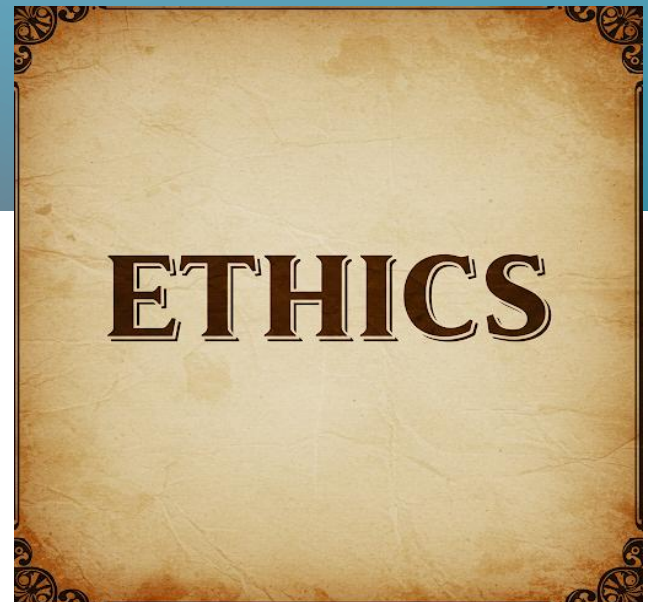


Ethics workshop: Empower your practice through ethics training

Time: 10:45-12:15

Holly Longstaff, PhD, (CIPP/C)
Director Research Integration and Innovation
UBC Children's & Women's Research Ethics
Board, Chair



Land acknowledgement

I live and work on the unceded traditional territories of the Skwxwú7mesh (Squamish), Səlílwətaʔ/Selilwítlh (Tseil-Waututh), and xwməθkwəyəm (Musqueam) Nations. Today I am presenting on the traditional territory of the Lekwungen-speaking peoples of the Songhees Nation and Xʷsepsəm (Esquimalt) Nation, and W̱SÁNEĆ peoples.

I am trying in my daily work in ethics to honor Indigenous led research and data sovereignty and ensure all people have the opportunity to benefit from scientific research.

**Bioethics
tools and
concepts**




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What is applied ethics?

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- 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).

Major events and privacy breaches (remedies to problems)

Office of the Information and Privacy Commissioner for British Columbia



Investigation Report 26-02

Privacy breaches following the Lapu Lapu Day Festival

February 2026

CANLII CITE: 2026 BCIPC 10
QUICKLAW CITE: [2026] B.C.I.P.C.D. No. 10

oipc OFFICE OF THE
INFORMATION &
PRIVACY COMMISSIONER
FOR BRITISH COLUMBIA

**Thoughts
on rule
following
in ethics...**



- Funding ▾
- Institutes ▾
- Strategies ▾
- Initiatives ▾
- Collaboration ▾
- Health research in action

[Home](#) → [Collaboration](#) → [Ethics](#)

Ethics in Research: A Science Lifecycle Approach

- Introduction
- Four Themes
- Integrating Ethics and the Knowledge-To-Action Cycle
- Hypothetical Scenarios
- Biomedical Research
- Clinical Research
- Health Services Research
- Social, Cultural, Environmental, and Population Health Research

Ethics in research: A science lifecycle approach

[Introduction to this workbook](#)

[Four themes of CIHR funded health research](#)

[Integrating ethics and the knowledge-to-action cycle](#)

[Ethics resources](#)

[Hypothetical scenarios:](#)

[Biomedical research](#)

- [Publishing your research](#)
- [Modifying research questions](#)

[Clinical research](#)

- [Who decides?](#)
- [Research with children and young adults](#)
- [Testing a new vaccine](#)

[Health services research](#)

- [Research choices](#)
- [Reporting research results](#)
- [Surgical robots](#)

[Social, cultural, environmental and population health research](#)

- [Research using social media](#)
- [Occupation health](#)

Other format

[PDF version \(1.19 MB\)](#)

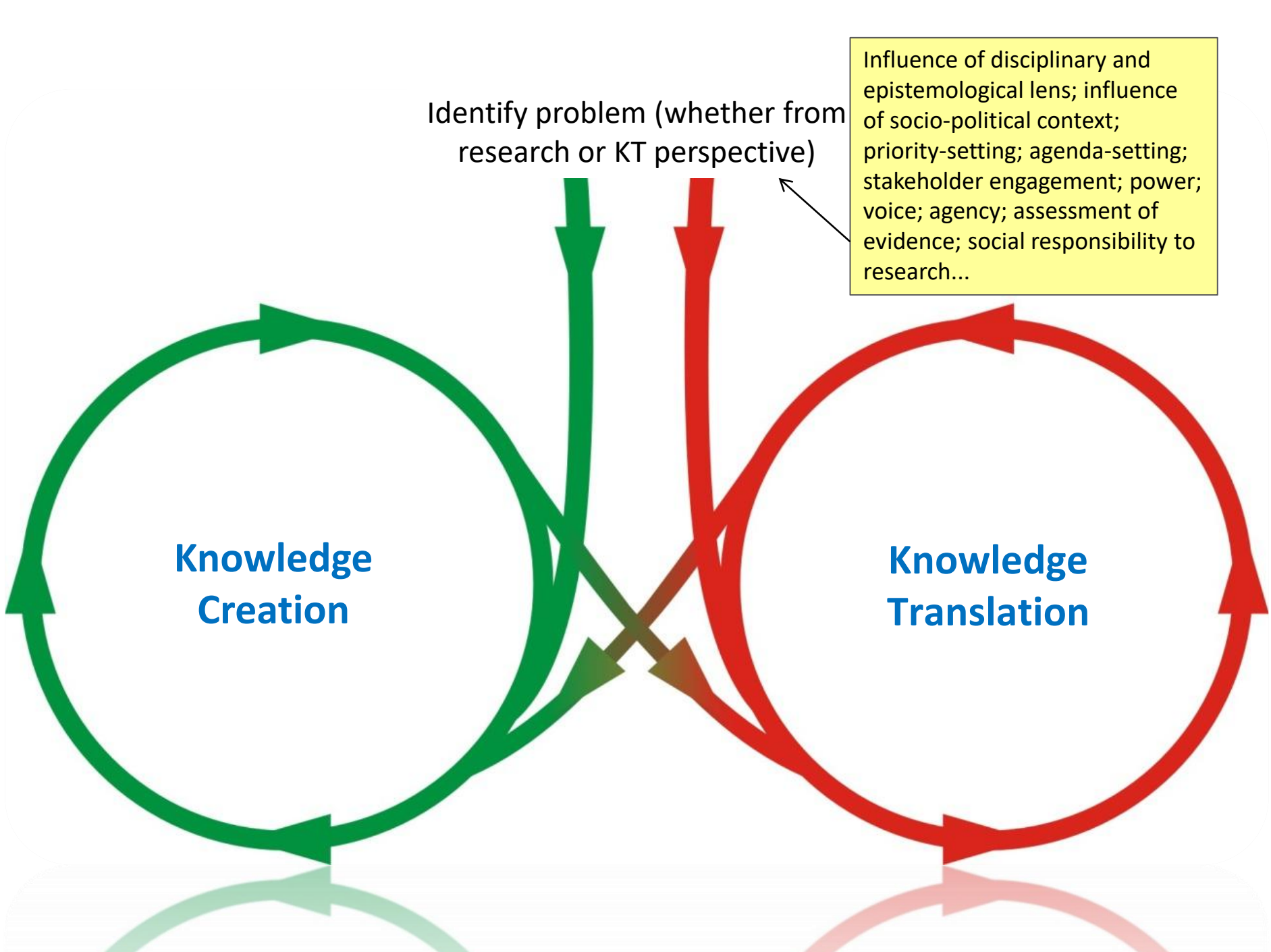
Contact Information

Ethics Office

Email: ethics-ethique@cihr-irsc.gc.ca

Date modified: 2014-11-24



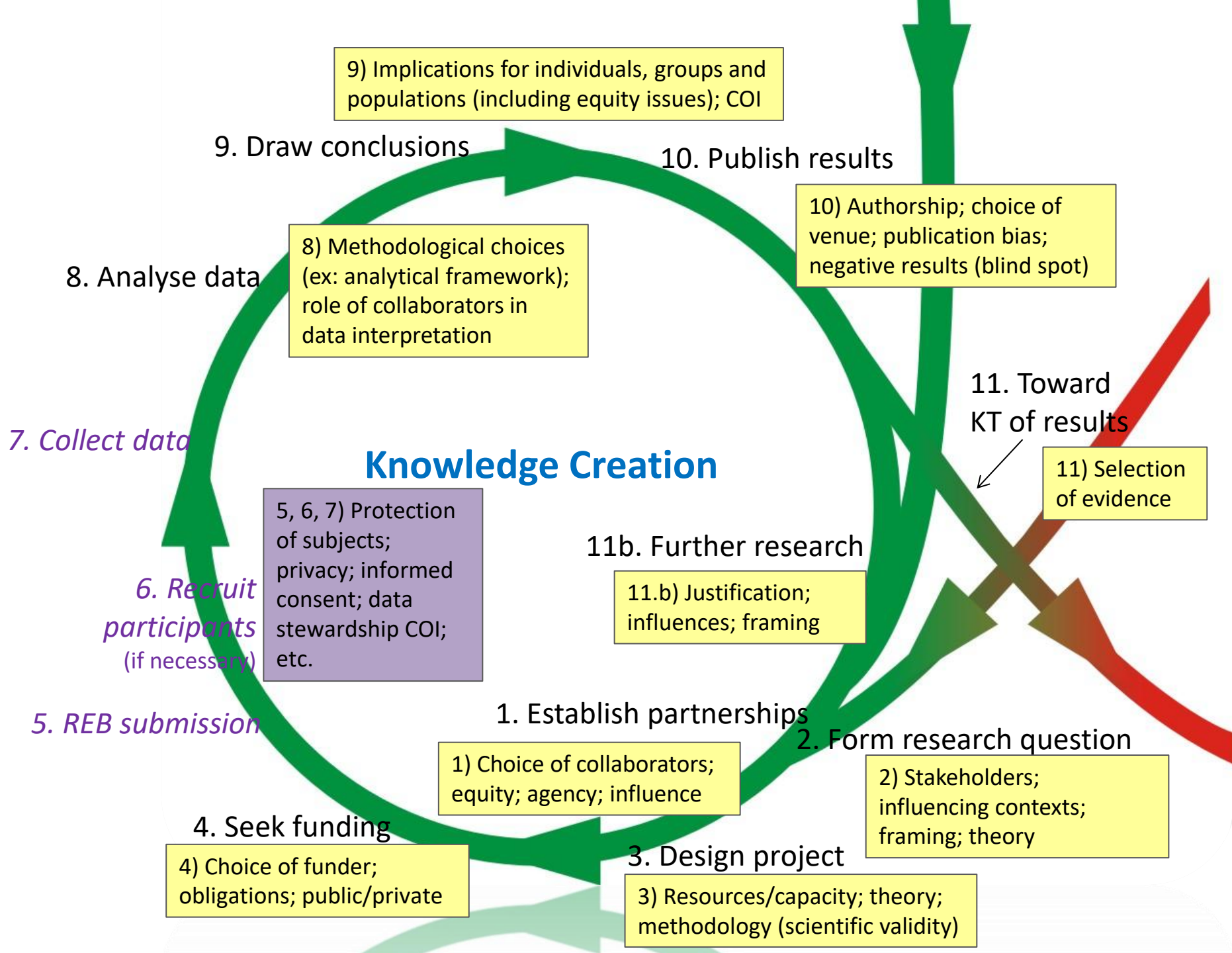


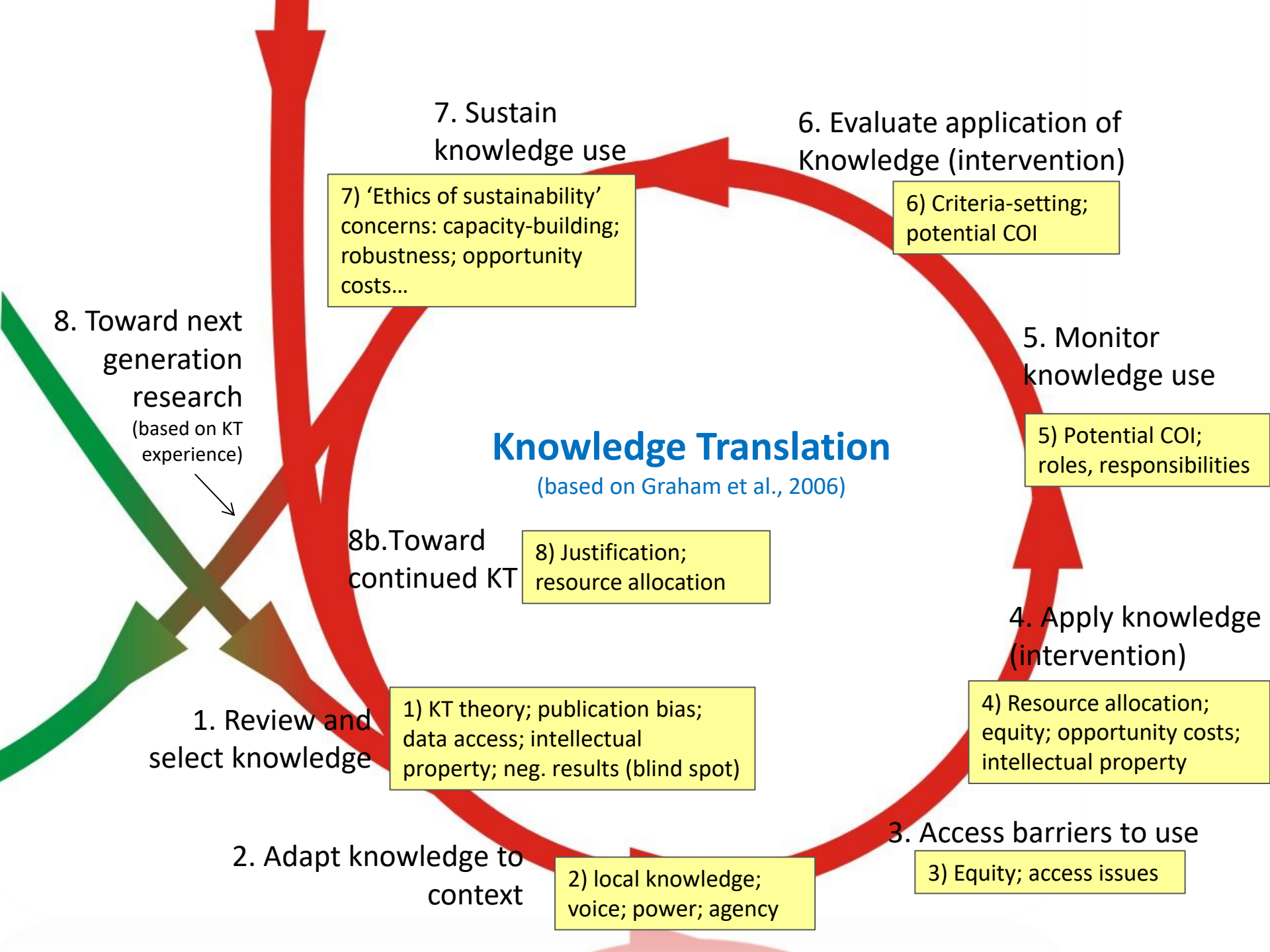
Identify problem (whether from research or KT perspective)

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

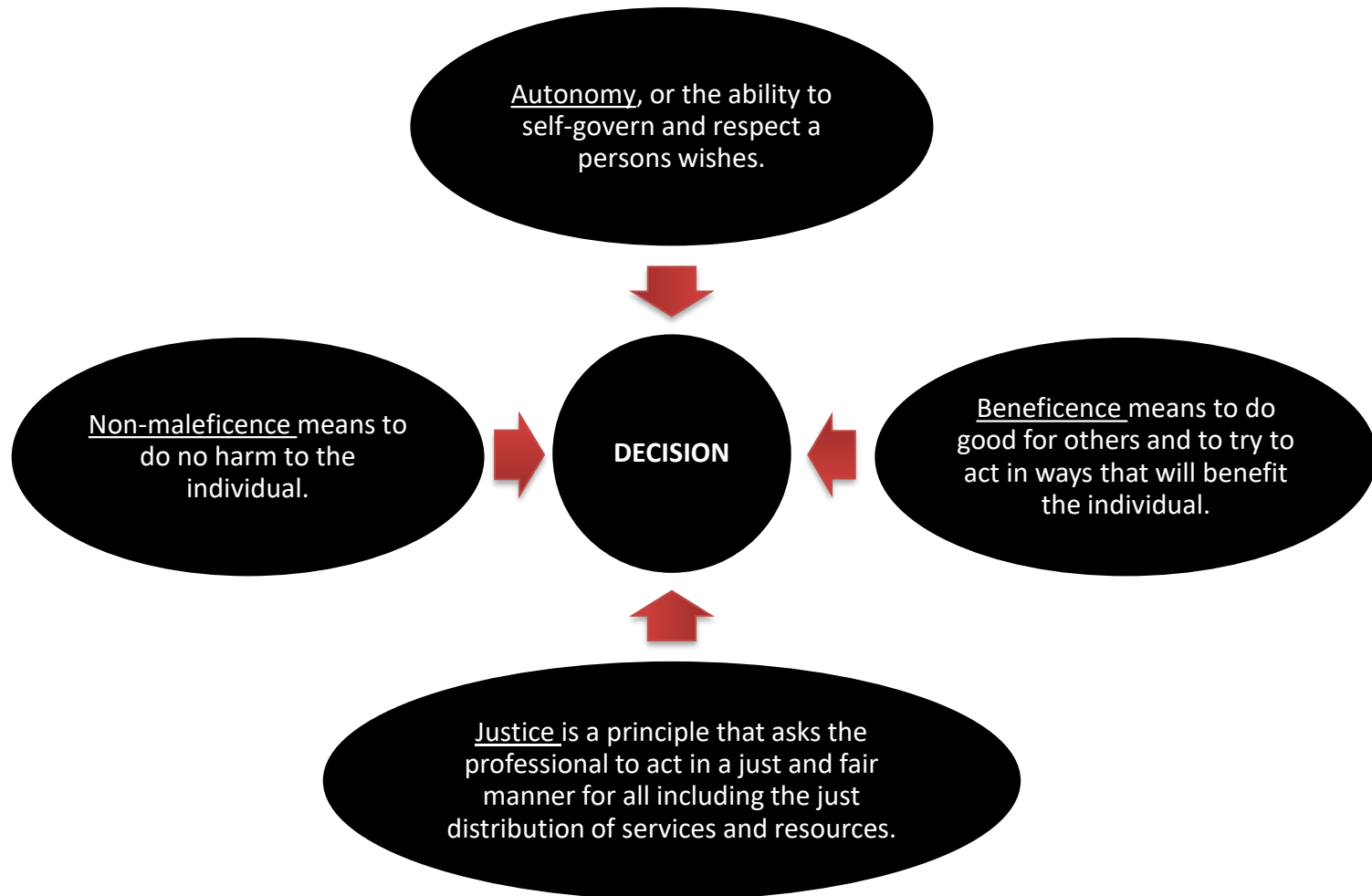
Knowledge Translation





Back to basics:

Applied ethics principles (all things considered judgments)



Conceptual framework (people centered)



Substantive ethics



Procedural ethics

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.

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?**

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?

Vulnerability

Inaction as value neutral?

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!

