**, University of Victoria

Caveats & assumptions

- Need to legitimate policies and practices
- Only one component of governance
- Compliance to ethics/law insufficient for maintaining public trust
- Important to
 - Carefully inform public input
 - Evaluate deliberative engagement
 - Assess policy relevance (process & outputs)

Deliberative Democracy

not simply to ensure that “excluded groups” are given access to decision making about technology, however desirable this may be in itself. . .

express a reasoned, informed, consensual judgment forged out of the initially disparate knowledge, values, and preferences of the participants, as these have evolved through the deliberative experience itself.

Hamlett, PW (2003). Technology theory and deliberative democracy. *Science, Technology, & Human Values* 28 (1): 121-2.

Evaluation of Deliberation

1. Representation
2. Structure of process or procedures
3. Information used in process
4. Outcomes and decisions arising

Abelson J, et al (2003). Deliberations about deliberative methods: issues in the design and evaluation of public participation processes. *Social Science and Medicine* 57, 239-251.

•Beierle, T. C. (1999). Webler, T. (1995).

Representation

“mini-public” can provide insight into how informed and deliberating citizens understand and assess important issues

- Goodin, RE, Dryzek, JS (2006). Deliberative Impacts: The Macro-Political Uptake of Mini-Publics. *Politics & Society*, 34(2): 219-244.

“Representation” not feasible

Diversity of life experiences

- Basic commitments
- Relative values
- Discursive styles
- Challenge to others

Recruitment

“Proxies” for diversity

- Random Digit Dial
- 5 Health care regions (urban/rural)
- Stratification: 2001 Canadian Census
 - 1505 unique households contacted
 - 1796 phone calls
 - oversampled to 34
 - 23 registered for the 1st meeting
 - 21 completed the 2nd weekend

Longstaff, Burgess. (In press). Recruiting for representation in public deliberation on the ethics of biobanks. *Public Understanding of Science*

Health Region

Fraser	7
Interior	2
Northern	2
Vancouver Coastal	9
Vancouver Island	2

History and Education

Chronic illness/disability	4
Risk of inherited disease	8
> High School	20
< High School	2

Demographics

Gender	Female	12
	Male	10
Number of children (17 responses)	none	6
	1	4
	2	3
	More than 2	4
Age (18 responses)	Under 30	3
	30-45	5
	46-60	4
	Over 60	6

Occupation

Bus - Finance - Administration	3
Chemical Engineering	1
Social - Educ- Gov - Religion – Health	4
Trades - Transport - Equipment	3
Unable to work	2
Looking for work	1
Retired	5

Income

< \$25K	1
\$25-49K	3
\$50-74K	3
\$75-99K	1
\$100-149K	3
>\$150K	0
Undisclosed	10
< \$25K	1

Religion

Atheist	1
Buddhist	1
Catholic	4
Christian	6
Muslim	1
Protestant	1
Sikh	2

Ethno-cultural

Caucasian	2
Chinese	3
Pakistan	1
Indian	1
Anglo	1
Ukrainian	1
First nations	2
German	1

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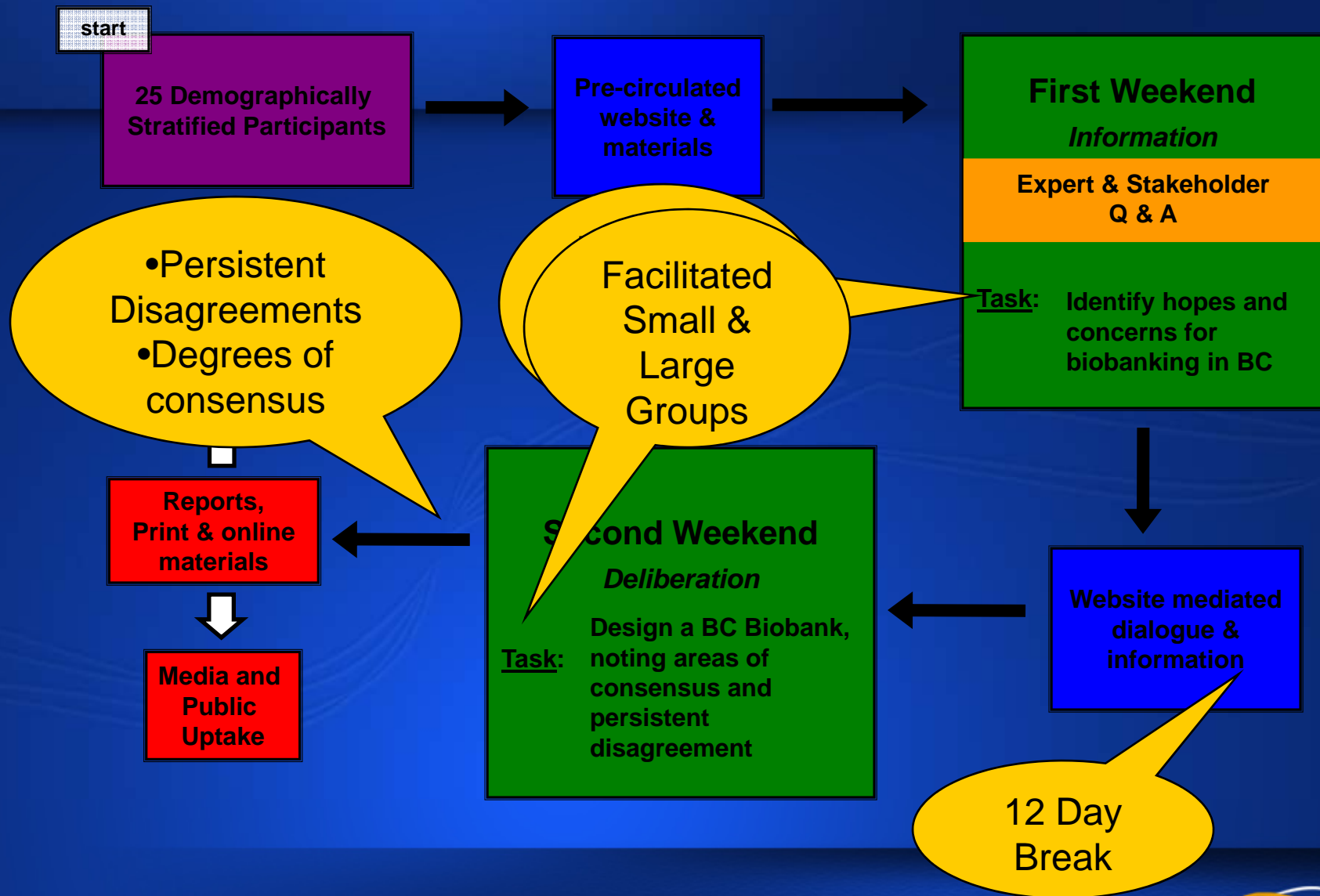
Deliberative Democracy Objectives

1. Augment legitimacy through accountability and participation
2. Encourage a public-spirited perspective on policies issues through cooperation
3. Promote mutual respect between parties through inclusion
4. Enhance quality of decisions and opinions through substantive and informed debates
Chambers (2003)
5. Allow the contestation of (notably dominant) discourses through the public sphere.

Dryzek, John S. (2000). *Deliberative Democracy and Beyond*; Oxford: Oxford University Press.

Beyond Traditional Consultation: Deliberation on Biobanks

What interests and values should guide a BC Biobank?



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Biobanking in British Columbia

a deliberative public consultation

Building a GE³LS Architecture
a Genome BC & Genome Canada Project
University of British Columbia

Biobanking in BC

- distributed in print
- online version public

Additional articles

- annotated bibliography
- 2 binders
- on private website

Background Materials

- informed consent & inadequacy
- privacy and practical limitations
- challenges of community consultation
- international harmonization
- racial typology
- 'medical' & 'enhancement' models of health
- individualist & bio-colonial practice of biomedical research
- **benefit-sharing**

H Walmsley (2009). Mad scientists bend the frame of biobank governance in British Columbia. *Journal of Public Deliberation* V.

Websites and Blogs

The screenshot shows a WordPress blog titled "Biobank Talk" with the subtitle "private website for participants". The browser address bar shows "Welcome « Biobank Talk". The navigation menu includes "HOME", "ABOUT YOU", "BLOG YOUR VIEWS", "EVENT INFO", "READINGS", "TRAVEL/HOTEL", and "WHAT IS A BIOBANK?".


Recent Comments

- Pam on [Share a new perspective](#)
- Pam on [Share a new perspective](#)
- Monica on [Share a new perspective](#)
- parmindermattu on [Share a new perspective](#)
- Heather on [Question an expert](#)

Public website

Leave the private participant area and enter public site

Welcome



Thank you for a great weekend of deliberation everyone!

Welcome to the new participant website. This is password-protected so that only participants and the research team can access it.

Consider this your space. You can **post to the blog** and share random thoughts, impressions of the event, ideas for discussion, anything you like... You can find out **more about biobanking**. And you can download a new copy of the **participant information booklet** or any of our suggestions for further reading.

The draft **CIHR Guidelines for Health Research Involving Aboriginal Peoples** that Doris Cook spoke about are available **here**. As is the booklet - **Annie's Story** - written by Barbara Farlow. Barbara also has a **website**.

Recent posts include a response to the query about **tissue taken during abortions**. And several **responses from Peter Watson** to questions you raised on Sunday...

The project team

Developed by

- GE3LS Arch Project
- W. Maurice Young Centre for Applied Ethics
- University of British Columbia

Funded by

- GE3LS Arch
- Genome Canada
- Genome BC
- BC BioLibrary (MSFHR Platform)
- CIHR Ethics Office
- Canadian Biotechnology Secretariat
- Western Canadian Policy Collaboration
- James Hogg iCAPTURE Centre
- Biomarkers in Transplantation
- Canadian Tumour Repository Network
- BC Cancer Agency Tumour Tissue Repository
- CIHR Institute of Genetics

Blog at WordPress.com. | Theme: Andreas09 by Andreas Viklund.

Speakers and topics

Why do we need biobanks?

- Peter Watson, Pathologist and Director of 2 tumor tissue repositories

What are the privacy concerns related to biobanks?

- Nola Ries, Legal scholar

What are the concerns related to people living with disabilities?

- Barbara Farlow, daughter's death due to genetic discrimination

What are the concerns of aboriginal peoples?

- Doris Cook, CIHR Project Manager on Aboriginal Ethics

How can communities be fairly treated?

- Daryl Pullman, Professor of Medical Ethics

Physical Model: The Process of Biobanking



Track how biological samples and data:

- Collected
- Stored
- Annotated and coded
- Produce knowledge
- Knowledge applied
- Profit

E Wilcox, Primary designer

Information Use & Challenge

Participants:

- understood the information provided through presentations
- challenged perspectives presented by experts and stakeholders
- carried out respectful debate
- respectfully and accurately articulated the opinions of other group members, even in the face of disagreement

S MacLean, Burgess (in press).
In the Public Interest: Assessing Expert and Stakeholder
Influence . . . *Public Understanding of Science*.

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Strong Consensus

1. Strong support for biobanks
2. Governing body
 - independent of funders & researchers
3. Standardising procedures for effectiveness

NB: Informed, deliberative engagement possible

Burgess, O'Doherty, Secko (2008).
Personalized Medicine 5(3):285-296.

Reports to:

- CIHR Ethics Office
- CIHR Institute for Genetics
- Canadian Biotechnology Secretariat
- Canadian Tumor Repository Network (CTRNet)
- BC BioLibrary: Banking for Health
- BC Cancer Agency Tumor Tissue Repository
- Better Biomarkers of Acute and Chronic Allograft Rejection (Genome Canada)
- The James Hogg iCAPTURE Centre, St. Paul's Hospital

Subsequent use of Deliberative approach

BC Biobank deliberation

- April/May 2007

Mayo Clinic, Minnesota, United States

- September 2007

Western Australia, Office of Population Health Genomics,

Department of Health

- Stakeholders: August 2008
- Public: November 2008

Salmon Genomics, Vancouver

- November 2008

BC BioLibrary, Vancouver

- March 2009; MSFHR, Genome BC

Analytic vs. deliberative outputs

Deliberative outputs

- Conclusions arrived at by participants

Analytic outputs

- Assessment of communication, use of knowledge, formation of positions, etc

O'Doherty, Burgess. (in press). Engaging the public on biobanks: Outcomes of the BC Biobank Deliberation. *Public Health Genomics*.

With Appreciation:

Funders:

- Genome Canada, Genome BC
- CIHR Ethics Office
- CIHR Institute for Genetics
- Canadian Biotechnology Secretariat
- Canadian Tumor Repository Network
- BC BioLibrary: Banking for Health (a MSFHR Technology/Methodology Platform)
- BC Cancer Agency Tumor Tissue Repository
- Better Biomarkers of Acute and Chronic Allograft Rejection (Genome Canada)
- The James Hogg iCAPTURE Centre, St. Paul's Hospital



The B2D2 team:

- Daniel Badulescu
- Helen Davidson
- David Hartell
- Daisy Laforce
- Holly Longstaff
- Samantha MacLean
- Kieran O'Doherty
- Nina Preto
- David Secko
- Kim Taylor
- Heather Walmsley
- Elizabeth Wilcox

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