19TH ANNUAL **PRIVACY & SECURITY** CONFERENCE

Security & Privacy: A Global Evolution

PRE-CONFERENCE EDUCATIONAL SESSIONS: FEBRUARY 7, 2018 | CONFERENCE: FEBRUARY 8-9, 2018

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Ethical decision making in research privacy

Wednesday, February 7th 9:00am-12:00pm

Holly Longstaff , PhD

Research Privacy Advisor for the Provincial Health Services Authority (PHSA), Ethicist for the BC Cancer Agency Research Ethics Board (REB), member of Schulman Institutional Review Board's Canadian panel

Agenda for this morning

1. Presentation on bioethics tools and concepts
   - Case study discussions

2. Presentation on the Tri-Council Policy Statement (TCPS) and The Office of the Information and Privacy Commissioner for BC (OIPC) guidance regarding the Freedom of Information and Protection of Privacy Act (FIPPA) and research
   - Case study discussions

3. Presentation on research ethics research: Global data & tissue sharing trends and public engagement
   - Case study discussions

1. Bioethics tools and concepts

What is applied ethics?

- Many different types of applied ethics.
- What is ethical analysis?
  - Systematic analyses of value laden areas involving "all things considered" judgments.

Why does research ethics matter?

Hela immortal cell line
1950-ongoing

Tuskegee syphilis experiment
1932-1972

Willowbrook Experiments on
mentally disabled children
deliberately infected with hepatitis
over 14 years in 1956

European Molecular Biology
Laboratory sequences the
genome of a HeLa cell line 2013

Aboriginal nutritional
experiments 1940's and 1950's

Hwang indicted on embezzlement and
bioethics violations 2006

1966 Henry Beecher paper

Beecher HK. Ethics and Clinical Research. N Engl J Med 1966;274:1354–1360

- Examples of unethical or questionably ethical studies
- Bioethics hero who received harsh criticism from the medical field for exposing these issues
  - Example 17: Live cancer cells were injected into 22 human subjects as part of a study of immunity to cancer. According to a recent review, the subjects (hospitalized patients) were ‘‘merely told they would be receiving ‘some cells’ ‘‘... the word cancer was entirely omitted... .’’

TCPS 2 (2014)— the latest edition of Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans

- TCPS is a joint policy of Canada's three federal research agencies – the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada(NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC), or "the Agencies."

- To be eligible to receive and administer research funds from the Agencies, institutions must agree to comply with TCPS and researchers are expected, as a condition of funding, to adhere to the TCPS.

- Principles-based guidance…
  - Respect for Persons
  - Concern for Welfare
  - Justice

7 requirements to make clinical research ethical

1. Value;
2. Valid;
3. Subject selection;
4. Risk-benefit;
5. Independent review;
6. Informed consent;
7. Respect for participants.

* Source: Emanuel, Wendler, Grady. What Makes Clinical Research Ethical? JAMA. 2000;283(20):2701-2711

What is an Research Ethics Board (REB)?

- Review studies for ethics compliance with TCPS, HC requirements, and international norms and guidance (such as ICH GCP)* and ensure scientific value
- Comprised of different experts including a community member
- Review all aspects of the study

* Good Clinical Practice and the International Conference on Harmonisation

How does REB and privacy review relate to ethics?

- Research ethics policy and regulatory review and compliance
- Privacy should be one integrated part of research REB review and REB review is part of the good governance of research

Good governance in research is proportionate

Good governance is about managing risk and lowering it where possible (the REB's risk benefit ratio). The threshold in TCPS2 is minimal risk or above minimal risk according to the daily life test not zero risk.

It is participant centered!!!!

- Zero risk studies or studies that lack scientific uncertainty can be unethical
  - Junk science cannot be ethical. All risk and inconvenience with no benefit plus unjustified use of resources and services
  - Clinical equipoise- There must be genuine uncertainty regarding treatment options (e.g., comparing study arms in clinical trial). If preferences are known then it is not ethical to withhold that treatment or expose subject participants to research risks
- Increasing individual privacy risks is a necessary trade-off to achieve the collective good in most research studies
- Participants can agree to accept risks and trade-off privacy to support the collective good in research (and even without consent it can still be ethical-common practice)

The reality: Silos and the compliance police

CTV news photo Published Saturday, June 2, 2012

Thoughts on rule following…

Ethics in research: A science lifecycle approach

Other format

PDF version (1.19 MB)

Contact Information

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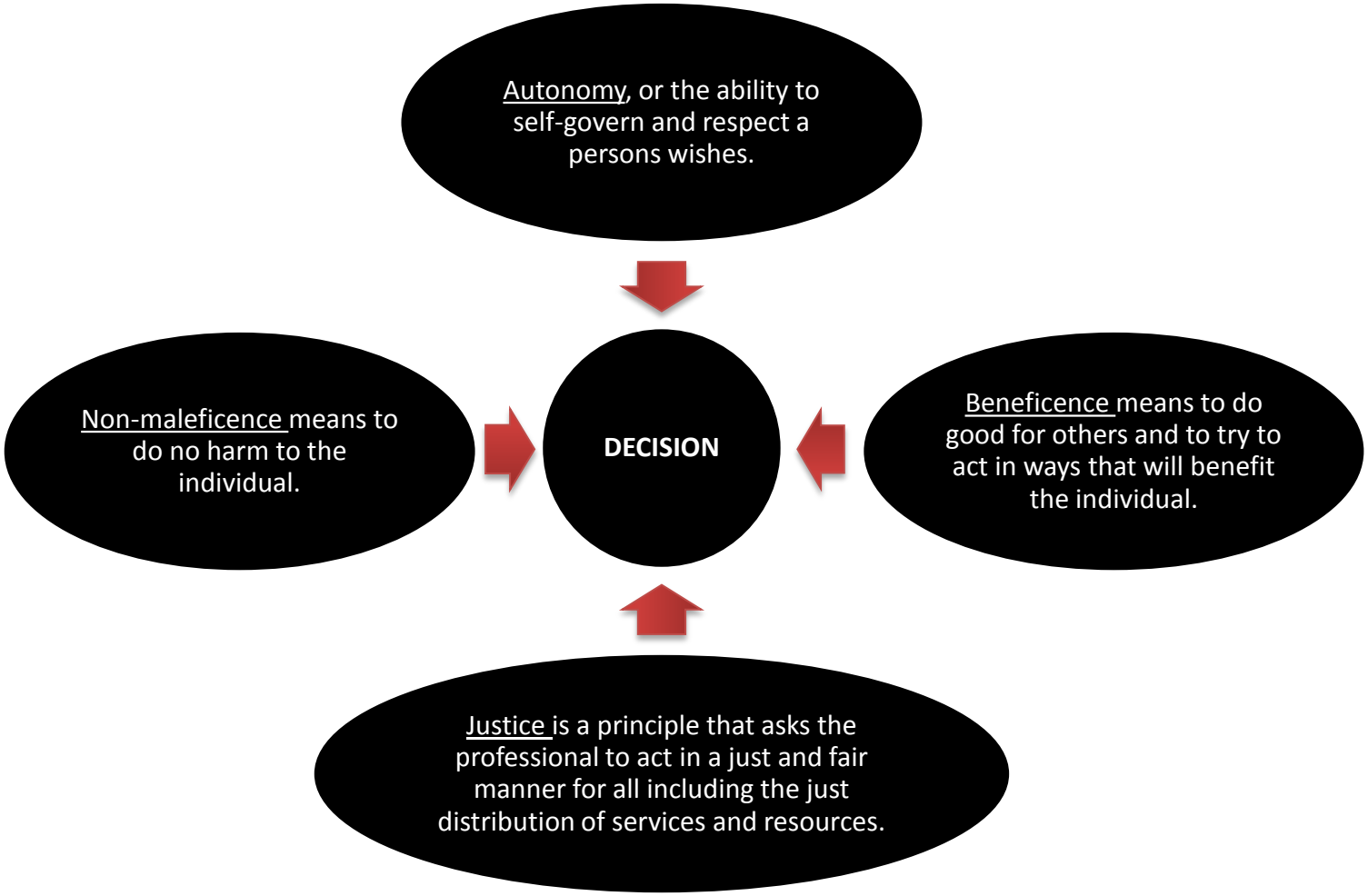
Date modified: 2014-11-24

Conceptual framework (participant centered)

Substantive ethics

Procedural ethics

Applied ethics principles



Autonomy and informed consent

➡ Full disclosure, individualistic models or consent to good governance?

"My view is that the focus on consent in contemporary biomedical research has become the modern equivalent of a fetish“

- Barbara A. Koenig

Ethics issues in the genetic context

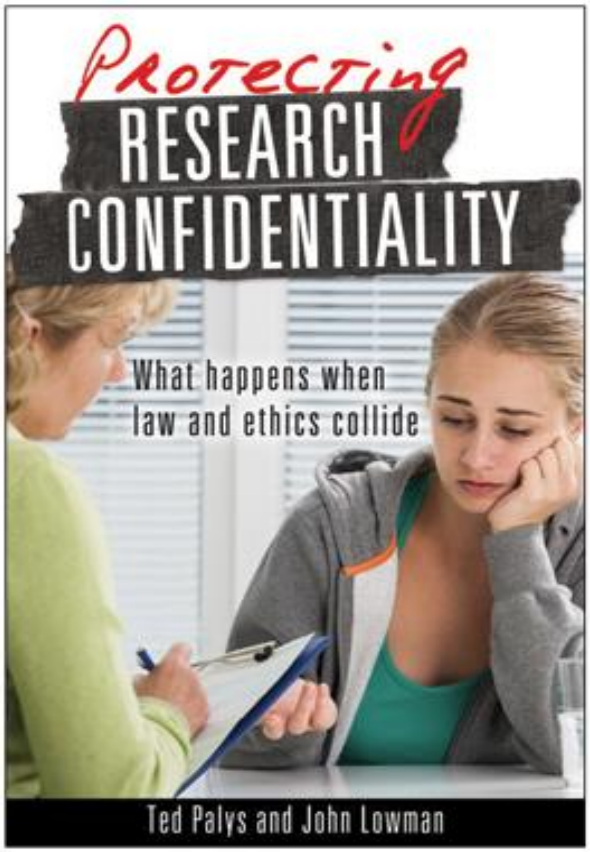
- Features of genetic information which might further complicate traditional individualistic, autonomy based approach to research ethics:
  - Both about and an integral part of a person
  - Familial nature of genetic information: implications beyond the individual


Vulnerability

The duty to protect participants

Taking extreme measures to protect powerful participants we find abhorrent (institutional liability, bad press, researcher safety, illegal activities, mandatory reporting, etc.)

The duty to maintain confidentiality- Russel Ogden v. SFU



THE GLOBE AND MAIL

"As a master's student at Simon Fraser University in the 1990s, Mr. Ogden was awarded $34,000 and an official apology after the school refused to pay his legal bills as he fought a coroner's request that he identify the participants in his master's thesis on assisted suicide in Canada.

In 1998, Mr. Ogden left a PhD program at the University of Exeter after a protracted battle with the school's ethics committee, which backtracked on its promise to support him by granting "absolute" anonymity to more than 100 people helping terminally ill AIDS patients commit suicide in Canada, Britain, the United States and the Netherlands.

In 2003, British authorities ordered the University of Exeter to pay Mr. Ogden about $140,000 for breaking the commitment."

Research ethics exceptionalism

- Calls for different procedural and substantive reviews.
  - Uncontested example: Research with Aboriginal peoples in Canada, including First Nations, Inuit and Métis peoples

Ethics exceptionalism is not static

1. Case study discussions

2. Presentation on TCPS2 and The Office of the Information and Privacy Commissioner for BC (OIPC) guidance regarding the Freedom of Information and Protection of Privacy Act (FIPPA) and research

TCPS

TCPS applies to research conducted with human research participants

- Research – An undertaking intended to extend knowledge through a disciplined inquiry and/or systematic investigation.

Exemptions for REB review –WHY?

- Research that relies exclusively on publicly available information
- Creative/artistic practice
- Surveillance
- Quality assurance, quality improvement studies, and program evaluation activities
- Performance reviews or testing within normal educational requirements
- Observation of people in public places with no intervention and with no expectation of privacy and no effort to re-identify
- Secondary use of anonymous information or biological materials

Informed consent

- Broad/blanket, study by study, re-consent, group/community consent, dynamic consent

Michigan BioTrust for Health - Consent Options

Centering the human participant in REB review:

Consent relationship is intended to be a flexible process and participant specific

Determining capacity to consent (third party consent always second best)

- Pediatrics: Rule of Sevens
- Adults:
  - Testing cognitive capacity (Mini Mental State Examination or MMSE)
  - Substitute decision makers, LARs, research directives, BC Health Care (Consent) and Care Facility (Admission) Act –health care includes medical research that must be reviewed by a *designated* REB.
    - Also talks about the *presumption of capability* and capacity cannot be determined solely through an adult's way of communicating with others.

<u>Other important ethical considerations:</u>

- Dissent
- Direct/therapeutic benefit and overriding assent or dissent
- Fluctuations in consent in longitudinal studies
- Regaining capacity

Is this process protecting human research participants?

Empirical data-the bad news ☹

- "Recent study conducted by Kaiser Permanente Colorado found that while the majority of those approached (69%) would be willing to participate in a biobank and 84% correctly understood that they would not receive personal results from studies, some issues were not as well understood (e.g., only 32% correctly understood that their sample would be linked to their medical record)."

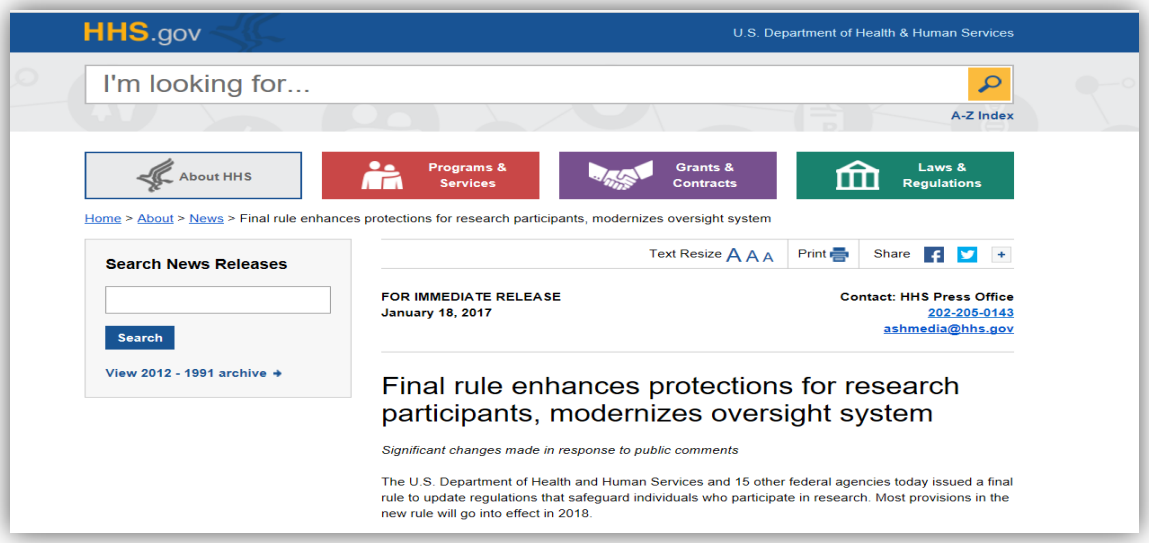
  (Virani and Longstaff, 2014)

The reality with high risk clinical research

- Very little flexibility in how consent ought to be obtained
  - Fragile populations who are often very ill
  - No room for mistakes
  - Information is highly complex (study and risk information)
  - Extensive set of risks
  - What information can properly be omitted?
  - Who should make decisions to omit information?
  - Harmonized internationally and must meet rules/ guidelines from around the world
- One small but significant example –use of appendices (BC Cancer REB)

Breaking news!!!!!

(agreement to be governed ethically)



Waver of consent -data

Article 5.5A Researchers who have not obtained consent from participants for secondary use of identifiable information shall only use such information for these purposes if they have satisfied the REB that:

(a) identifiable information is essential to the research;

(b) the use of identifiable information without the participants' consent is unlikely to adversely affect the welfare of individuals to whom the information relates;

(c) the researchers will take appropriate measures to protect the privacy of individuals, and to safeguard the identifiable information;

(d) the researchers will comply with any known preferences previously expressed by individuals about any use of their information;

(e) it is impossible or impracticable (see Glossary) to seek consent from individuals to whom the information relates; and

(f) the researchers have obtained any other necessary permission for secondary use of information for research purposes

Article 5.5B Researchers shall seek REB review, but are not required to seek participant consent, for research that relies exclusively on the secondary use of non-identifiable information

Waiver of consent-tissue

Article 12.3A Researchers who have not obtained consent from participants for secondary use of identifiable human biological materials shall only use such material for these purposes if they have satisfied the REB that:

(a) identifiable human biological materials are essential to the research;

(b) the use of identifiable human biological materials without the participant's consent is unlikely to adversely affect the welfare of individuals from whom the materials were collected;

(c) the researchers will take appropriate measures to protect the privacy of individuals and to safeguard the identifiable human biological materials;

(d) the researchers will comply with any known preferences previously expressed by individuals about any use of their biological materials;

(e) it is impossible or impracticable to seek consent from individuals from whom the materials were collected; and

(f) the researchers have obtained any other necessary permission for secondary use of human biological materials for research purposes

Article 12.3B Researchers shall seek REB review, but are not required to seek participant consent, for research that relies exclusively on the secondary use of nonidentifiable human biological materials.

Material incidental findings (MIFs)

- Article 3.4 Researchers have an obligation to disclose to the participant any material incidental findings discovered in the course of research.

- Application: In some areas of research, such as medical and genetic research, there is a greater likelihood of material incidental findings. When material incidental findings are likely, researchers should develop a plan indicating how they will disclose such findings to participants, and submit this plan to the REB. If there is uncertainty as to whether a research project warrants such a plan, researchers and REBs can make this determination on a case-by-case basis. When necessary, researchers should direct participants to a qualified professional to discuss the possible implications of the incidental findings for their welfare. Insome cases, incidental findings may trigger legal reporting obligations and researchers should be aware of these obligations (see Article 5.1). A researcher may request an exception to the obligation to disclose material incidental findings, based on the impracticability or impossibility of disclosing such findings to the participant. “Impracticable” refers to undue hardship or onerousness that jeopardizes the conduct of the research; it does not mean mere inconvenience. Disclosure may be impossible or impracticable (see Glossary) when the group is very large or its members are likely to be deceased, geographically dispersed or difficult to track. The onus is on the researcher to justify to the REB the need for the exception. REBs should decide whether exceptions apply on a case-by-case basis.

- **Key points: Actionable findings, the right not to know, MIF plans, team expertise to analyze, interpret, and communicate the MIF, new Canadian The Genetic Non-Discrimination Act.**

Research with Indigenous communities

Requirement of Community Engagement in Indigenous Research

Article 9.1 Where the research is likely to affect the welfare of an Indigenous community, or communities, to which prospective participants belong, researchers shall seek engagement with the relevant community. The conditions under which engagement is required include, but are not limited to:

- research conducted on First Nations, Inuit, or Métis lands;
- recruitment criteria that include Indigenous identity as a factor for the entire study or for a subgroup in the study;
- research that seeks input from participants regarding a community's cultural heritage, artefacts, traditional knowledge or unique characteristics;
- research in which Indigenous identity or membership in an Indigenous community is used as a variable for the purpose of analysis of the research data; and
- interpretation of research results that will refer to Indigenous communities, peoples, language, history or culture.

Privacy Commissioner for BC (OIPC) guidance regarding the Freedom of Information and Protection of Privacy Act (FIPPA) and research

OIPC guidance regarding FIPPA and research

In January, 2018, the OIPC produced a 14-page document intended to outline the legal provisions that apply to the disclosure of personal information of British Columbians for the purpose of health research. Access to data for health research continues to be a key frustration of health researchers in BC.

- The document clarifies that FIPPA authorizes public bodies to disclose personal information for research purposes (without the consent of the individual) under a number of conditions, and reinforces the role of the REB in ensuring adequate terms and conditions are followed.
- It clarifies that FIPPA does not apply to de-identified data. Many BC data holders incorrectly believe that FIPPA applies to all data and apply restrictions that are not required.
- It confirms that restrictive provisions of FIPPA do not apply when a research participant has provided appropriate informed consent authorizing the release of their personal information.
- For more information, please visit: https://www.oipc.bc.ca/guidance-documents/2115

2. Case study discussions

3. Presentation on research ethics research: Global data & tissue sharing trends and public engagement

Data and tissue

Biobanking defined

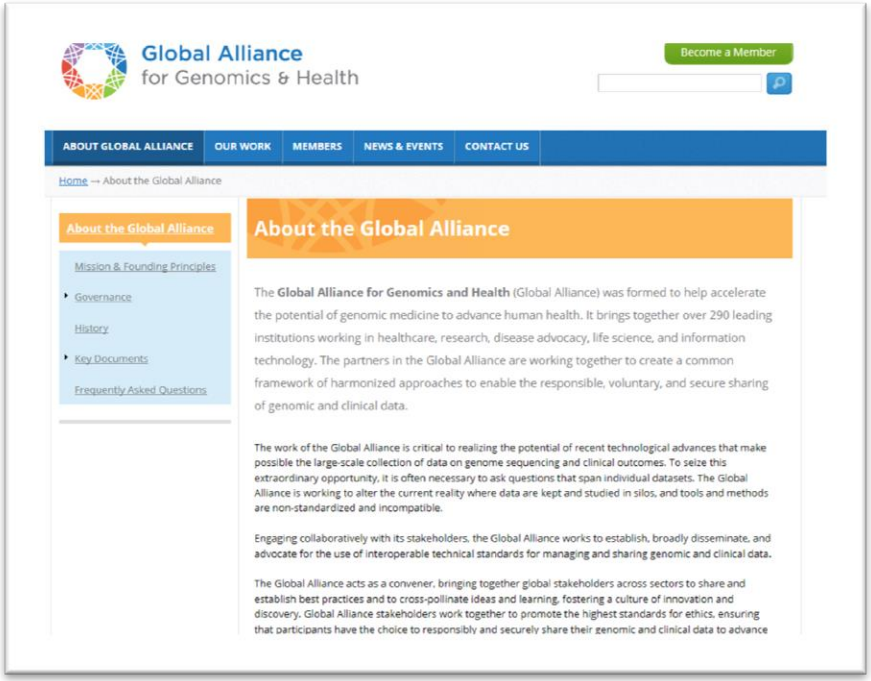
"A biobank is a collection of data and biological samples of human blood and tissue for use in research. Samples are frozen or stored to be used at a later time. Biobanks are critical resources for research." (UC Participant Booklet)

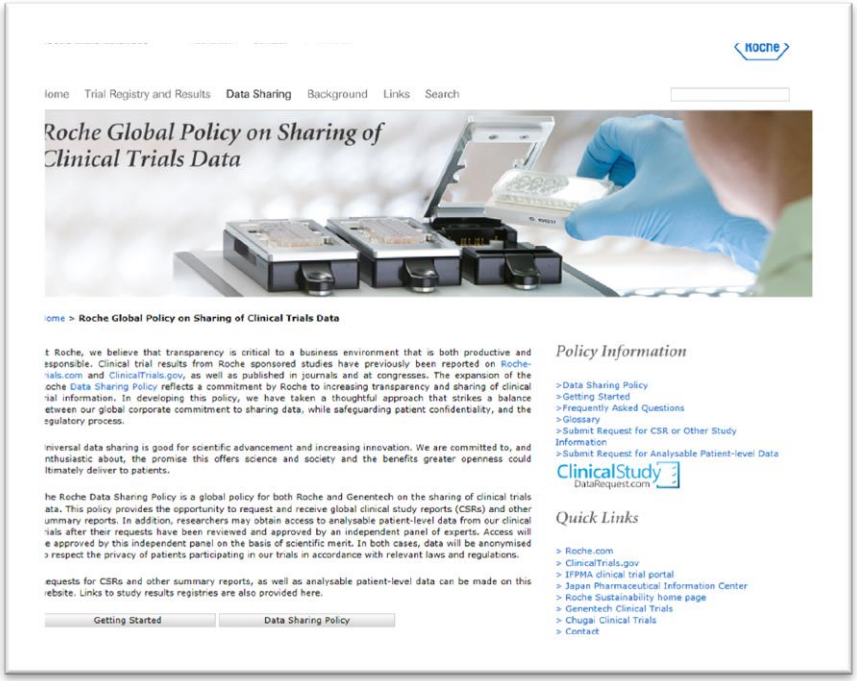
Clinical ethics

Public health ethics

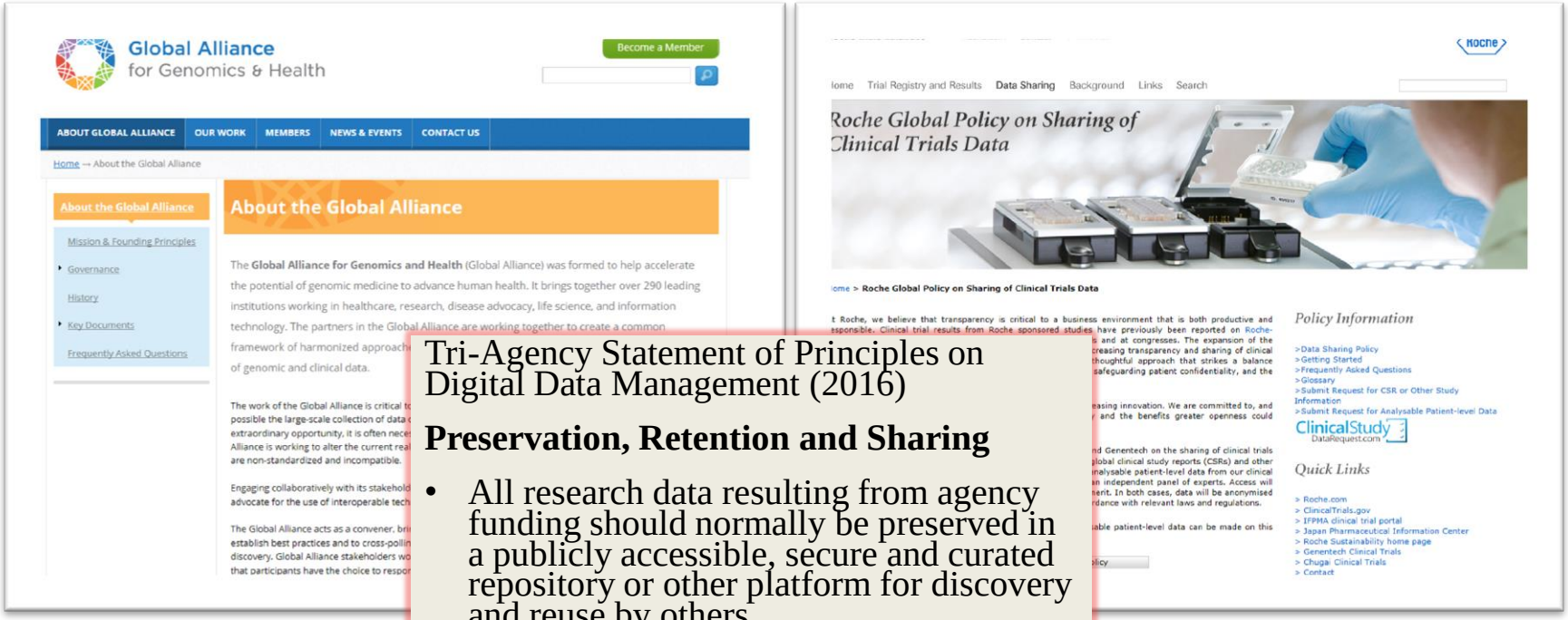
Research ethics in biobanking

Big data & international harmonization efforts: The expectations





Big data & international harmonization efforts: The expectations



Tri-Agency Statement of Principles on Digital Data Management (2016)

Preservation, Retention and Sharing

- All research data resulting from agency funding should normally be preserved in a publicly accessible, secure and curated repository or other platform for discovery and reuse by others.

But…. *How to operationalize?*

- We can all follow *TCPS2 (2014)* Article 5.5 and 12.3 criteria but are we doing it consistently?
- Uncertainty about legal implications
- How do we define de-identification and identifiable data?
- Who can be a data steward?

"Canada's governance of research ethics is fragmented, with significant differences across the provinces/territories. As well, laws on sharing data across provinces/territories & between countries differ or are lacking, sometimes leading to confusion for researchers and REBs about whether, or on what basis, data can be shared."

"The risk of potential harm resulting from access to data is tangible but low. The level of risk can be further lowered through effective governance mechanisms."

***Accessing Health and Health-Related Data in Canada* (2015) Key Findings (Council of Canadian Academies Expert panel)**
http://www.scienceadvice.ca/uploads/eng/assessments%20and%20publications%20and%20news%20releases/Health-data/HealthDataFullReportEn.pdf

Current focus of privacy review

Opinions from the bioethics community

Townend et al., 2016 point out that concerns over legal action or the "myth of liability" pose a significant impediment to international research, which in turn slows down the production of beneficial research outcomes for patient groups and society at large.

Council of Canadian Academies 2015 Expert panel report:

- "Despite these benefits, working with the data on which the research is based can be challenging. …..The greatest challenges, which are indeed barriers to beneficial research, are institutional. These include the application of differing, and in some instances overly cautious, interpretations of privacy legislation, and complex and lengthy approval processes that impede researchers' access to data".
- "The risk of potential harm resulting from access to data is tangible but low. The level of risk can be further lowered through effective governance mechanisms. "
- "Best Practices – Privacy Governance Dedicated Privacy Evaluation: The best practice entities have developed dedicated processes (parallel to REBs) that specifically evaluate privacy concerns when enabling data access."
- "The Panel found that legal definitions and interpretations differ across provinces/ territories and countries, which can lead to confusion or overly cautious interpretations of whether data can be accessed or shared. As a result, careful ethical judgments must be taken sometimes in the absence of specific laws."

-Townend et al. 2016. Streamlining ethical review of data intensive research. BMJ. http://www.bmj.com/content/354/bmj.i4181
-*Accessing Health and Health-Related Data in Canada* (2015) Key Findings (Council of Canadian Academies Expert panel) http://www.scienceadvice.ca/uploads/eng/assessments%20and%20publications%20and%20news%20releases/Health-data/HealthDataFullReportEn.pdf

Big data disconnect in practice

Table 3. Gap analysis results.

Procedural ethics theme	**Significant**	**Brief**	**Gap**
Data and tissues stored	88%	13%	0%
Accessibility	63%	19%	19%
Requirements for permission to access data and tissues	56%	31%	13%
Confidentiality	56%	31%	13%
Volume of data and tissues stored	56%	6%	38%
Data quality control	50%	19%	31%
Consent/assent guidelines	44%	38%	19%
Data management/ updating	38%	38%	25%
Requirements to store data and tissues	25%	38%	38%
Control to check if data/tissues are being submitted	6%	13%	81%
Disaster recovery	6%	13%	81%
Substantive ethics theme	**Significant**	**Brief**	**Gap**
Benefit sharing	44%	31%	25%
Commercial ties	25%	31%	44%
Special considerations for minors	13%	25%	63%
Incidental findings (IFs)	6%	6%	88%

Totals may not equal 100% due to rounding error.

*Longstaff, Khramova, Portales-Casamar, Illes. (2015). Sharing with More Caring: Coordinating and Improving the Ethical Governance of Data and Biomaterials Obtained from Children. PLOS One. 10(7): e0130527. doi:10.1371/journal.pone.0130527

The price of ignoring substantive and procedural ethics

Loss of public trust

- Nuu-chah-nulth blood scandal at UBC where samples were used for purposes not in line with donors objectives
- Texas blood spots used without informed consent of donors eventually led to the destruction of approximately five million samples
- Gymrek 2013 study in which researches were able to breach the anonymity of genetic databases in order to recover participant surnames

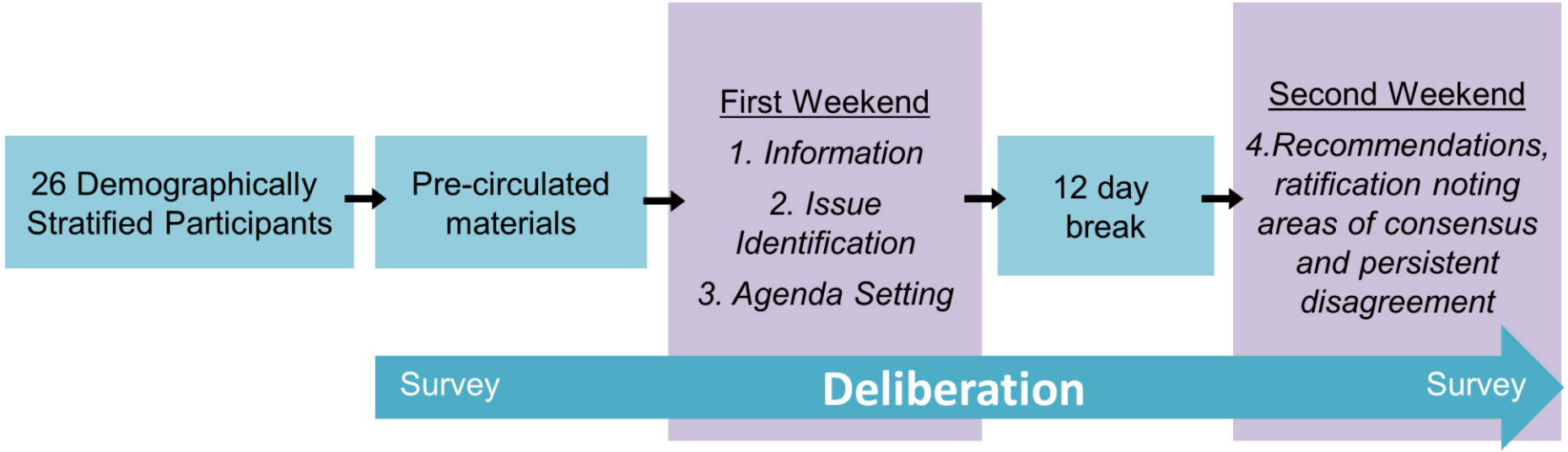
Engaging the public to establish good governance mechanisms

Public engagement methods: What is your intention?

Public engagement methods

- Focus groups, interviews, deliberative democracy public engagement event, poll, online risk communication, ethnographic observations, oral history, artistic installation .....?

Burgess Model of deliberative engagement



Deliberative democracy, democratic deficits, and public policy (PIs Mike Burgess, Stuart Peacock, et al.)

BC Biobank deliberation

- Vancouver April/May 2007

Mayo Clinic, Biobanks

- September 2007

Rochester Epidemiology Proj.

- November 2011

Western Australia

- Stakeholders: Aug 2008
- Public: November 2008

Salmon Genomics

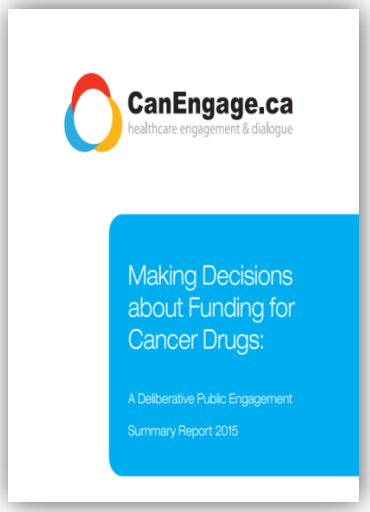
- Vancouver November 2008

BC BioLibrary

- Vancouver March 2009

RDX Bioremediation

- Vancouver April 2010



Biofuels

- Montreal Sept/Oct 2012

Biobank Project Tasmania

- April 2013

California Biobanks

- LA: May 2013
- SF: Sept/Oct 2013

Priority setting in Cancer Control

- Vancouver June 2014

Newborn Screening

- California Sept/Oct 2015

Canadian Partnership Against Cancer

- Across Canada 2016

Informing policy: How, why, and persistent challenges

Recruiting for representation of interests (n=25)

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Recruiting for representation in public deliberation on the ethics of biobanks

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Abstract

This paper addresses the dilemmas of participant sampling and recruitment for deliberative science policy projects. Results are drawn from a deliberative public event that was held in April and May, 2007. The research objective of *The BC Biobank Deliberation* was to assess deliberative democracy as an approach to legitimate policy advice from a subset of British Columbians concerning the secondary use of human tissues for prospective genomic and genetic research. The overall goal was to have participants identify key values that should guide a biobank in British Columbia. This paper assesses our team's group decision-making processes concerning participant sampling for the 2007 event. Results presented here should allow the reader to critically examine our team's choices and could also be used to assist advocates of deliberative democracy and others who may wish to propose similar events in the future.

ethics | participation in science policy | public participation

Table 3. Demographics of participants for the 2007 event[ab]

Gender	Female	12	Income	Less than $25 000	1
	Male	10	(21 responses)	$25 000–$49 999	3
Health region	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
Employment (20 responses)	Business/finance/ administration	3	Chronic illness/disability	Yes	4
	Chemical engineering	1		No	18[a]
	Social/education/ government/religion/ health	4	Risk of inherited disease	Yes	8
	Trades/transportation/ equipment	3		No	14[a]
	Unable to work	2	Religion	Atheist	1
	Looking for work	1		Buddhist	1
	Retired	5		Catholic	4[a]
	Other	1		Christian	6
Ethno-cultural	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	Number of children (17 responses)	None	6
	First Nations	2		1	4
	German	1		2	3
	Filipino	1		More than 2	4
	Other	7	Age (years) (18 responses)	Under 30	3
Education	More than high school	20		30–45	5
	Less than high school	2		45–60	4
				Over 60	6

[a]These demographics include one person who participated in only the first weekend's deliberation.
[b]Demographic information concerning income, number of children, and age were all collected during post event telephone interviews with participants.

Importance of education concerning deliberative topic

Case studies, decision scenarios, workbooks, field trips, videos.....

Lots of tricky concepts and difficult subjects

Whole genome sequencing (WGS)

- Whole genome sequencing (WGS), sequencing the full, complete, entire genome, determines the complete DNA sequence of an organism's genome at a single time.

Confidentiality versus the right to privacy

Anonymized data **De-identified data**

Importance of evaluation

- The importance of evaluating deliberative public engagement events is well recognized, but such activities are rarely conducted for a variety of theoretical, political, and practical reasons.
- Key challenges for our events:
  - Which frameworks and indicators should we use?
  - How should the events be evaluated?
  - Who should evaluate them? (*Arms length*)
  - How can we track and measure longer term impacts of deliberation on participants, policy makers, and others?

Example: The 2008 National Academy of Sciences report on Public Participation in Environmental Assessment and Decision Making (pre and post test) (See Longstaff and Secko, 2014)

1.	Quality of Assessments or Decisions
a)	Concerns expressed by publics were addressed in analysis
b)	Information was added; more information was considered in the process
c)	**Technical analyses were improved***
d)	Outputs reflected a broad view of the situation that addressed all issues considered important by participants
e)	Conclusions were based on and consistent with the best available evidence
f)	Innovative ideas were generated for solving problems
2.	Legitimacy of Process and Decisions
Pre-existing conflict was reduced or dissent clearly acknowledged and dealt with:	
a)	Mistrust among participants, including government agencies, was reduced
b)	Participants accepted the assessment or decision process as having conformed to standards of sound analysis and decision making, even if they did not agree with the final assessment or recommendation for action
c)	**The assessment or decision was widely accepted, even among nonparticipants***
d)	**Participants went outside the process to overturn its results, for example, with legal challenges or attempts to influence legislation (a negative indicator)***
3.	Capacity for Future Decisions
a)	Public participants became better informed about relevant environmental, scientific, social, and other issues
b)	**Participants and public officials gained a better understanding of each other***
c)	**Public officials gained skill in organizing decision processes***
d)	Participants gained skill in participatory decision making
e)	**Scientists gained understanding of public concerns***
f)	**Scientists developed, or committed to develop, new data or methods***

Filling the Void: Public Engagement Around a New Model for Access to Research Resources
*PI Kim McGrail from UBC

Canada has a long history of innovative and privacy-sensitive use of data for research. Current policies, however, have been criticized for being slow and complicated, and more importantly have not kept up with changes in data, technology, researcher desires, and public expectations. One important development is the use of tissues, blood and other specimens taken from individuals, including children, and in particular the linkage of that information to other existing data. **The public has had little role in creating the rules around use of these linked data and specimens for research. This is an important missing piece, because privacy legislation enables research that is for the public good, but nowhere is "public good" defined**. The goal of this program of research is to engage citizens deliberatively, give them information about data access, use of specimens in research and protection of privacy, and ask them to discuss the issues that matter to them and provide advice.

The research questions we will address include:

- What policy advice about access to data and specimens does the public provide?
- What rules of access do they recommend?
- Do deliberative participants question or change their decisions over time?
- And can an ongoing group of citizens have meaningful influence on operations of a data access system?

3. Case study discussions

Thank you!!

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