

# ETHICS IN COMMUNITY-BASED RESEARCH

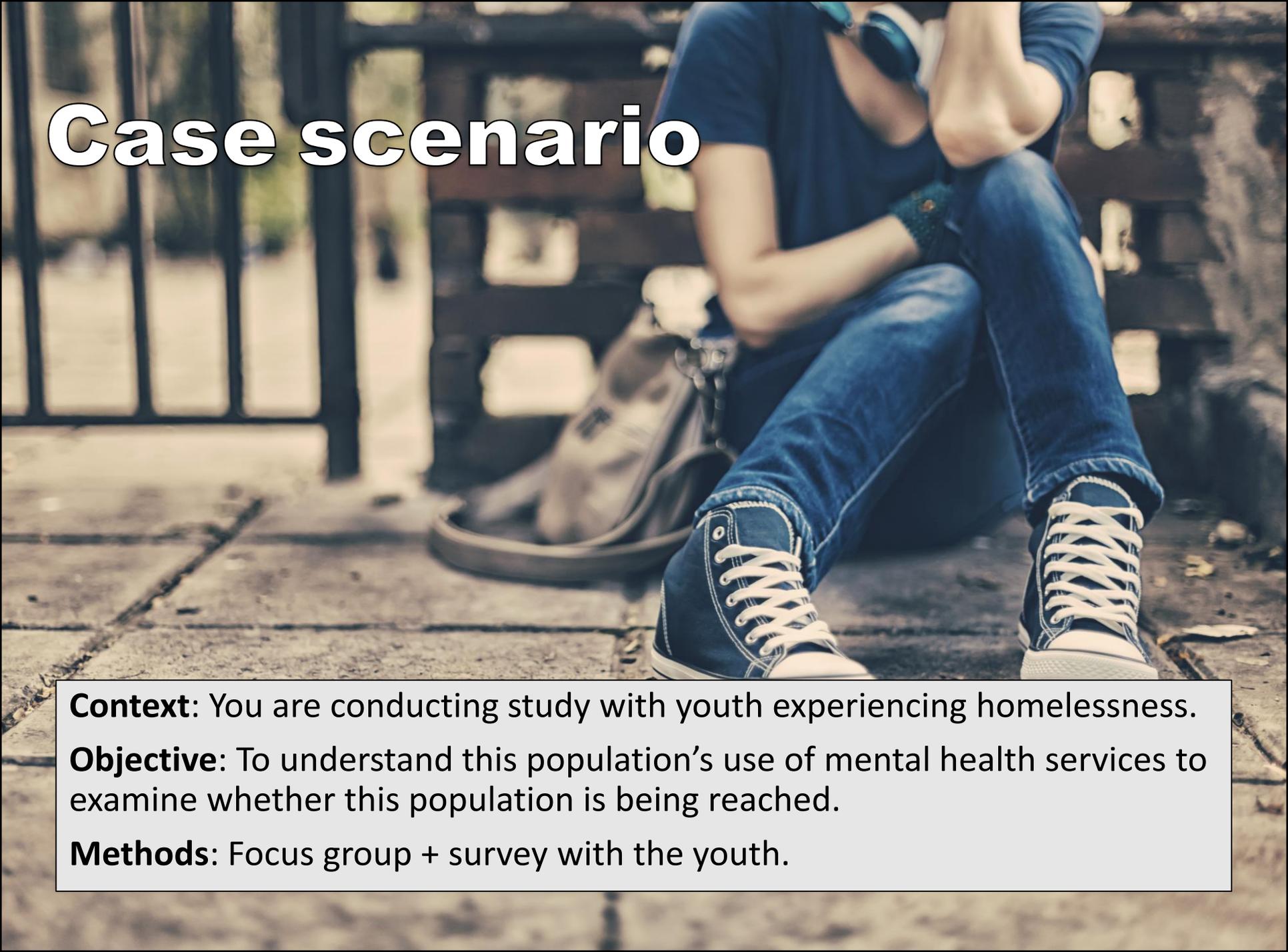
Engaging Communities Through Research:  
A Capacity-Building Event for Faith-Based Campuses

November 24, 2017



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# Case scenario

A person wearing a blue t-shirt, blue jeans, and blue sneakers with white laces is sitting on a dark wooden bench. They are holding a camera with a blue strap. The background is a blurred outdoor setting with a black metal fence and some foliage.

**Context:** You are conducting study with youth experiencing homelessness.

**Objective:** To understand this population's use of mental health services to examine whether this population is being reached.

**Methods:** Focus group + survey with the youth.

# Your facilitator – Katelyn Godin



- PhD Candidate in Public Health and Health Systems, University of Waterloo
- Board of Directors, Community Research Ethics Office (CREO)
- Occasional tree hugger



# Ask the audience...

Why did you choose to attend this workshop on research ethics in community-based research?

- a) “I am a research ethics enthusiast! Bring on the ethics!”
- b) “I don’t know much about research ethics, but I know they are important and want to learn more.”
- c) “My friend(s) planned to go to this workshop, so I tagged along.”
- d) “Research ethics? I think I’m in the wrong room...”



# Ask the audience...

What is your current level of research ethics knowledge?

- a) Expert
- b) Advanced
- c) Intermediate
- d) Beginner



# Ask the audience...

Have you prepared an ethics application for a research project before?

- a) Yes; several
- b) Yes; once or twice
- c) Kind of; I prepared parts of an application with a larger team
- d) Never



# Workshop objectives

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- *Long-term:* Contribute to the integrity and quality of CBR by facilitating more ethical research



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- *Long-term:* Contribute to the integrity and quality of CBR by facilitating more ethical research
- *In a nutshell:* think ethics!



# Workshop overview

- Section 1: Community-based research ethics
- Section 2: Research ethics principles & guidelines
- Section 3: Applying the ethical principles & guidelines
- Section 4: The Community Research Ethics Office
- Section 5: Closing

# Workshop expectations

- Questions & clarifications throughout
- Active participation from participants throughout
- Recognition that research ethics are an ongoing learning process and that the field is continuously evolving
- This is just the tip of the iceberg!



# Section 1:

## Community-based research ethics

# What is “research”?

- “An undertaking intended to extend knowledge through a disciplined inquiry or systematic investigation.”
- A means of satisfying the desire to understand and to improve the world in which we live

TCPS2, p. 7



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# Types of research

- **Evaluation research**
- Experimental research
- **Participatory action research**





Research is risky...

# What is research ethics?

- A code of conduct or norms of behaviour that researchers are expected to follow while conducting research
- Provide guidance for our actions and decisions, considering their impact on others



# Where do ethics fit into research?

- Selection of the problem/background, purpose and objectives
- Selection of methodology and methods
- Recruitment of participants and collection of data
- Analysis of data and synthesis of results
- Reporting of the findings
- Working with other researchers, clients, participants, etc.



# Who assesses what is “ethical”?

- Ethics boards
  - Academic research ethics boards
  - Hospital and other institutional research ethics boards
  - Community research ethics boards



# Discussion questions

- What type of research is most relevant to your work?
- How is your perception of research ethics the same or different to what we have discussed?



# Section 2:

## Research ethics principles & guidelines



# Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS-2)



- Joint policy of Canada's 3 federal research agencies
- Benchmark for ethical research involving humans
- Requisite for all agencies-funded research projects

[http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS\\_2\\_FINAL\\_Web.pdf](http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf)

# 3 (+1) key principles of TCPS-2

1. Respect for persons
2. Concern for welfare
3. Justice
4. Respect for communities



# Community Research Ethics

## Respect for Persons

### Free and Informed Consent

Participants are informed of:

- What they will be asked to do
- Risks/benefits of participation
- How their information will be used
- Their rights as a participant

### Vulnerable Persons

- Information is presented in an accessible format
- Autonomy is respected

## Respect for Community

### Honour Community Identity

- Understand means and dimensions of self-identification
- Learn and respect norms, customs, language and culture

### Respect Self-Determination & Decision-Making

- Understand community's rights and capacities
- Ensuring community's role in shaping research
- Be aware of common concerns related to community research

## Concern for Welfare

### Privacy and Confidentiality

- Who has access to participant information?
- How is personal information protected?
- Data storage processes
- Assurance of anonymity

### Consideration of whole persons and whole communities

- Recognize physical, social, economic, cultural, spiritual and other dimensions of individuals and communities

## Justice

### Justice

- Participants are treated equally
- Over-researching particular groups is avoided
- Consider community needs and priorities
- Maximize benefits, minimize harms

### Inclusiveness

- Consider participation with respect to scope, objectives, and methods
- Consider participation of sub-groups within communities
- No exclusion for reasons not related to the research

# 1. Respect for persons

- Recognizes the intrinsic value of human beings and the respect and considerations that they are due
- Respect autonomy & protecting those with diminished autonomy
- Two sub-principles:
  - i. Respect for free, informed, & ongoing consent
  - ii. Respect for vulnerable persons



# 1. Respect for persons

## i. Free, informed, & ongoing consent

- Allow opportunities and information to make an informed decision
- Enable complete understanding of the research study, participants' role in it, and how participation may affect them
- Consent letter
- Documenting consent





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Strengthening and Supporting Community Research  
Waterloo Region, Ontario, Canada and Internationally

## **Guidelines – Informed Consent Form or Information Letter**

### Introduction to these guidelines

An informed consent form/information letter has two purposes:

1) to enable potential research participants to make an informed choice as to their participation in a study, and 2) to document their decision to participate.

In order to make an informed choice, potential participants must understand the study, how they are involved in the study, and what sort of risks it poses to them. The words and language used to describe these factors must be understandable to potential participants. Evidence of informed consent by the participant or an authorized third party should often be obtained in writing. However, there are instances in which written consent is culturally unacceptable, or where there are good reasons for not needing to or wanting to record informed consent in writing. In such cases, the procedures to seek free and informed consent should be documented. In cases of mailed or telephone interviews, the participants may be sent an information letter prior to participation and willingness to participate in the interview or to complete the questionnaire will often constitute evidence of consent. In many projects, potential participants will read your consent form/information letter prior to deciding whether or not to participate, but in some cases you may read your consent form/information letter to potential participants and they will decide whether or not to participate after listening to your reading.

A template of an informed consent form/information letter is provided at the end of these guidelines. Following the template will help to ensure that the necessary items for approval

<http://www.communityresearchethics.com/wp-content/uploads/2014/08/CREO-guidelines-for-informed-consent-form-letter-of-information.pdf>

1. Respect for persons
- ii. Respect for vulnerable persons

### People with diminished autonomy

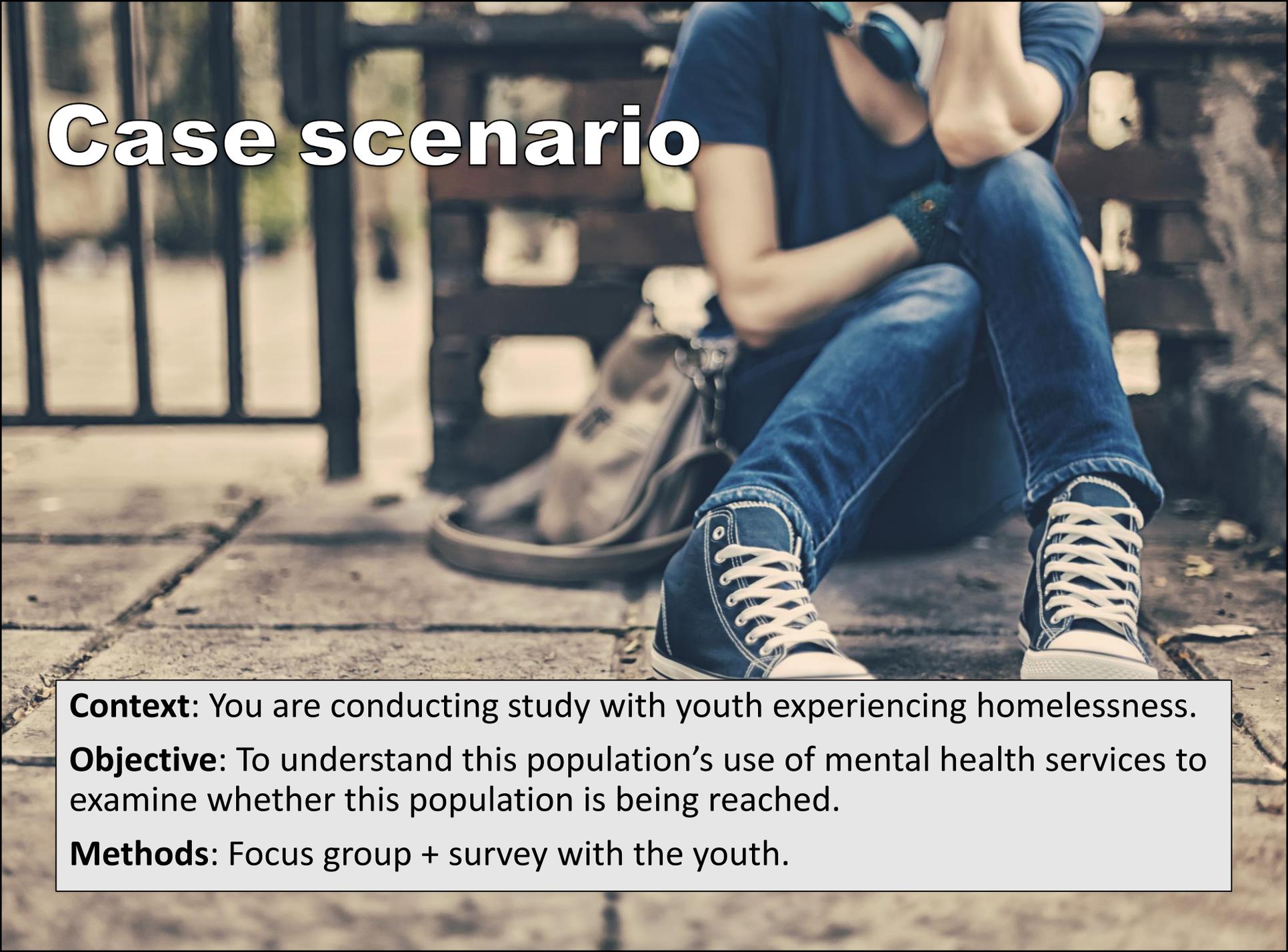
- Those lacking information/understanding
- Those lacking freedom due to coercion or controlling influences

### People less capable of exercising autonomy\*\*

- Youth
- Those with cognitive impairments
- Those with mental health issues/illness



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## 2. Concern for welfare

- “Concern for the quality of participants’ experience of life in all of its aspects”
  - Physical, mental, and spiritual health
  - Physical, economic, social circumstances
- Minimize harms, maximize benefits
- Two sub-principles:
  - i. Respecting privacy and confidentiality
  - ii. Consideration of whole persons/communities



## 2. Concern for welfare

### i. Respecting privacy and confidentiality

- Identifiability of participants + the potential harms this may cause to them or their affiliated communities
- Important at all stages in research cycle
  - Data collection, sharing, analysis, disseminating findings, storing data, disposal of data, etc.
- Various safeguards to protect participants
  - Physical, administrative, and technical



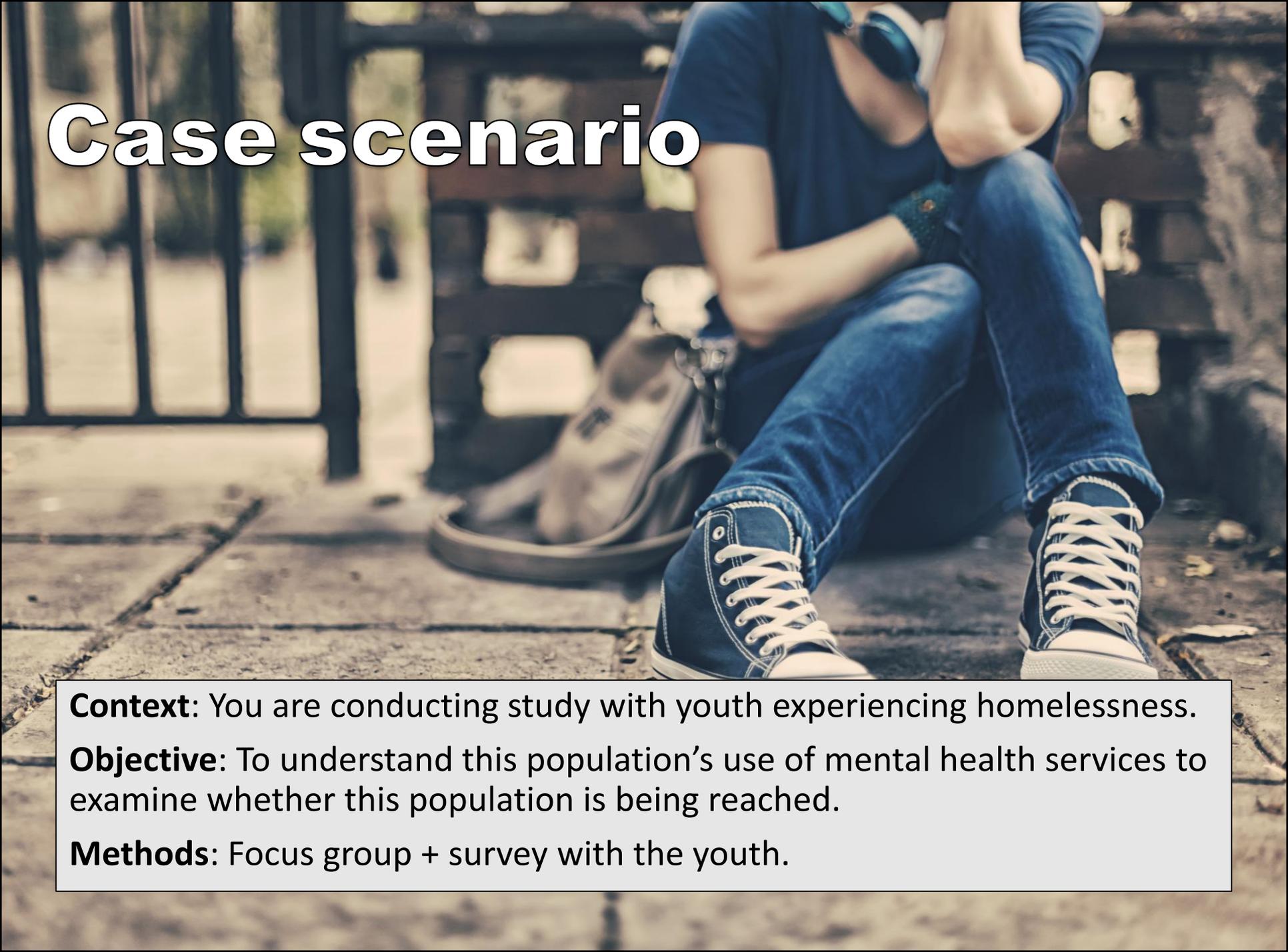
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### ii. Consideration of whole persons/communities

- Interconnectedness between two scales
- Individuals and/or groups may suffer harms as a result of participation
  - E.g., stigmatization, discrimination, and damage to reputation
- Benefits at one scale may entail risks to another



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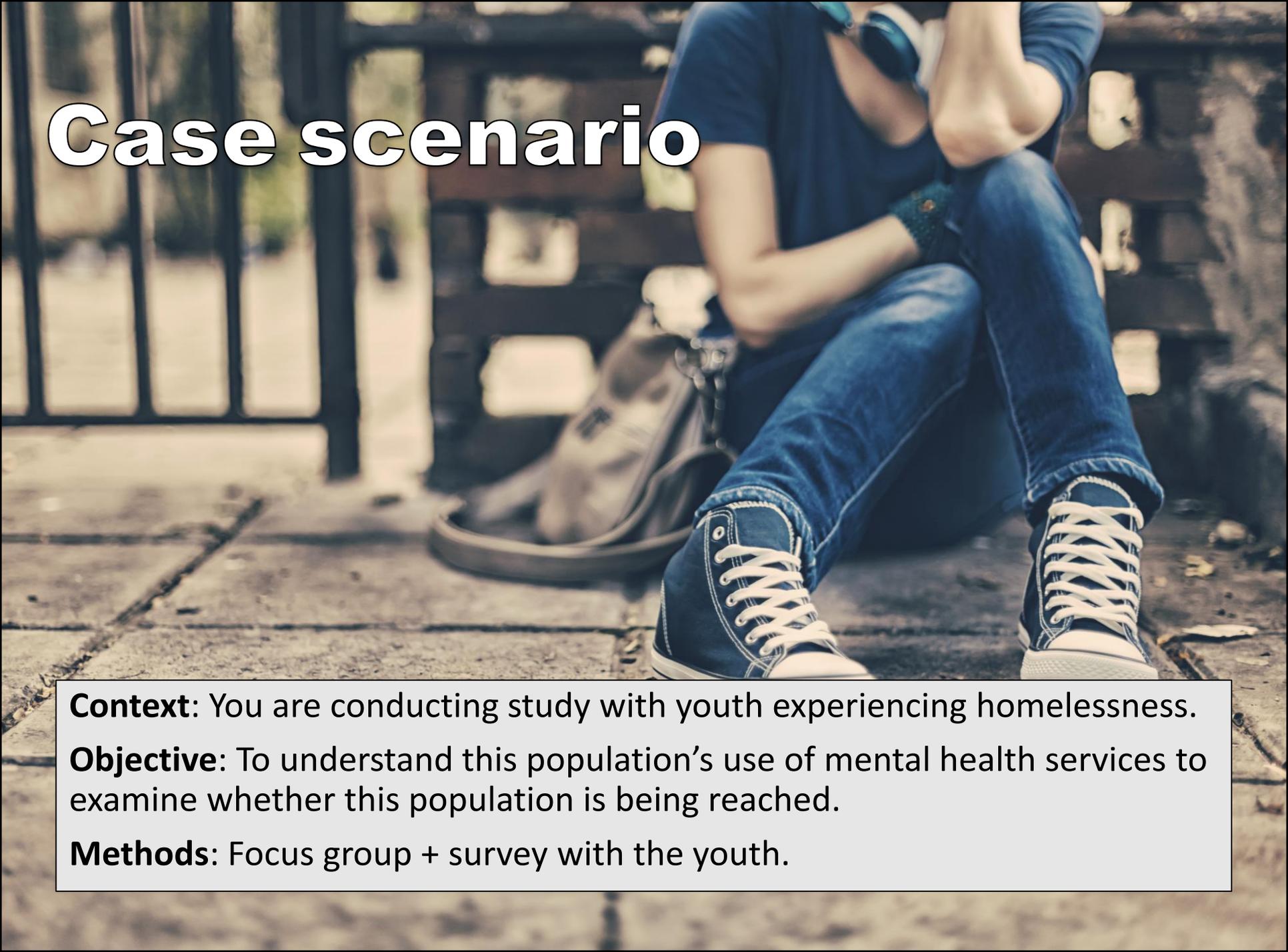
**Methods:** Focus group + survey with the youth.

## 3. Justice

- “Obligation to treat people fairly and equally”
- Equity in distributing both the benefits and burdens of research participation
- Importance of recognizing vulnerability
  - Appropriate inclusion
  - Inappropriate exclusion



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# Section 3:

Applying the ethical principles & guidelines



# Small group activity

Task	Timing
Form into group of 3-5 people	10 min.
Read over your specific ethical scenario	
Work through the discussion questions	
Present a summary to the larger group	3 minutes/group
Large group reflection	5 minutes



# Discussion questions

1. What are the ethical issue(s) at play in this scenario?
2. What principles of research ethics are most relevant to this scenario?
3. What sections of the consent form are relevant/should speak to this issue?
4. What kind of information would you include in these sections?



## Ethical scenario #1:

- The youth you would like to recruit range in age, from 12 to 20 years old. You know that free and informed consent is important, but are concerned that the younger participants lack the capacity to weigh the risks and benefits of participating. However, you are unsure if and how to contact their parents to consent on their behalf, and are unsure what else to do.



# Discussion questions

1. What are the ethical issue(s) at play in this scenario?
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3. What sections of the consent form are relevant/should speak to this issue?
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## Ethical scenario #2:

- You hope to have a large sample of youth in your study, but worry that the youth will be reluctant to volunteer their time to participate in the study. In order to encourage participation, you would like to offer the youth a \$50 gift card to participate, making it clear that they will only receive the gift card if they stay for the full focus group and complete the follow-up survey.



# Discussion questions

1. What are the ethical issue(s) at play in this scenario?
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## Ethical scenario #3:

- During the focus group discussion on participants' use of mental health supports in the community, you have noticed that one of the participants in the group is visibly upset by the questions. After ten minutes, he stands up suddenly and says, "I can't take it anymore. I want to leave."



# Discussion questions

1. What are the ethical issue(s) at play in this scenario?
2. What principles of research ethics are most relevant to this scenario?
3. What sections of the consent form are relevant/should speak to this issue?
4. What kind of information would you include in these sections?



## Post-activity reflection

- What were some common threads/considerations you noticed across scenarios?
- What challenges did you encounter when working through the discussion questions?
- Any other reflections on the exercise?



# Section 4:

## The Community Research Ethics Office (CREO)



# Purpose

- To promote the ethical conduct of community-based research that is consistent with the principles of TCPS-2
- To support community-based researchers that lack access to institutional research ethics boards and other support services



# History

- The development took place over four important milestones:
- Initial Community Meeting (2008)
- Needs Assessment and Feasibility Study (2008-09)
- Community Forum (2010)
- Implementation of CREO (2011)



# Who we are

- 12 board members
- 1 Chair
- 1 intern
  
- Faculty members
- Community organizations
- Students
- Members of institutional ethics boards

# Services

- Consultations
- Training/education
- Ethics reviews
  
- TCPS-2
  
- Pricing
  - Sliding scale for ethics reviews



# Who we work with

- Organizations at local, national, and international levels
- Not-for-profits, foundations, governments, private sector and other institutions and individual researchers
- In general – those who do not have access to institutionally based Research Ethics Boards

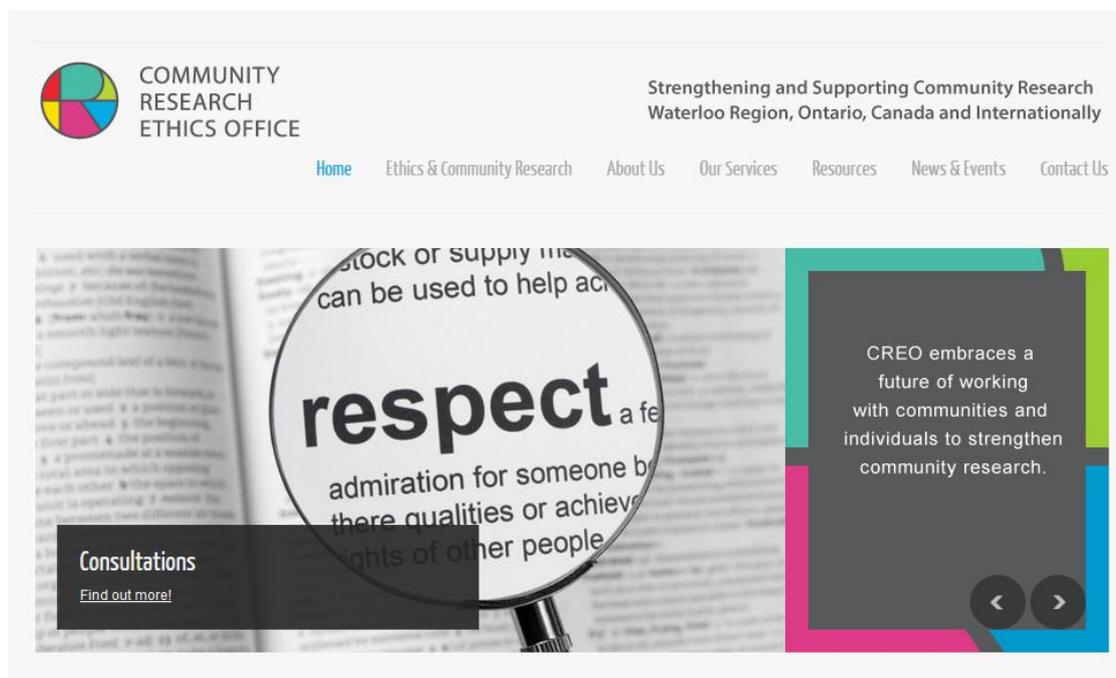


# CREO ethics applications & reviews

- Materials needed in application:
  - Main application
  - Consent forms
  - Data collection tools (surveys, focus group guides, etc.)
- Review process
  - Lead reviewer & second
  - Full board ratification
- ~4 week for first review



# Think CREO can support your research?

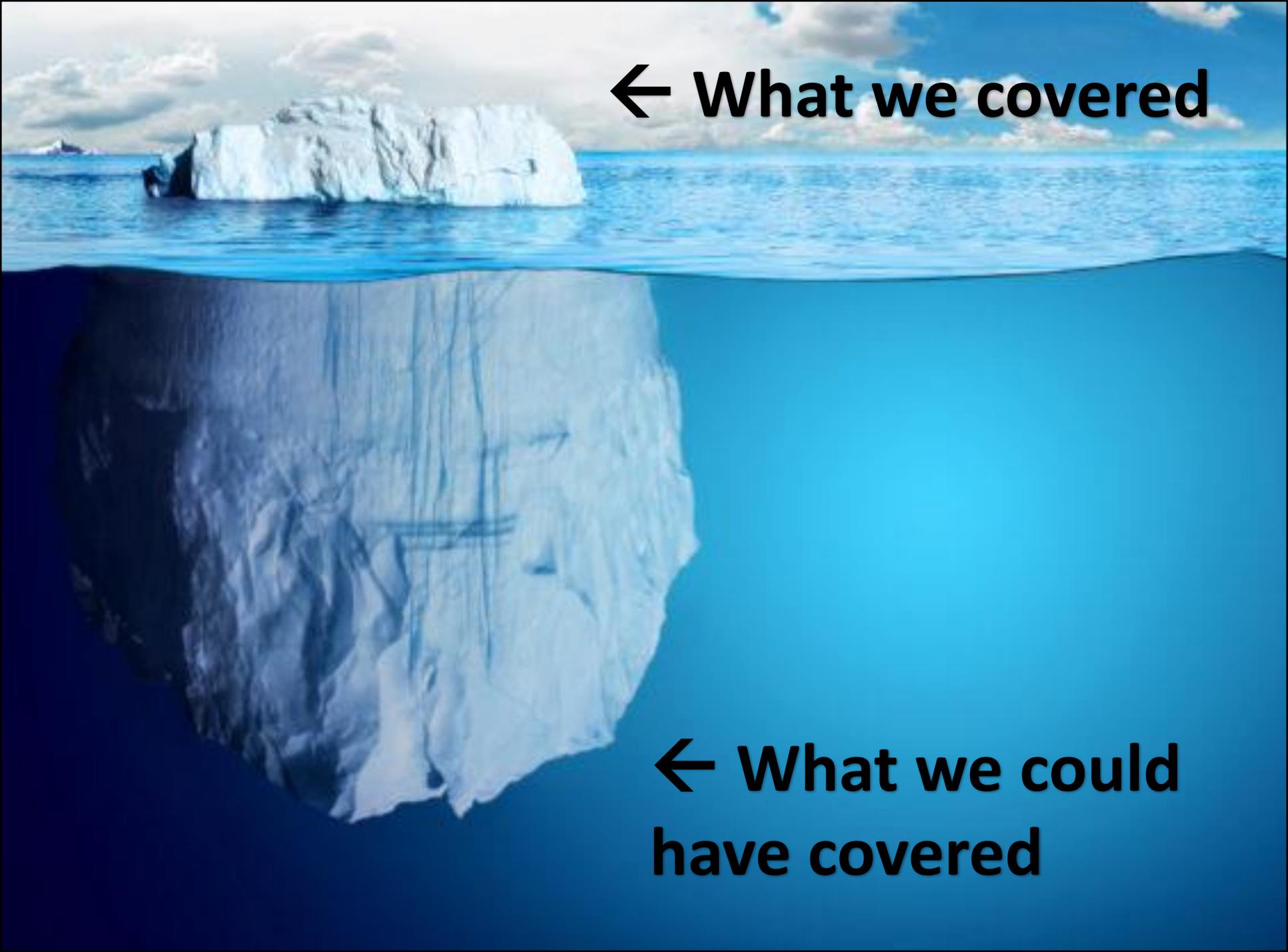


<http://www.communityresearchethics.com/>

- E-mail: [creo@communitybasedresearch.ca](mailto:creo@communitybasedresearch.ca)

# Section 5: Closing



An iceberg floating in the ocean. The top part is above the water surface, and the bottom part is submerged. The water is blue, and the sky is blue with white clouds. The iceberg is white and jagged.

**← What we covered**

**← What we could  
have covered**

# Thank you!

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