Ethics workshop: Empower your practice through ethics training

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Land acknowledgement

I live and work on the unceded traditional territories of the Skwxwú7mesh (Squamish), Səl̓ílwətaʔ/Selilwitulh (Tsleil-Waututh), and xwməθkwəy̓əm (Musqueam) Nations. I am trying in my daily work on the REB to honor Indigenous led research and data sovereignty and ensure all people have the opportunity to benefit from scientific research.

Case study

Middlemist, Knowles, and Matter (1976) conducted a study about personal space invasion in the men's restroom.

The facts:

- "The observer used a periscopic prism imbedded in a stack of books lying on the floor of the toilet stall. An 11-inch (28-cm) space between the floor and the wall of the toilet stall provided a view, through the periscope, of the user's lower torso and made possible direct visual sightings of the stream of urine. (p. 544)"

The abstract:

- "Personal space invasions produce arousal was investigated in a field experiment. A men's lavatory provided a setting where ...personal space invasions could occur in the case of men urinating …where proximity-induced arousal could be measured. Research on micturation indicates that social stressors inhibit relaxation of the external urethral sphincter, which would delay the onset of micturation, and that they increase intravesical pressure, which would shorten the duration of micturation once begun. Sixty lavatory users were randomly assigned to one of three levels of interpersonal distance and their micturation times were recorded. In a three-urinal lavatory, a confederate stood immediately adjacent to a subject, one urinal removed, or was absent. Paralleling the results of a correlational pilot study, close interpersonal distances increased the delay of onset and decreased the persistence of micturation. These findings provide objective evidence that personal space invasions produce physiological changes associated with arousal."

Sources: https://vault.hanover.edu/~altermattw/courses/220/readings/Ethics_reading.pdf and Middlemist, Knowles, and Matter. (1976). Personal space invasions in the lavatory: Suggestive evidence for arousal Journal of Personality and Social Psychology 33(5):541-6 · June 1976

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

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... .’’

A Framework for Ethical Decision-Making (McDonald et al)

1. Collect information and identify the problem.
2. Specify feasible alternatives.
3. Use your ethical resources to identify morally significant factors in each alternative (principles, moral models, ethically informed sources, formal tools like ethics consults, etc)
4. Propose and test possible resolutions.
5. Make your choice (live with it and learn from it).

Thoughts on rule following in ethics…

Ethics in research: A science lifecycle approach

Other format

PDF version (1.19 MB)

Contact Information

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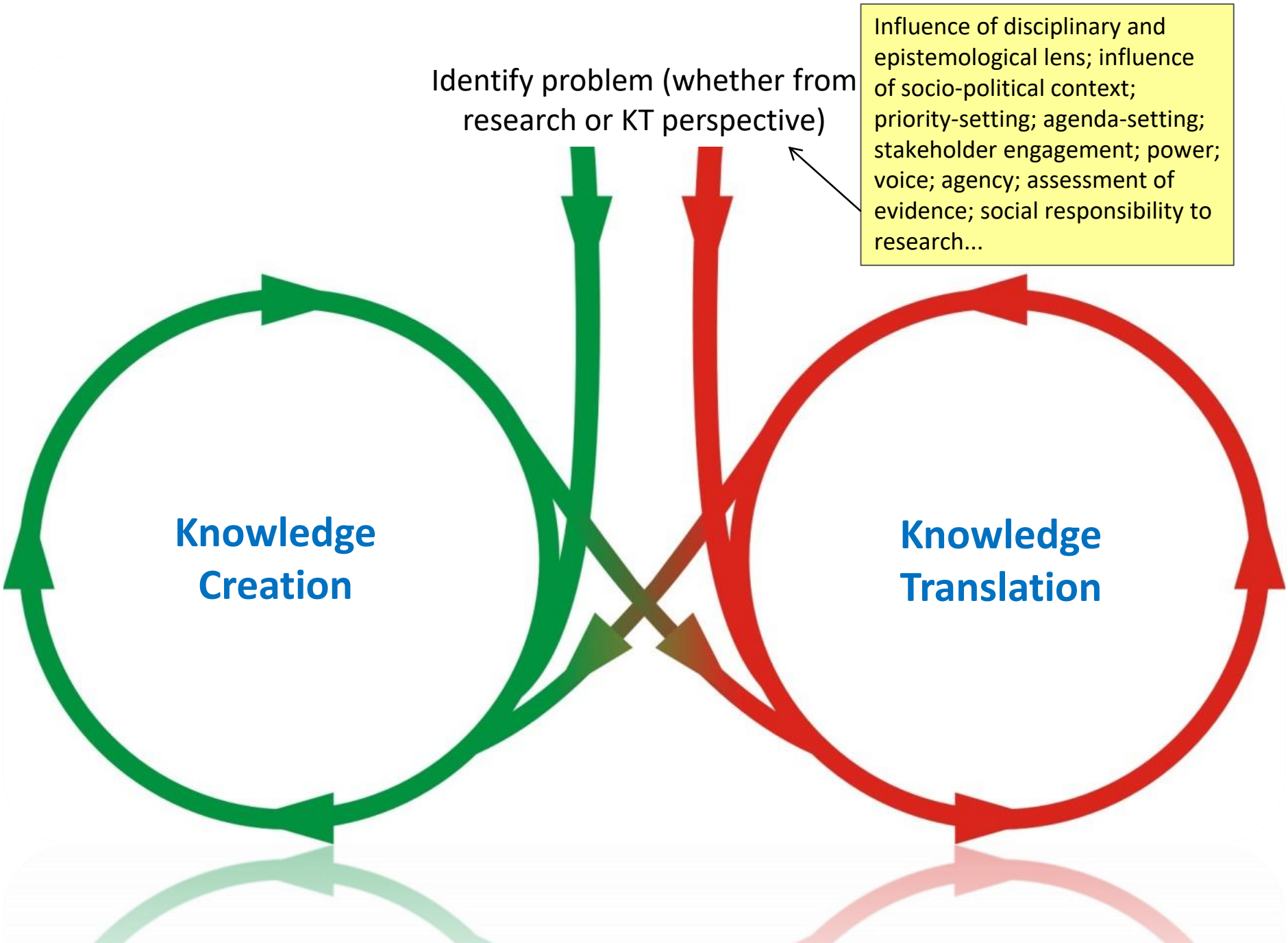
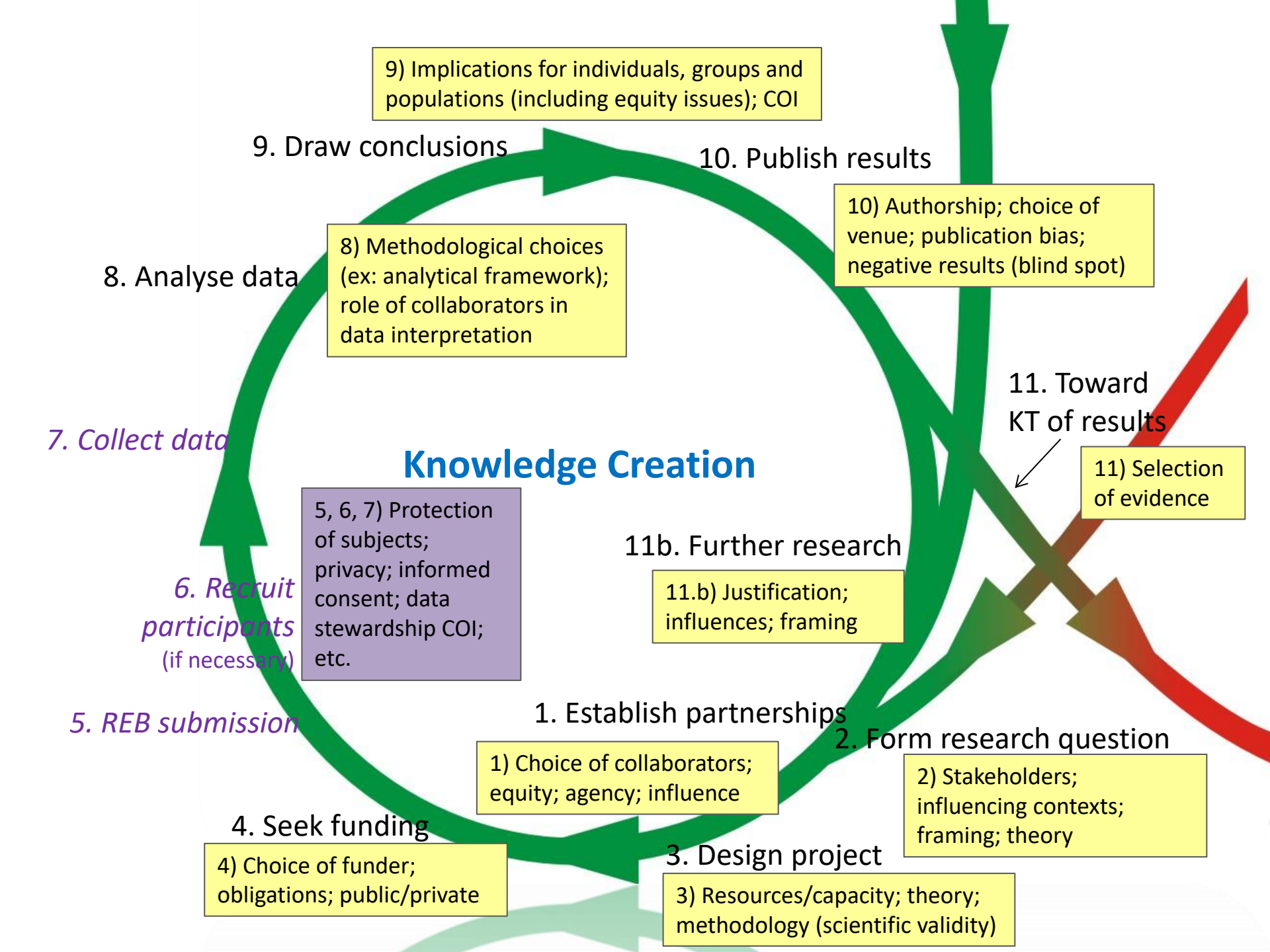
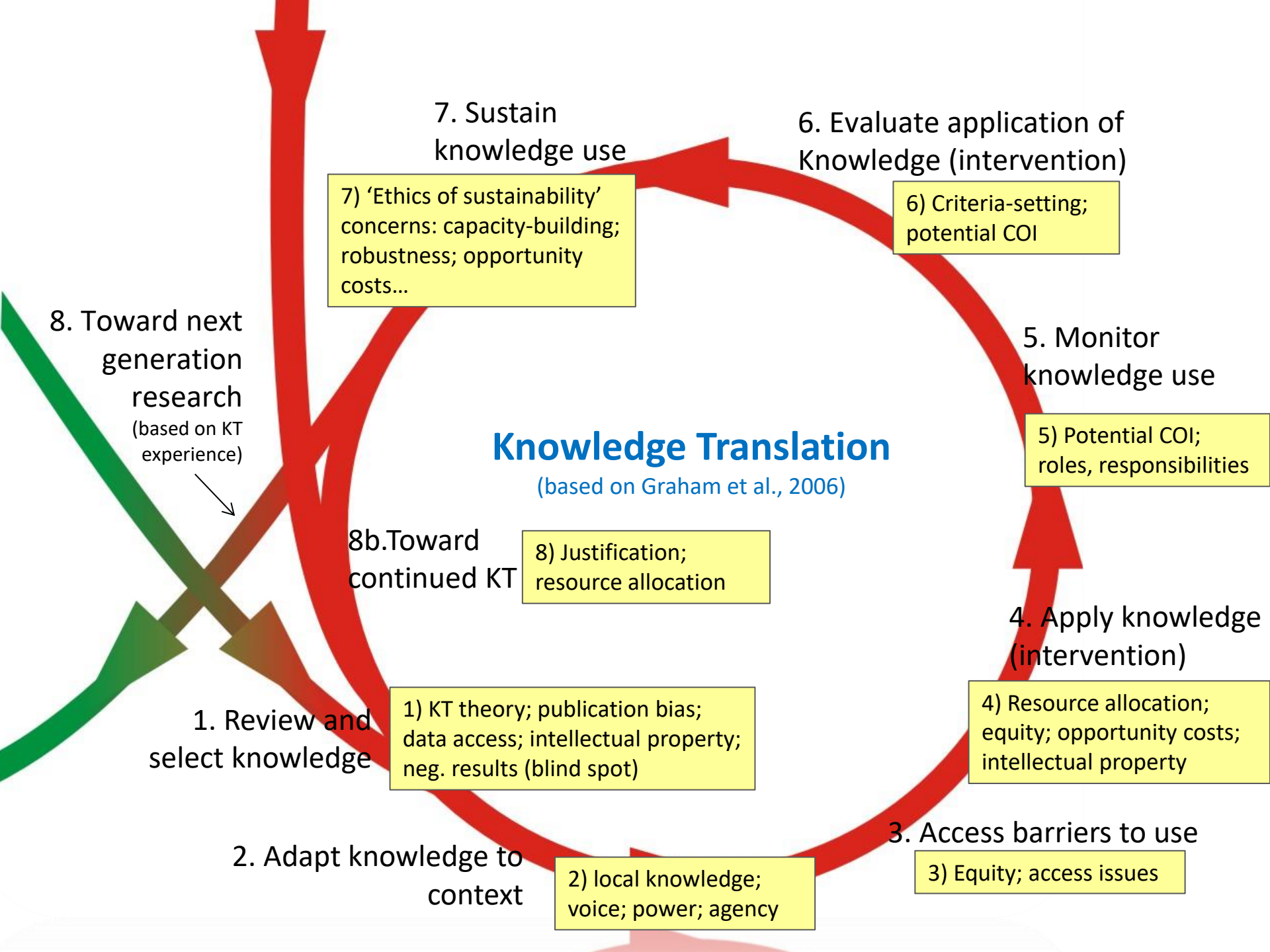
Date modified: 2014-11-24


Identify problem (whether from research or KT perspective)
Influence of disciplinary and epistemological lens; influence of socio-political context; priority-setting; agenda-setting; stakeholder engagement; power; voice; agency; assessment of evidence; social responsibility to research...
Knowledge Creation
Knowledge Translation


9) Implications for individuals, groups and populations (including equity issues); COI
9. Draw conclusions
10. Publish results
10) Authorship; choice of venue; publication bias; negative results (blind spot)
8. Analyse data
8) Methodological choices (ex: analytical framework); role of collaborators in data interpretation
11. Toward KT of results
7. Collect data
Knowledge Creation
11) Selection of evidence
5, 6, 7) Protection of subjects; privacy; informed consent; data stewardship COI; etc.
11b. Further research
11.b) Justification; influences; framing
6. Recruit participants
(if necessary)
5. REB submission
1. Establish partnerships
1) Choice of collaborators; equity; agency; influence
2. Form research question
2) Stakeholders; influencing contexts; framing; theory
4. Seek funding
4) Choice of funder; obligations; public/private
3. Design project
3) Resources/capacity; theory; methodology (scientific validity)

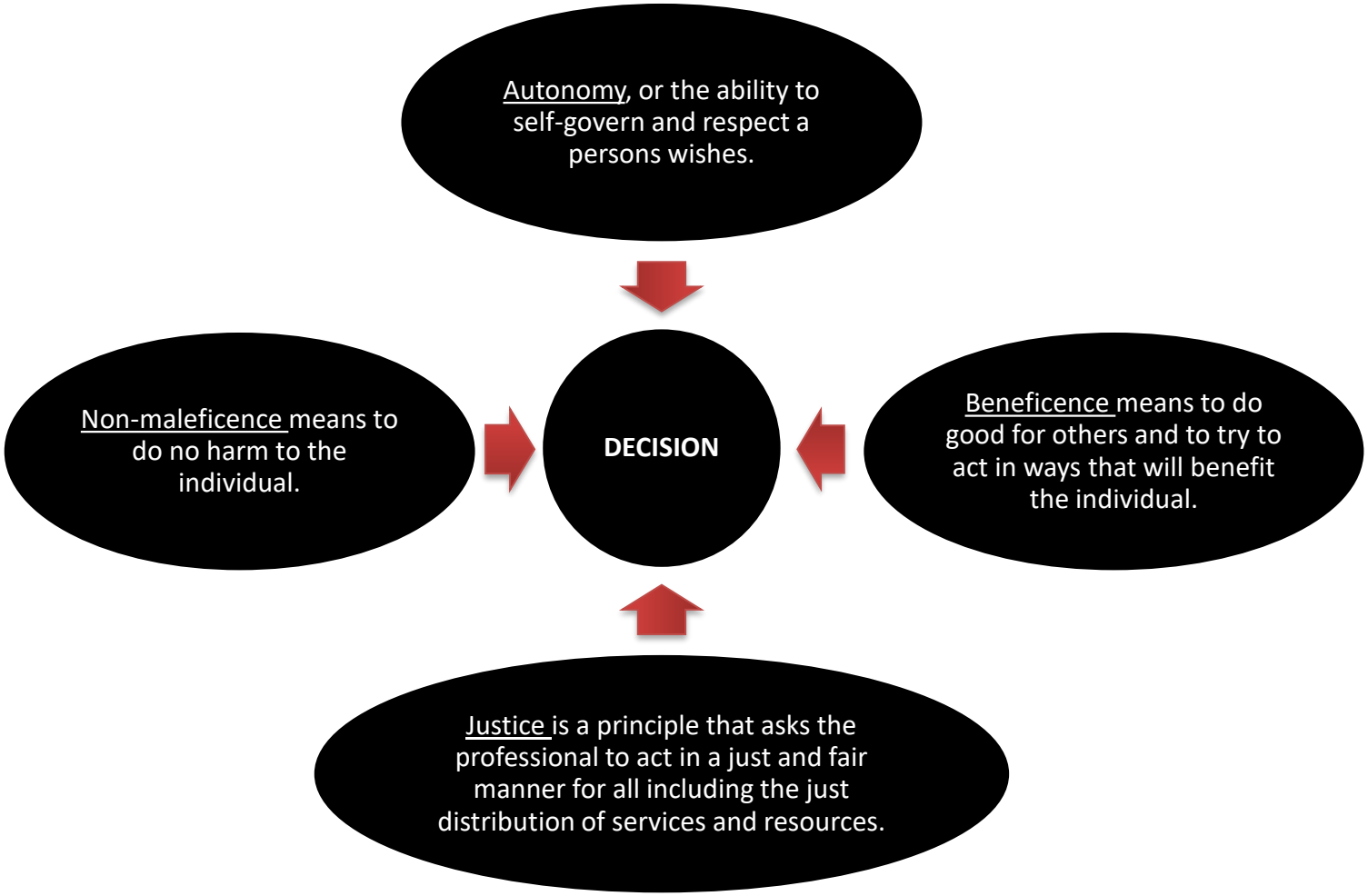

Knowledge Translation
(based on Graham et al., 2006)
1. Review and select knowledge
1) KT theory; publication bias; data access; intellectual property; neg. results (blind spot)
2. Adapt knowledge to context
2) local knowledge; voice; power; agency
3. Access barriers to use
3) Equity; access issues
4. Apply knowledge (intervention)
4) Resource allocation; equity; opportunity costs; intellectual property
5. Monitor knowledge use
5) Potential COI; roles, responsibilities
6. Evaluate application of Knowledge (intervention)
6) Criteria-setting; potential COI
7. Sustain knowledge use
7) 'Ethics of sustainability' concerns: capacity-building; robustness; opportunity costs…
8. Toward next generation research
(based on KT experience)
8b.Toward continued KT
8) Justification; resource allocation

Silos and the compliance police

CTV news photo Published Saturday, June 2, 2012

Back to basics:

Applied ethics principles (all things considered judgments)



Conceptual framework (people centered)

Substantive ethics

Procedural ethics

Ethics and artistic practice: 2014 Instagram experiment by artist Amalia Ulman

"The digital artist spent four months curating an Instagram profile that documented the life of a wannabe it-girl trying to make it in LA…climaxing with a (fake) [breast augmentation] and public apology. At the point when almost 90,000 followers were invested in Ulman's life, she announced that it had all been a hoax."

How this 2014 Instagram hoax predicted the way we now use social media | Dazed

Notions of risk and harm

- REB and privacy review must take many notions of risk and benefit into consideration when conducting principles-based work.
- Risk – The possibility of the occurrence of harm. The level of foreseeable risk posed to participants by their involvement in research is assessed by considering the magnitude or seriousness of the harm and the probability that it will occur, whether to participants or to third parties.
- Harm – Anything that has a negative effect on participants' welfare, broadly construed. The nature of the harm may be social, behavioural, psychological, physical or economic (concern for welfare principle).
- Balancing harms and benefits, minimizing harm and maximizing benefit are, in fact, not principles, but are the means by which the principle of concern for welfare is put into effect.

Notions of benefit

- Direct benefits to participants
- Potential benefits (may be physical, social, psychosocial)
- Research that offers no direct benefit but instead offers potential benefits to other future others (who you represent!!!). Also referred to as aspirational benefits
- Collateral, indirect, or side benefits (example-a learning opportunity, meeting other people with your condition)
- Charitable participation standard (example-appreciating the rewards of altruism)

Notions of justice

Belmont: Who ought to receive the benefits of research and bear its burdens? This is a question of justice, in the sense of "fairness in distribution" or "what is deserved." An injustice occurs when some benefit to which a person is entitled is denied without good reason or when some burden is imposed unduly

TCPS2: A core principle of TCPS2 that refers to the obligation to treat people fairly and equitably. Fairness entails treating all people with equal respect and concern. Equity requires distributing the benefits and burdens of research participation in such a way that no segment of the population is unduly burdened by the harms of research or denied the benefits of the knowledge generated from it.

*Justice also includes the just distribution of resources and services. For example, there are costs associated with participating in many studies that are not a priority for a community. Sometimes communities use gatekeepers to address this issue.

Also, benefits in research could be viewed as a way of addressing past injustices.

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Distinguishing ethics notions of privacy from privacy law (institutional issue)

Privacy is not an absolute value. It is one of the things we take into consideration while making "all things considered judgements" in ethics. There are times when it is reasonable to trade-off privacy to achieve just outcomes and there are times when privacy considerations will prevail. Making these decisions requires a multi-disciplinary team to consider both the procedural (doing things properly) and substantive (the moral values that guide you) ethics of a case. Input from the research team and patients is also essential.

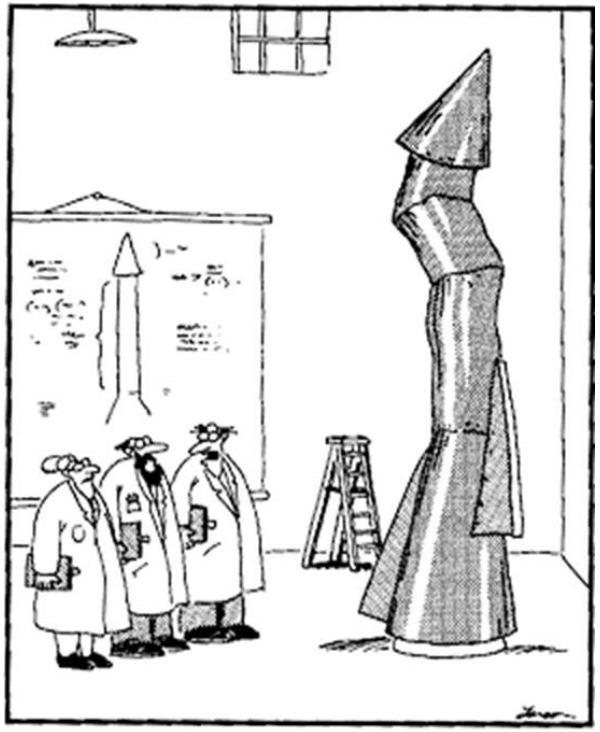
What does it mean to “do good” and who should decide?

Case study: Violence against nurses and critical inquiry

A nurse approaches you about a quality improvement study they want to do. They are concerned about violent encounters other nurses have experienced in their emergency room although they have never experienced one firsthand. They are proposing to interview nurses in their hospital about their experiences with violence and plan to publish the results in a high-profile medical blog.

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.



"It's time we face reality, my friend. ... We're not exactly rocket scientists."

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

Case study: Moral permissibility of not knowing or informing

The condition: Autosomal dominant arrhythmogenic right ventricular cardiomyopathy (ARVC)

The facts:

- Very high chance of inheriting the condition where one parent affected
- 50% of affected males die in the absence of treatment by 40 years and 80% by 50 years, with corresponding risks for females of 5% and 20%
- Effective primary prevention of potentially lethal condition is available with implantable cardioverter defibrillator therapy
- In their report, Pullman and Hodgkinson explain that at the outset of the research there was no known genetic location for the condition under study; however, it later became "clear that DNA testing could define disease status pre-symptomatically" (p.200).

The following case arose within this context:

- A female individual at 50% a priori pedigree risk participated in genetic linkage analysis research.
- There was no experience in immediate family of serious symptoms of ARVC, even though multiple sudden cardiac death in young people in the extended pedigree;
- Research revealed woman had a high-risk DNA haplotype [ie affected]. Nevertheless, this subject refused to learn her DNA results or to receive further clinical testing;
- The woman in question had eight adult children, including five males who were between 20 and 40 years of age.

*But what about the issue of moral distress of researchers?

* Case from Pullman and Hodgkinson. (2006). Genetic knowledge and moral responsibility: ambiguity at the interface of genetic research and clinical practice. Clin Genet 2006: 69: 199–203.

Autonomy

- The right to self-govern and make decisions. The right to self-determination. We have the duty to respect the decisions made by other people concerning their own lives.

Relational notions of autonomy

- “Oppression permeates both personal and public relationships.
- A richer, more politically sensitive standard of autonomy should make visible the impact of oppression on a person’s choices as well as on their very ability to exercise autonomy fully.
- Despite its focus on individuals, standard interpretations of autonomy have tended to think of selves as generic rather than distinctive beings.
- Under a relational view, autonomy is best understood to be a capacity or skill that is developed (and constrained) by social circumstances. It is exercised within relationships and social structures that jointly help to shape the individual while also affecting others’ responses at their efforts at autonomy.”

- What might influence a person’s ability to exercise autonomy? Colonization, racism and racist systems, past history (residential school system)……..? Examples?

Quoted from -Sherwin. A relational approach to autonomy in health care. Readings in health care ethics.

Operationalizing autonomy – participant centered informed consent

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

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, medical research with LARs must be reviewed by a *designated* REB.
    - *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

A few more important concepts

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
  - How might genetics research impact Indigenous individuals, families, and communities?

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 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.**

Case study

- A woman who is very ill with ovarian cancer goes for genetic testing at her hospital. She dies before the results are produced.
- The tests reveal that she had an inherited genetic mutation that put her at significant risk for ovarian and other cancers.
- The woman is married but has no children. She does however have several nieces and nephews.
- Her partner does not get along with her family.


Vulnerability

Case study: Incel communities

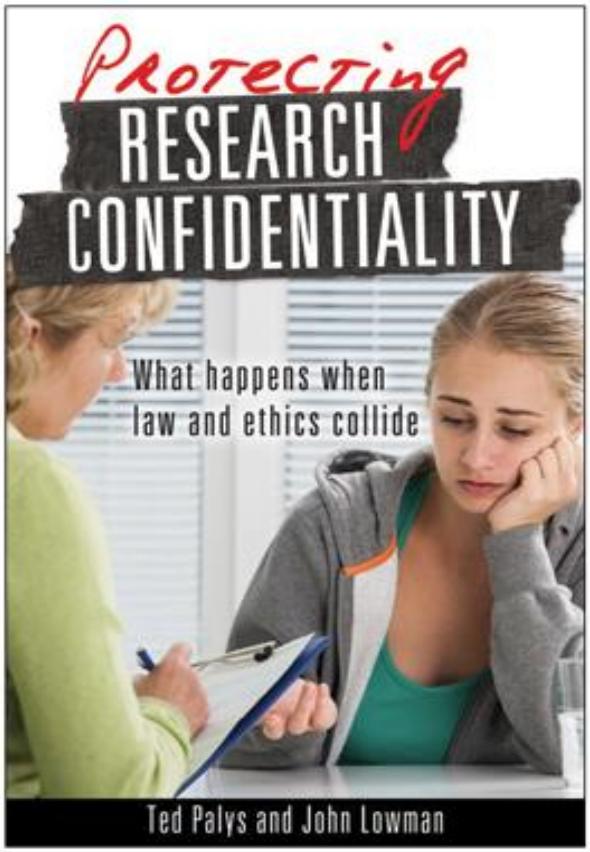
- A researcher wants to explore the reasons that motivate teenagers to join the incel community. As part of their research, they plan to join online incel groups and invite them to discuss their view in smaller focus groups or interviews and then publish the findings in a peer reviewed journal.

"The incel subculture's attitudes can be characterized by extremist resentment, hostility, sexual objectification … blaming of women and the sexually successful for their situation. … Over time the subculture has become associated with extremism and terrorism, and since 2014 there have been multiple mass killings, mostly in North America, perpetrated by self-identified incels, as well as other instances of violence or attempted violence…. Incel communities continue to exist on more lenient platforms including 4chan, 8chan, and Gab…"(WIKI)

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."

How do we decide when a decision in a complex system like healthcare is reasonable and just?

The new therapeutic orphans

- It is not uncommon to leave entire Health Authorities or populations out of research studies because of privacy barriers (the *Asterisk Nation).
- Eshera et al, found that for new drug applications and biologic license applications 77% of study participants were whites (Eshera et al. *Am J Ther* 2015; 22:435-55).
- This is often blamed on mistrust of non-white populations and lack of willingness to participate but researchers are finding that this is not always the case.
  - See for example, Wendler et al. *PLos Med* 2006; 3: e19 and Kaplan et al. Knowledge and attitudes regarding clinical trials and willingness to participate among prostate cancer patients. *Contemp Clin Trials* 2015; 45(Pt B):443-448).

 But we cannot let our concerns override the importance of collaboration!

Case study: What kind of animal is it?

- Public health professionals are creating a national data sharing platform for what they view as disease X surveillance.
- There is concern about how to share unconsented data from various provinces because some local sites view this as a research study requiring consent or a waiver of consent from the REB.
- The team decides to compromise and send the project to a REB.

Case study

A clinician tells you that some of their pregnant patients are using marijuana to help with pain and discomfort during their pregnancies.

The clinician would like to investigate the benefits and risks of using this substance during pregnancy and asks for ethics advice about how best to conduct such a study.

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Working with health data in B.C.- Access

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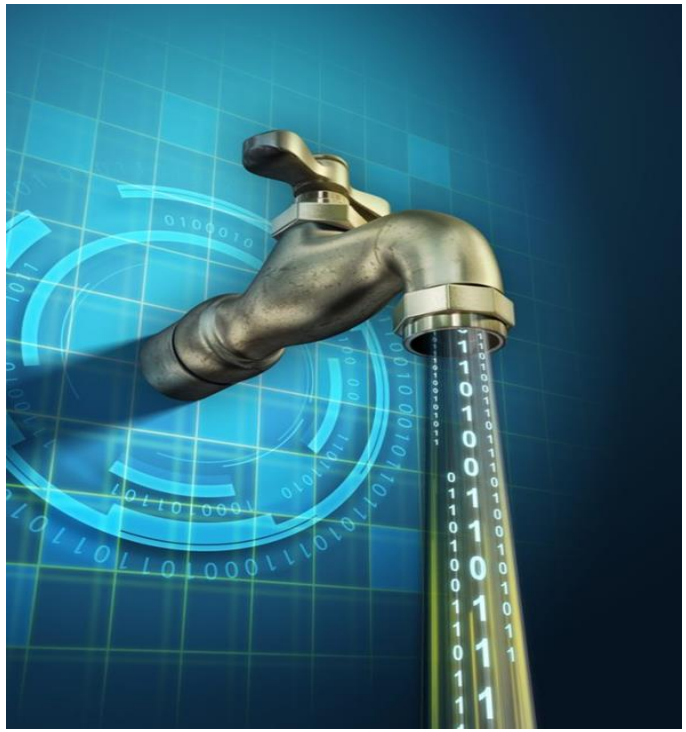
Aspirational: Learning Heath System (LHS)

Easterling et al., published the results of a literature review in 2022 that sought to identify LHS elements emphasized most by LHS researchers. They identified 4 main enabling conditions that support a LHS including:

- expertise,
- data systems and informatics infrastructure,
- investment of LHS-dedicated resources, and
- a supportive culture



*Easterling D, Perry AC, Woodside R, Patel T, Gesell SB. Clarifying the concept of a learning health system for healthcare delivery organizations: Implications from a qualitative analysis of the scientific literature. Learn Health Syst. 2021 Jul 22;6(2):e10287. doi: 10.1002/lrh2.10287. PMID: 35434353; PMCID: PMC9006535.

Surveying the PHSA research community to inform my work (n=224)

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Top 2 priorities

- Better and more efficient data access within PHSA (70%)
- Streamlining research compliance at PHSA and reducing bureaucracy (67%)

BC Ministry of Health work in progress

We need to transform how all of us work to support a learning health system: Illustrative survey quotes

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"Patients and families want their data collected and used for good purposes, and there are SO many roadblocks to doing this. [We need to] work together so we can translate our research results through PHSA widely to families, public."

"The whole organization needs to realize that research and care and intrinsically intertwined and one cannot succeed without the other, and that for the most part this is what our patients want."

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Health datasets in BC currently available for research, QI, and/or clinical purposes

- Clinical, quality improvement and research access to Health Authority data by internal users and external users (different processes)
- Health Data Platform BC
- Panda platform (PHSA)
- Data registries (clinical, QI, and research)
- Research registries
- Ministry data for research
  - Data Stewardship Committee (DSC) established under the E-Health (Personal Health Information Access and Protection of Privacy) Act reviews requests to use information contained in a health information bank or a prescribed MoH database or PharmaNet data (as mandated by the Pharmaceutical Services Act)

CanPath Portal

The Canadian Partnership for Tomorrow's Health (CanPath) Portal provides the research community with the necessary resources to identify epidemiological and biological data available from six participating cohorts to answer innovative research questions. A request for access to CanPath data is initiated directly through the CanPath Portal.

Cohort

Find out more about the six regional cohorts of CanPath.

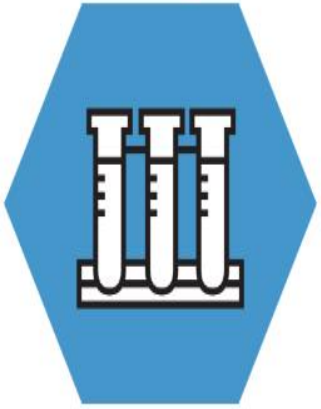
Read more

Data

Find out more about CanPath's datasets and data harmonization approach.

Read more

Biosamples



Find out more about CanPath's biological sample collection and its upcoming availability.

Read more

Access

Find out more about the CanPath Access Policy, access process, and approved research projects.

Read more

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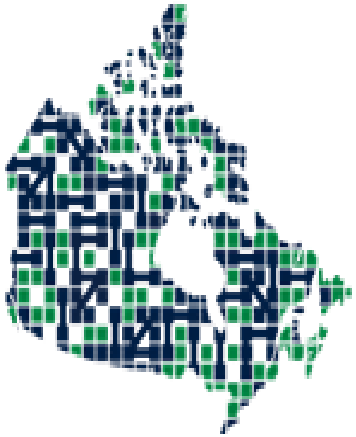

Réseau de recherche sur les données de santé du Canada

Health Data Research Network Canada

Filters

Specimen Collector Sample ID

e.g. AB-12345

Study ID

BCCDC-BC	169,794
PHO-ON	120,891
ABPL-AB	74,571
LSPQ-QC	72,350
RRPL-SK	29,944

7 More

Sample Collected By

BCCDC Public Health Laboratory	169,794
Public Health Ontario (PHO)	120,891
Alberta Precision Labs (APL)	74,571
Laboratoire de santé publique du Québec (LSPQ)	72,350
Saskatchewan - Roy Romanow Provincial Laboratory (RRPL)	29,944

10 More

Sequence Submitted By

BCCDC Public Health Laboratory	169,794
Public Health Ontario (PHO)	120,890
Alberta Precision Labs (APL)	74,571
Laboratoire de santé publique du Québec (LSPQ)	72,348
National Microbiology Laboratory (NML)	31,426

6 More

Submission Date

YYYY/MM/DD to YYYY/MM/DD

← Start by selecting filters

511,276 Files | **~ 510,000 Viral Genomes** | **12 Studies** | **15.69 GB**

Showing 1 - 20 of 511,276 files

Download Dataset | Columns

Study ID	Specimen Co...	Sample Colle...	Sequence Su...	Submission ...	Sample Colle...	Lineage Name	Scorpio Call	Geo_loc_na...	Purpose Of S...	Host Age	Host Age Bin	Host Gender	Purpose Of S...	Sequencing I...	Consensus S
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LSPQ-QC	QC_29569	Laboratoire d...	Laboratoire d...	2021-12-17	2020-03-29	B.1.1.176		Quebec	Diagnostic te...		20 - 29	Female	Not Provided	Illumina Nova...	iVar
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PHO-ON	ON_460932	Public Health...	Public Health...	2022-07-15	2022-06-20	BA.2.9	Omicron (BA....	Ontario	Diagnostic te...		Missing	Male	Baseline surv...	Illumina MiSeq	Freebayes
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LSPQ-QC	QC_291443	Laboratoire d...	Laboratoire d...	2022-02-02	2020-03-26	B.1		Quebec	Diagnostic te...	43	40 - 49	Female	Baseline surv...	Illumina Nova...	Freebayes
LSPQ-QC	QC_40889	Laboratoire d...	Laboratoire d...	2021-12-17	2020-10-06	B.1.1.176		Quebec	Diagnostic te...		40 - 49	Male	Baseline surv...	Illumina Nova...	iVar
LSPQ-QC	QC_546004	Laboratoire d...	Laboratoire d...	2022-11-16	2022-10-30	BA.5.1.37	Omicron (BA....	Quebec	Diagnostic te...	1	0 - 9	Male	Baseline surv...	Illumina Next...	Freebayes
ABPL-AB	AB_81692	Alberta Precis...	Alberta Precis...	2021-08-26	2021-03-28	B.1.438.1		Alberta	Diagnostic te...		Not Provided	Not Provided	Baseline surv...	Oxford Nano...	ARTIC
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Canadian Precision Health Initiative

CGEn proudly supports the newly launched Canadian Precision Health Initiative (CPHI) led by Genome Canada

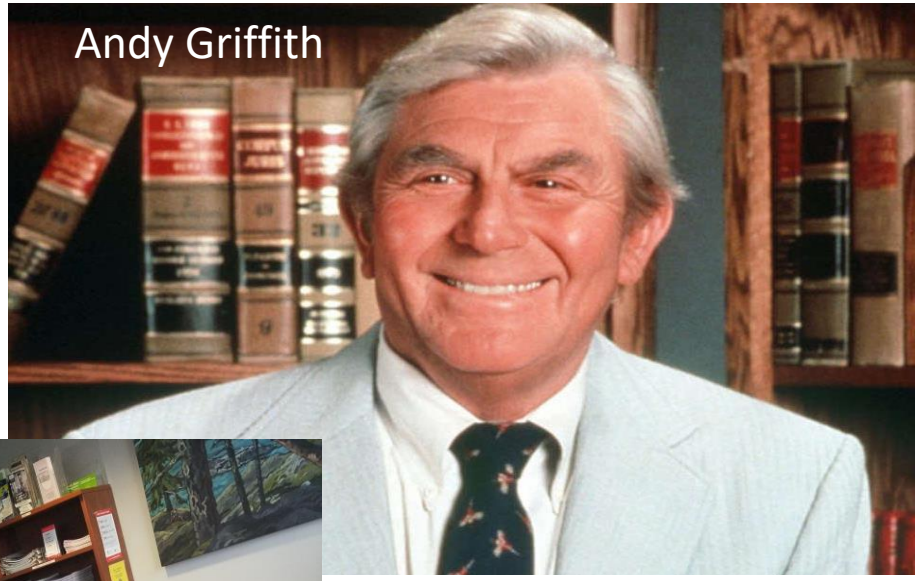
CGEn is supporting the CPHI through its three nodes (The Centre for Applied Genomics at The Hospital for Sick Children, the McGill Genome Centre at McGill University, and Canada's Michael Smith Genome Sciences Centre at BC Cancer) by generating high-quality genomic data for 11 CPHI data generation projects.

"CGEn is proud to play a significant role in this important initiative for Canada. Our three nodes will support whole genome sequence data generation and analysis for more than 90,000 samples, as well as data transfer to the Pan-Canadian Genome Library. Thanks to investments in CGEn by the Canada Foundation for Innovation's Major Science Initiatives and Innovation Funds, provincial governments and other partners, we are well-positioned to contribute high-quality data and expertise, foundational to Canada's leadership in harnessing genomic data to improve health for all." – Dr. Meredith McLaren, CEO, CGEn.

Read more on our website.

Inaction as value neutral?


Alexander the Great


Andy Griffith


Me!!

- "The right to benefit from scientific progress and its application is an important part of article 15 of the International Covenant on Economic, Social and Cultural Rights, and therefore, a fundamental aspect of cultural rights that the mandate has looked into."
- The right to enjoy scientific progress and its application covers all sciences: …Implementation of this right means:
  - Access for all without discrimination to the benefits of science and its application necessary to live a dignified life, including scientific knowledge;
  - Opportunities for all to contribute to science and scientific research;
  - The information necessary for individuals and communities to engage in decision-making regarding areas of research and development, and the related right to information; and
  - An environment that promotes the conservation, development and diffusion of science and technology, and the freedom indispensable for scientific research."

Ethics exceptionalism

Calls for different procedural and substantive reviews.

- Uncontested example: Indigenous People
- There are many great resources for those who wish to engage with Indigenous peoples for research, QI, etc. Please see below for some examples:
  - Disaggregated demographic data collection in British Columbia: The grandmother perspective
  - UBC Indigenous Research Support Initiative
  - Centre for Indigenous Research & Community-Led Engagement
  - British Columbia Network Environment for Indigenous Health Research
  - The First Nations Principles of OCAP®

Research with Indigenous communities and community consent

Requirement of Community Engagement in Aboriginal Research

Article 9.1 Where the research is likely to affect the welfare of an Aboriginal 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 Aboriginal 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 Aboriginal identity or membership in an Aboriginal community is used as a variable for the purpose of analysis of the research data; and
- interpretation of research results that will refer to Aboriginal communities, peoples, language, history or culture.

Waiver 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

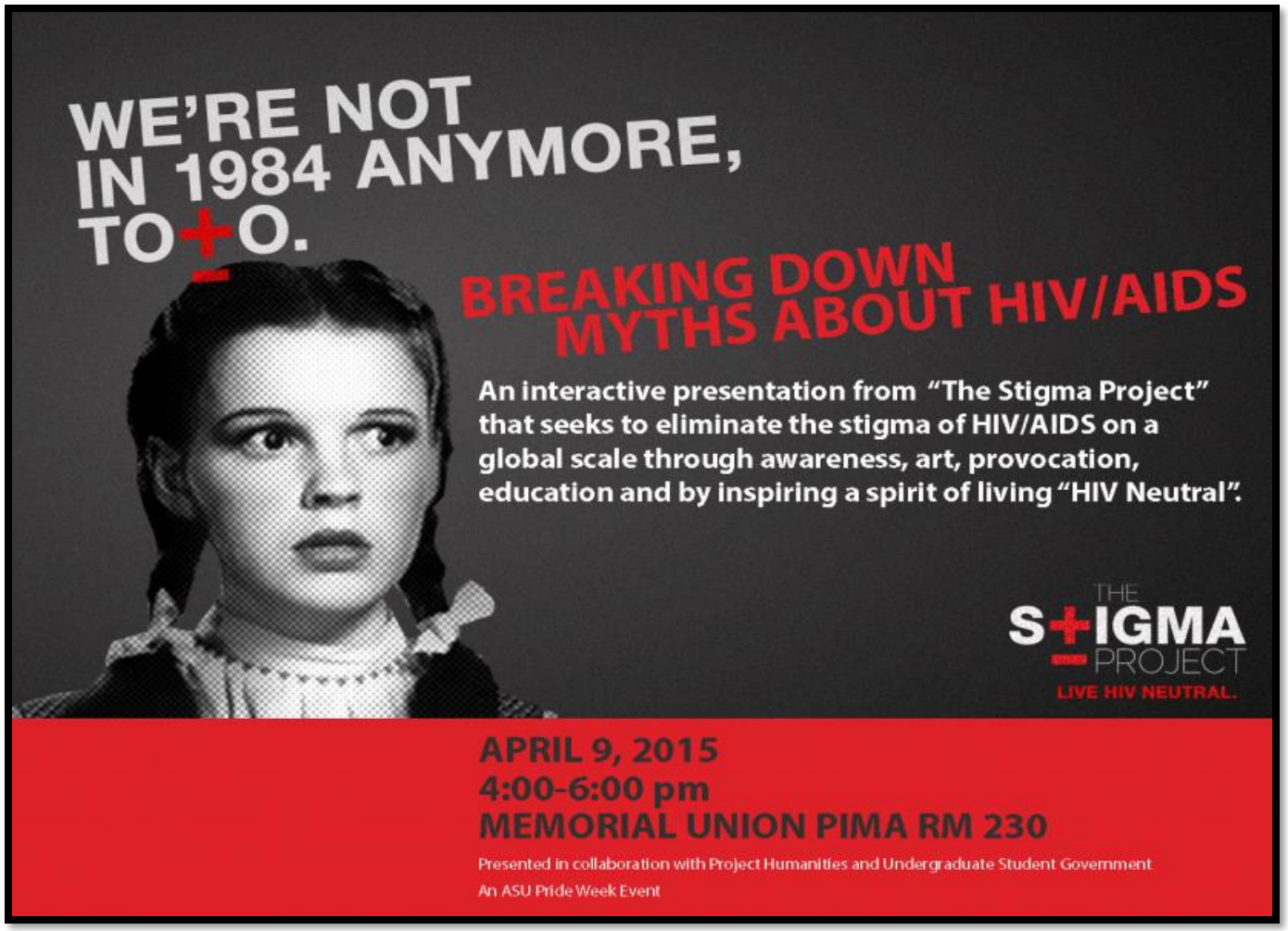
Article 12.3B Researchers shall seek REB review, but are not required to seek participant consent, for research that relies exclusively on the secondary use of nonidentifiable human biological materials.

Our data. Our stories. Our future.

We envision that every First Nation will achieve data sovereignty in alignment with its distinct world view.

LEARN MORE ABOUT WHO WE ARE

Ethics exceptionalism is not static



Cultural shift…..Who do we serve?

Consent to good governance

Ethics theory and reality: Closing the gap

We must all make a commitment to empower patients/publics and stop protecting institutions

We must all acknowledge the harms we actively create by relying on consented data when it is not appropriate


thank you