

# Ethics

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## DATA 201: Thinking With Data Winter 2022

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# Human Research Ethics

# UofC Ethics

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- <https://research.ucalgary.ca/conduct-research/ethics-compliance/human-research-ethics>
- The University of Calgary promotes high ethics standards consistent with the Tri-Council Policy Statement (TCPS2 2018), Ethical Conduct for Research Involving Humans thereby ensuring respect for persons, concern for their welfare and justice
- All research, funded or unfunded, involving humans, their data, or human biological materials conducted within the University of Calgary's jurisdiction or under its auspices, regardless of where the research is conducted must be reviewed by, and receive approval from, the appropriate University of Calgary Research Ethics Board (REB) before research begins.

# Research?

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- Research is defined as “an undertaking intended to extend knowledge through a disciplined inquiry and/or systematic investigation” (TCPS2: p 13)
- There are two REBs that review research applications:
  1. the Conjoint Faculties Research Ethics Board (CFREB)
    - Rest of us
  2. the Conjoint Health Research Ethics Board (CHREB)
    - Kinesiology, Nursing, and the Cumming School of Medicine

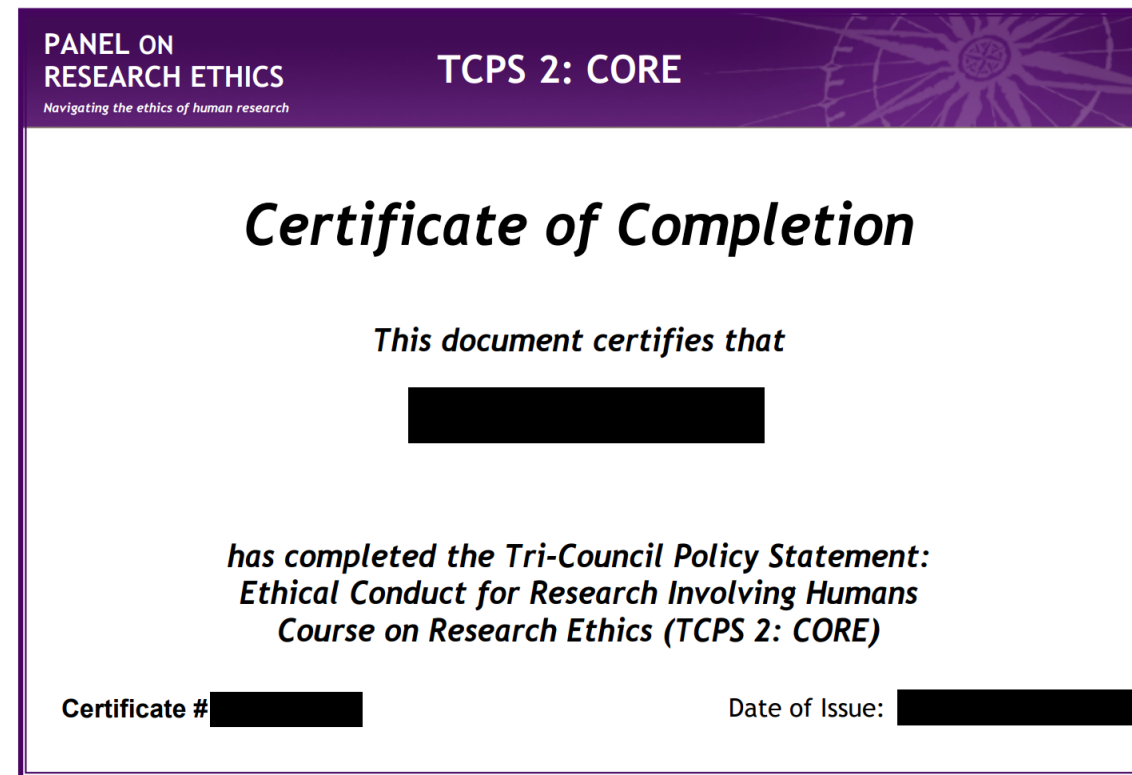
# Training

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- Training
- All University of Calgary researchers engaging in research with humans must complete human research ethics training **prior** to submitting an application for ethics review.
- This training requirement can be fulfilled by completing either
  1. TCPS2 CORE Tutorial, or
  2. CITI Human Subjects Research Course
- Principal Investigators are responsible for ensuring that all study team members have one of the above training modules complete. These must be available upon request.

# TCPS2 CORE Tutorial [tcps2core.ca](http://tcps2core.ca)

- Adhering to the TCPS2 guidelines helps foster a community of conscientious researchers who carry out research in an ethically sound environment and are aware of how to ethically conduct research involving humans.
- Retroactive to 2012, ethics applications require the CORE Tutorial certificate.
- Once the tutorial is complete and you are issued a certificate, include your certificate in your application.



# TCPS2 CORE Tutorial [tcps2core.ca](http://tcps2core.ca)

- CORE-2022 consists of nine modules and a knowledge consolidation exercise:

1. Module A1 – Introduction
2. Module A2 – Scope of TCPS 2
3. Module A3 – Risks and Benefits
4. Module A4 – Consent
5. Module A5 – Fairness and Equity
6. Module A6 – Privacy and Confidentiality
7. Module A7 – Conflicts of Interest
8. Module A8 – Research Ethics Board Review
9. Module A9 – Research Involving Indigenous Peoples

- Knowledge Consolidation Exercise



# TCPS2 CORE Tutorial [tcps2core.ca](https://tcps2core.ca)

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- Each module ends with 4-5 quiz questions for you to test the knowledge that you have acquired.
- CORE-2022 also includes a knowledge consolidation exercise consisting of 25 multiple-choice questions randomly selected from a larger question bank.
- To obtain a CORE-2022 Certificate of Completion, you will need to correctly respond to 20 questions (80%).
  - Those who do not correctly respond to at least 20 questions will not obtain a Certificate of Completion. However, they will have the opportunity to retake the knowledge consolidation exercise.
- Completing CORE-2022 should take approximately 4 hours.



# TCPS2 CORE Tutorial [tcps2core.ca](http://tcps2core.ca)

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# IRISS

- IRISS (Institutional Research Information Services Solution) is an online system that manages all human ethics and animal care protocols for the University of Calgary.

The screenshot displays the IRISS web application interface. At the top, there is a navigation bar with 'My Home', 'Researcher Profile', and 'Help' links. The user is identified as 'Jonathan Hudson'. The main content area is titled 'Certification: Teaching Data Science (REB20-0687)'. It features a 'Current State' sidebar on the left with an 'Approved' status and buttons for 'View Study', 'Printer Version', 'View Differences', 'Create a Modification', 'Request Closure', and 'Create Reportable Event'. The main area contains a table of certification details:

Formal Title:	Teaching Undergraduate Introductory Data Science		
Legacy File ID:		Application Type:	Instructor Course-based
Approving Board:	CFREB	REB Admin:	[Redacted]
Principal Investigator:	[Redacted]	Last Updated:	[Redacted]
Funding Status:		Clinical Trial:	No
Original Approval Document(s):	Certificate	Current Approval Document(s):	Certificate

Below the table is a tabbed interface with 'History', 'Renewals', 'Attachments', 'Reviewer Notes', and 'Change Log' tabs. The 'History' tab is active, showing an activity log with columns for 'Activity', 'Author', and 'Activity Date'. One activity is listed: 'Updated Study Team' by a redacted author on a redacted date. Below the activity log, there is a section for 'Study Coordinator(s): Added:' with a redacted name.

# A Study?

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- Identify a PI (Principle Investigator) must have TCPS2 CORE
- Also add co-investigators (or other study coordinators)
- PI owns, CO-I can make changes, study coordinators are knowledgeable but don't control
- Pick what type of research (in this case instructor-led course-based )
- *Course-based research activities are pedagogical activities normally required of students at all levels with the objective of providing them with exposure to research methods in their field of study. This form is for instructors who have designed a course assignment that involves research with human participants. This can be instructor-designed (where all students do the same project and use the same materials) or instructor guided (where students plan their own research projects within the parameters established by the instructor and vetted by the REB for recruitment, data collection, etc.).*

# A Study?

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- Will be questions unique to each type. A sample for Course-Based
  1. *Is the goal of the student research activity entirely pedagogical and limited to developing research methods skill?*
  2. *Provide a brief description of the human participant component in the course assignment(s) from the perspective of the research participants, including what research methods will be used, the nature of the research experience, and the range of topics:*
  3. *Will all students have the same or similar topics, methods, participants, participant materials?*
  4. *Briefly explain the oversight the instructor will have over the students while conducting the course assignment:*
  5. *List the potential types of participants and describe the range of methods by which they will be recruited:*

# A Study?

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- Will be questions unique to each type. A sample for Course-Based
- 6. *Describe the potential risks to participants, and the measures that will be taken to minimize risks, as well as mitigate harm:*
- 7. *Explain how the instructor will prepare students to comply with Tri-Council Policy Statement (TCPS2) guidelines.*
- 8. *How will informed consent be indicated and documented? (Select all that apply)*
- 9. *If there is a possibility that the course assignment will involve participants who might not be capable of providing informed consent?*
- 10. *How will confidentiality of the data be maintained?*
- 11. *Describe who will have access to the raw data and how any data collected will be stored (physical and electronic storage to protect confidentiality and privacy). Specify the plans for destruction of the data once the course-based research activities are complete.*

# A Study?



- Providing a sample
  1. Recruitment message
  2. Sample consent form
  3. Sample project topic
  4. Course outline

## CERTIFICATION OF INSTITUTIONAL ETHICS APPROVAL

Ethics approval for the following research has been renewed by the Conjoint Faculties Research Ethics Board (CFREB) at the University of Calgary. The CFREB is constituted and operates in compliance with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS 2).

Ethics ID:



Principal Investigator:

Co-Investigator(s):

Student Co-Investigator(s):

Study Title:

Teaching Undergraduate Introductory Data Science

Sponsor:

Effective:



Expires:



### Restrictions:

**This Certification is subject to the following conditions:**

1. Approval is granted only for the research and purposes described in the application.
2. Any modification to the approved research must be submitted to the CFREB for approval.
3. An annual application for renewal of ethics certification must be submitted and approved by the above expiry date.
4. A closure request must be sent to the CFREB when the research is complete or terminated.

Approved By:



Date:

# TCPS2 Ethics

# Core Principles

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1. Respect for Persons
2. Concern for Welfare
3. Justice



# Respect for Persons

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Respect for Persons recognizes the intrinsic value of human beings and the respect and consideration that they are due.

It encompasses the treatment of persons involved in research directly as

participants and

those who are participants because their data or human biological are used in research.

Respect for Persons incorporates the **dual moral obligations to respect autonomy and to protect those with developing, impaired or diminished autonomy.**

# Concern for Welfare

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The welfare of a person is the quality of that person's experience of life in all its aspects. Welfare consists of the impact on individuals of factors such as their

1. physical,
2. mental and
3. spiritual health, as well as
4. their physical, economic and social circumstances.

Thus, determinants of welfare can include housing, employment, security, family life, community membership and social participation, among other aspects of life.

# Justice

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Justice 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

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Treating people fairly and equitably **does not always mean treating people in the same way!!!!**

Differences in treatment or distribution are justified when failures to take differences into account may result in the creation or reinforcement of inequities.

# Justice

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One important difference that must be considered for fairness and equity is vulnerability.

Vulnerability is often caused by limited decision-making capacity, or limited access to social goods, such as rights, opportunities and power.

Individuals or groups whose circumstances may make them vulnerable in the context of research have historically included children, the elderly, students, women, prisoners, those with mental health issues and those with diminished capacity for self-determination.

# Proportionate Approach to Research Ethics Board Review

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Given that research involving humans spans the full spectrum of risk, from minimal to substantial, a crucial element of REB review is to ensure that the level of scrutiny of a research project is determined by the level of risk it poses to.

*the intention is to ensure adequate protection of participants is maintained while reducing unnecessary impediments to, and facilitating the progress of, ethical research.*

# The Law!

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In addition to the principles and guidelines in this Policy, researchers are responsible for ascertaining and complying with all applicable legal and regulatory requirements with respect to consent and the protection of privacy of participants.

These legal and regulatory requirements may vary depending on the jurisdiction in Canada in which the research is being conducted, and who is funding and/or conducting the research. They may comprise constitutional, statutory, regulatory, common law, and/or international or legal requirements of jurisdictions outside of Canada.

Where the research is considered to be a governmental activity, for example, standards for protecting privacy flowing from the Canadian Charter of Rights and Freedoms, federal privacy legislation and regulatory requirements would apply.

# The Perspective of Participant

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In designing and conducting research or reviewing the ethics of research, researchers and REBs must be mindful of the perspective of the participant.

It may be necessary to consider the various contexts (e.g., social, economic, cultural) that shape the participant's life, to properly evaluate the implications of the research in terms of the core principles.



# Something that doesn't require REB review is not by default ethical!

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Quality assurance and quality improvement studies, program evaluation activities, and performance reviews, or testing within normal educational requirements when used exclusively for assessment, management or improvement purposes, do not constitute research for the purposes of this Policy, and do not fall within the scope of REB review.

The above may still raise ethical issues that would benefit from careful consideration by an individual or a body capable of providing some independent guidance, other than an REB.

**Consent!**

# Definition

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Throughout TCPS2, the term “consent” means “**free, informed** and **ongoing** consent.”  
“free” and “voluntary” are used interchangeably.

*Respect for Persons implies that individuals who participate in research should do so voluntarily, understanding the purpose of the research, and its risks and potential benefits, as fully as reasonably possible.*

*Where a person has the capacity to understand this information, and the ability to act on it voluntarily, the decision to participate is generally seen as an expression of autonomy.*

*Equally, Respect for Persons implies that those who lack the capacity to decide for themselves should nevertheless have the opportunity to participate in research that may be of benefit to themselves or others. (Authorized third party consent!)*

# Responsibility

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The head of the research team, also known as the “principal investigator,” is responsible for ensuring that the consent process is followed.

This person is also responsible for the actions of any member of the research team involved in the consent process.

# Article 3.1

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- a. Consent shall be given voluntarily.
  - Free of undue influence (coercion)
  - What about incentives? (\$25 gift card? More?)
- b. Consent can be withdrawn at any time.
- c. If a participant withdraws consent, the participant can also request the withdrawal of their data or human biological materials.

# Incentives

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- Because incentives are used to encourage participation in a research project, they are an important consideration in assessing voluntariness.
- Where incentives are offered to participants, they should not be so large or attractive as to encourage reckless disregard of risks.
- This is a particular consideration in the case of healthy volunteers for the early phases of clinical trials
- The offer of incentives in some contexts may be perceived by prospective participants as a way for them to gain favour or improve their situation.
- This may amount to undue inducement and thus negate the voluntariness of participants' consent.
- **This Policy neither recommends nor discourages the use of incentives. Up to REB.**

**Informed and on-going**

# Article 3.2 Informed

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Researchers shall provide to prospective participants, or authorized third parties, full disclosure of all information necessary for making an informed decision to participate in a research project.

- *That they were invited*
- *Purpose in plain language*
- *Risks/benefits clear*
- *Assurance of obligation not required, request withdrawal, etc.*
- *Commercialization*
- *Disseminations*
- *Identify contact for questions, another non research group contact*
- *What information collected*
- *Incentives*
- *Waiver and points of possible removal*



## Article 3.3 On-Going

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Consent shall be maintained throughout the research project.

Researchers have an ongoing duty to provide participants with all information relevant to their ongoing consent to participate in the research.

*Article 3.4 Within the limits of consent provided by the participant, researchers shall disclose to the participant any material incidental findings discovered in the course of research.*

*Material -> Important to the participant*

*Incidental -> Not part of research*

*If a study on a different medical condition determines you have cancer!*

## Article 3.5/3.10

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Research shall begin only after the participants, or their authorized third parties, have provided their consent.

Consent should be documented.

# Inclusion

# Appropriate Inclusion

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Researchers shall not exclude individuals from the opportunity to participate in research on the basis of attributes such as culture, language, religion, race, disability, sexual orientation, ethnicity, linguistic proficiency, gender or age, unless there is a valid reason for the exclusion.

Women shall not be inappropriately excluded from research solely on the basis of gender or sex, reproductive capacity, or because they are pregnant or breastfeeding.

## Other categories

Children, elderly, lack decision making capacity, vulnerable groups

Key is that any exclusion must be justifiable and not for 'ease of study' or other non research based reasoning.

# Dissemination

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Researchers have to disseminate results, even those that don't support the hypothesis and

Encouraged to make data available if it is possible while safe-guarding privacy of participants.

# Privacy

# Privacy terms

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Privacy – right to be free from intrusion or interference of others

Confidentiality – obligation to safely trust information

Security – measure used to protect information

Identifiable information – no one single answer and it is responsibility of researchers to consider for each piece of information is this information able to identify someone by itself, or in combination with other information

This info can be collected be falls under much greater protections than non-identifiable information

# Types of information

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Directly identifying (SIN, UCID) [most concern]

Indirectly identifying (DOB and location of birth)

Coded information (replace data)

Anonymized information – the information is irrevocably stripped of direct identifiers, a code is not kept to allow future re-linkage, and risk of re-identification of individuals from remaining indirect identifiers is low or very low.

Anonymous information – the information never had identifiers associated with it (e.g., anonymous surveys) and risk of identification of individuals is low or very low [least concern here]



# Ethical Duty of Confidentiality

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## Article 5.1

Researchers shall safeguard information entrusted to them and not misuse or wrongfully disclose it.

Institutions shall support their researchers in maintaining promises of confidentiality.

Qualtrics!

Delete data after grading is complete!

# Safeguard!

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## Article 5.3

Researchers shall provide details to the REB regarding their proposed measures for safeguarding information, for the full life cycle of information: its collection, use, dissemination, retention and/or disposal.

# Conflicts of Interest

# Examples

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## 1. Institutional

- Obligations association to institution (benefits from research to school)

## 2. REB

- Someone on review board could benefit

## 3. Researcher

- Person running study could benefit, or create pressure, changes, etc.

# Research Involving First Nations, Inuit, and Metis People

# Newer Chapter/Module 9 Addition to TCPS Core

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Research involving Indigenous peoples in Canada, including Indian (First Nations

First Nations, Inuit and Métis communities have unique histories, cultures and traditions.

They also share some core values such as reciprocity – the obligation to give something back in return for gifts received – which they advance as the necessary basis for relationships that can benefit both Indigenous and research communities.

# Colonialized Research

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Research involving Indigenous peoples in Canada has been defined and carried out primarily by non Indigenous researchers.

The approaches used have not generally reflected Indigenous world views, and the research has not necessarily benefited Indigenous peoples or communities.

As a result, Indigenous peoples continue to regard research, particularly research originating outside their communities, with a certain apprehension or mistrust.

# Repairing Research

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The landscape of research involving Indigenous peoples is rapidly changing.

Growing numbers of First Nations, Inuit and Métis scholars are contributing to research as academics and community researchers.

Communities are becoming better informed about the risks and benefits of research.

Technological developments allowing rapid distribution of information are presenting both opportunities and challenges regarding the governance of information.



# Fundamentals

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## 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:

# Fundamentals

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- a. research conducted on First Nations, Inuit or Métis lands;
- b. recruitment criteria that include Indigenous identity as a factor for the entire study or for a subgroup in the study;
- c. research that seeks input from participants regarding a community's cultural heritage, artefacts, traditional knowledge or unique characteristics;
- d. 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
- e. interpretation of research results that will refer to Indigenous communities, peoples, language, history or culture.

# Qualitative Research

# Qualitative Research (Unique!)

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Qualitative research aims to understand how people think about the world and how they act and behave in it.

This approach requires researchers to understand phenomena based on discourse, actions and documents, and how and why individuals interpret and ascribe meaning to what they say and do, and to other aspects of the world (including other people) they encounter.

# Qualitative Research (Unique!)

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Some qualitative studies extend beyond individuals' personal experiences to explore interactions and processes within organizations or other environments.

Knowledge at both an individual and a cultural level is treated as socially constructed.

This implies that all knowledge is, at least to some degree, interpretive, and hence, dependent on social context. It is also shaped by the personal perspective of the researcher as an observer and analyst.

As a result, qualitative researchers devote a great deal of attention to demonstrating the trustworthiness of their findings using a range of methodological strategies.

# Qualitative Research (Unique!)

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- General Approach and Methodological Requirements and Practices
  1. Inductive Understanding (need different mindset, open questioning of own bias)
  2. Diversity of Approaches (more likely to be biased if done one way)
  3. Dynamic, Reflective and Continuous Research Process
  4. Diverse, Multiple and Often Evolving Contexts (highly varied)
  5. Data Collection and Sample Size (often smaller)
  6. Research Goals and Objectives ('giving voice' can be a challenge)
  7. Dynamic, Negotiated and Ongoing Consent (negotiation may add bias)
  8. Research Partnerships (to get access setup biases may set in)
  9. Results (transferable)

# Resources

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- <https://research.ucalgary.ca/conduct-research/agreements>
- <https://research.ucalgary.ca/conduct-research/additional-resources/iriss-human-ethics-and-animal-care>
- <https://ethics.gc.ca/eng/documents/tcps2-2018-en-interactive-final.pdf>
- <https://tcps2core.ca/>

# Onward to ... Constructive Criticisms?

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