Joanna Ochocka Rich Janzen Charlotte Loppie



# COMMUNITY-BASED RESEARCH

#### WORKSHOP #3: RESEARCH PLANNING

MENTAL HEALTH COMMISSION OF CANADA (MHCC) JANUARY 22, 2021 Funded by:



Commission of Canada Commission de la santé mentale du Canada

### Supporting Lived Experiences with Cannabis through Community-Based Research

Centre for Community Based Research Workshop

January 22, 2021

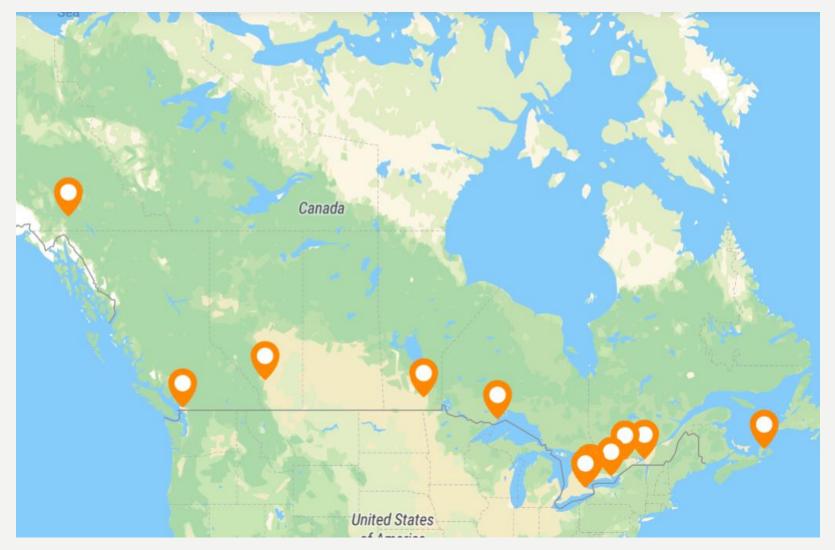
Julia Armstrong, Mental Health Commission of Canada

# CHECK-IN

WHAT'S THE MOST RIDICULOUS GIFT YOU'VE EVER RECEIVED?



# **14 MHCC RESEARCH PROJECTS**





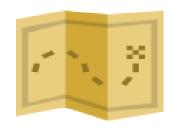
### **PROJECT #14:** THE IMPACTS OF CANNABIS USE ON THE MENTAL HEALTH OF IN-RISK COMMUNITIES CALGARY, AB

**Priority population:** People living with mental illness who use cannabis and are homeless, racialized, and/or face poverty

**Research purpose**: To examine the social and structural factors associated with cannabis use and its impact on mental health and experiences with support systems

Lead organizations: Alberta Addicts Who Educate and Advocate Responsibly (AAWEAR)

### AGENDA



Phase 2: Research Planning



Adapting the Plan

(Break-out Discussion)



Ethical Considerations

> (Break-out Discussion)

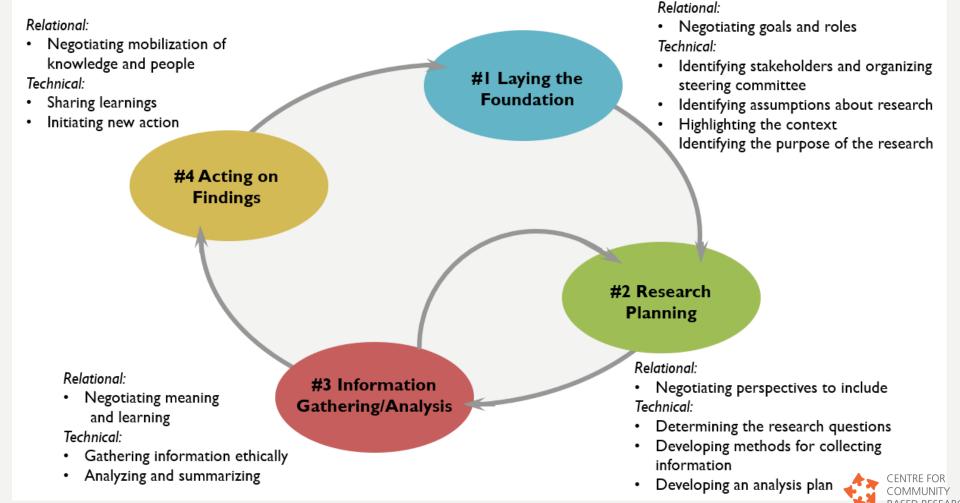


Coaches' Corner

(Optional)



## FOUR PHASES AND 11 STEPS OF COMMUNITY-BASED RESEARCH





### THREE HALLMARKS OF COMMUNITY-BASED RESEARCH

### A RESEARCH APPROACH THAT STRIVES TO BE...

Community- Driven	The research is practically relevant to those most affected by the issue under study and leads to their self determination.
Participatory	Community members and researchers equitably share control of the research agenda through active and reciprocal involvement in the research design, implementation and dissemination.
Action- Oriented	The process and results are useful to community members in making positive social change and in contributing to communities where everyone is supported and belongs.
	CENTRE CENTRE



### THREE FUNCTIONS OF COMMUNITY-BASED RESEARCH

#### COMMUNITY MOBILIZATION

Facilitating relationship building, engagement and action

#### **PRODUCTION** Learning together through systematic

**KNOWLEDGE** 

and rigorous research

#### KNOWLEDGE MOBILIZATION

Communicating research results with external audiences



# OVERVIEW OF PHASE 2

**RESEARCH PLANNING** 

 $\checkmark$  Determine the research questions

 Develop methods for collecting information

✓ Develop an analysis plan



#2 Research Planning

# **REFLECTIVE QUESTION**



THINK OF YOUR RESEARCH PROJECT...

What are the research questions you want answered by the end of your study?



# **MAIN RESEARCH QUESTIONS**

- Your questions are linked to the research purpose
- By answering these questions, you start to fulfill the purpose
- Reflect the interests of all stakeholders
- The questions that should be answered at the end of the research study





# METHODS FOR COLLECTING INFORMATION

### **START...EXISTING DATA**

- What information does your community already have, or collect?
- How do these data help answer your main research questions?

### THEN...NEW DATA

- Are there gaps in the information needed to answer your main questions?
- What *new* data are needed to fill these gaps and better understand your main questions?





# **CHOOSING APPROPRIATE METHODS**

### QUANTITATIVE

- Deductive
- Often uses standardized instruments
- Quality depends on careful instrument construction and a standardized manner of administration

### QUALITATIVE

- Inductive
- Often uses exploratory discussions
- Quality depends on the ability of the researcher to facilitate conversation, including probing



# SUMMARY OF 14 PROJECT METHODS



### QUALITATIVE

#### **Primary Data**

- Interviews
- Focus groups
- Storytelling
- Photovoice
- Stakeholder dialogue process / Community engagement discussions
- Consultation meeting / workshop
- Conversation circles / "siim'ohksin wahkotiwin"
- Elder validation circle
- Citizen journalism
- Group co-design

#### Secondary Data

Literature review



#### QUANTITATIVE

#### **Primary Data**

- Questionnaires
- Surveys (e.g., longitudinal, baseline)

### Secondary Data

- Database review
- Crosstabulation analysis of indicators in literature

# **ANALYSIS PLAN**

Come up with a plan to analyze and summarize all your data across methods in a way that answers your main research questions.

### **SOME CONSIDERATIONS**

- I.Review research questions
- 2. Decide who will be involved in the data analysis
- 3.Budget enough time for analysis and reflection
- 4.Assess the soundness of the analysis plan with the steering committee





# **ANALYZE & SUMMARIZE INFORMATION**

#### WAYS TO ANALYZE INFORMATION



With qualitative data perform content analysis (e.g., thematic, discourse)



**By method** What does each method say about the main research questions? ~

With quantitative data perform statistical analysis (e.g., univariate, bivariate, multivariate)



**By stakeholders** What does each stakeholder group say about the main research questions?

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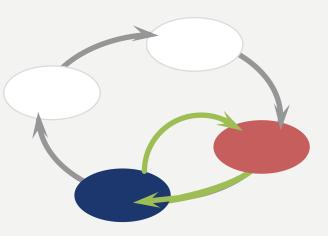
#### Across stakeholders

#### WAYS TO SUMMARIZE INFORMATION



**Across methods** 

## **BE OPEN FOR THE UNEXPECTED**









COLLECT data according to the plan that was developed

#### CONSULT

with the steering committee if any changes are needed regarding the collection or analysis of the data ADJUST as necessary

# ADAPTING THE PLAN

#### WHEN, WHAT, AND HOW



#2 Research <u>Planni</u>ng

# **REFLECTIVE QUESTION**



THINK OF YOUR RESEARCH PROJECT...

What are the parts of your research plan that might need adaptation?



# WHEN IS ADAPTATION ENCOURAGED?



Community-based research is always situated in the context of people, organizations, communities, funders and/or resources.

- Change of context (e.g., COVID-19)
- Additional information received
- Partnership changes
- Changes in funding



## WHAT PARTS OF THE PLAN COULD NEED ADAPTING?



- Methods
- Data Analysis
- Project Structure



# WHAT: METHODS



- Changes in methods could occur due to:
  - What methods are used to gather data
  - Who is sampled
  - How people are recruited
- There could be ethical ramifications for these changes
  - For example, what are the ethical implications of switching to online interviewing?



# WHAT: DATA ANALYSIS



- Changes to a data analysis plan could occur due to:
  - Changes in data gathering methods
  - Changes in timelines
  - Changes in partner involvement



# WHAT: PROJECT STRUCTURE

- Changes to project structure could occur due to:
  - People joining or leaving the team
  - New leadership
  - Creation of subcommittees or groups



# HOW: BEST TO ADAPT?



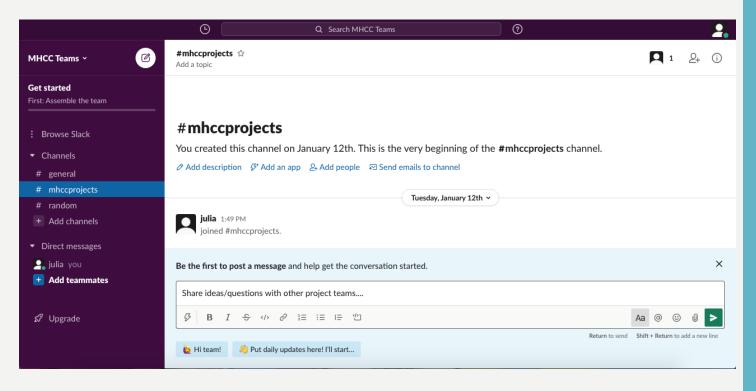
- Internally
  - Discuss with the research team
  - Check-in with the steering committee
  - Check-in with Ethics Board as needed
- Externally
  - Consult with other projects (Slack platform?)
  - Consult with CCBR Coaches



## SLACK

Slack is a space where you can share ideas, questions, resources, etc., with other MHCC project teams in a secure, private space

 If additional teammates are interested in being on this platform, please email Julia at julia@communitybasedre search.ca



# **BREAKOUT DISCUSSION**



THINK OF YOUR RESEARCH PROJECT...

What are the aspects of your project that may need to be adapted?

How could your team best respond?



# ETHICAL CONSIDERATIONS

#### **REFLECTING ON WHAT WE ARE DOING**



# WHY TALK ETHICS?

### ETHICS IN RESEARCH

Do no harm on both
 an <u>individual</u> and
 <u>community</u> level

 Maximizing benefits for both <u>individuals</u> and the <u>community</u>





## ETHICS AND MARGINALIZED POPULATIONS

### Addressing inequities

- Unequal power relationships between participants and researchers
- ✓ Literacy rates may be low
- May be unfamiliar with Western research and consent procedures
- Emotional fatigue/re-traumatization in sharing personal stories
- Precarious legal status
- Mistrust/conflict between researchers and communities

(Block et al., 2013; Clark-Kazak, 2017; Mackenzie, McDowell & Pittaway, 2007)



# WHY TALK ETHICS?

### **KEY CONSIDERATIONS**

### Initial Informed Consent

- Ensure people are aware of the purpose of the research
- Seek agreement from people to participate

### $\checkmark$ Throughout the Research Process

- Ensure cultural safety for all stakeholders (especially the equity deserving groups)
- Recognize power dynamics and competing agendas

### Promoting Research Use

- Ensure relevance for community and other stakeholders
- Improve the lives of people you involve and serve

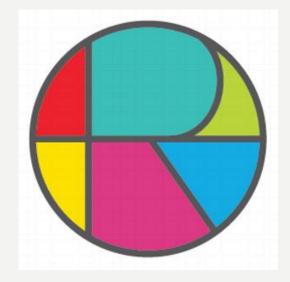


# THREE MECHANISMS OF ETHICAL REFLECTION

- I. The steering committee playing an ongoing role in discussing ethical issues
- 2. Community researchers bring lived experience and culturally ethical standards and practices
- 3. Formal ethics review upfront to assess whether the proposed research does no harm and maximizes benefits to the community (may need to be reassessed based on adaptations)



### COMMUNITY RESEARCH ETHICS OFFICE





Tri-Council Policy Statement Ethical Conduct for Research Involving Humans

**TCPS2 2018** 

- Does ethical review for community-based research
- CREO mission is to strengthen and support community research by responding to the needs of community researchers to easily access an ethical support and review process.
- Reviews projects:
  - Methodology
  - Risks and Benefits
  - Recruitment
  - Consent Process
  - Data Protection
  - Impact on Individuals and Community
- More info: <u>www.communityresearchethics.com</u>



### PRINCIPLES IN COMMUNITY-BASED RESEARCH ETHICS

#### **Respect for Persons**

#### Concern for Welfare

#### **Concern for Justice**

#### Free and Informed Consent

Researchers will inform participants in clear language: what they will be asked to do; risks/benefits of participation; how their information will be used; their rights as a participant; etc.

#### Autonomy and Voluntariness

Potential participants understand that they will have the choice how or if their data will be used, without negative consequence

#### Vulnerability

All people, regardless of capacity, will be fully informed directly and/or through those authorized to make decisions on their behalf

#### Balance of Risks and Benefits

Harm to individuals, groups, and society, through the research process or its results, will be mitigated where foreseen. Harm may be: social, behavioural, psychological, physical, or economic

#### Participant Perspective In all aspects of the

research, participants' perspective and context (social, economic, cultural) will be considered

#### Confidentiality

Anonymity, confidentiality, and the privacy of participants, including any potential limitations, will be fully explained through the consent process

#### Equitable Treatment

All persons impacted by the research will be treated with equal respect and concern; the benefits of the research will be shared, where feasible, with all of those affected by its results

# Appropriate inclusion Individuals or groups will not be excluded from research for reasons unrelated to the research (e.g. gender, race, ethnicity, age, or disability

#### • Power Researchers will be cognizant of, and work to mitigate, imbalances in power - between themselves and participants, among individual participants, or between participants and the groups to which they belong

#### **Respect for Community**

#### Understanding the Community

Researchers will seek to understand and include relevant geographic or organizational communities and/or communities of interest related to their research

 Respect for Community Researchers will learn about and respect a community's cultural traditions, customs, and codes of conduct through the development of respectful relationships, collaboration, and engagement where appropriate

#### Community Inclusion

Communities and groups relevant to or likely to be affected by the research will be included in shaping the research and benefitting from its results



# OCAP

OCAP<sup>™</sup> originated in 1998 at a brainstorming session held by the National Steering Committee (NSC) of the First Nations and Inuit Regional Longitudinal Health Survey, later incorporated as the First Nations Information Governance Centre (FNIGC) in 2010

• More info: <u>https://fnigc.ca/what-we-do/ocap-and-information-governance/</u>

The First Nations Principles of OCAP™



#### OCAP

**Ownership** – "of information by an Indigenous "community <u>collectively</u> in the same way that an individual owns their personal information"

**Control** – "over all aspects of research and information management processes which impact them...from <u>conception to completion</u>".

Access – "to information and data about themselves and their communities, <u>regardless of</u> <u>where it is currently held</u>...to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols."

**Possession** – as "a <u>mechanism</u> by which ownership can be asserted and protected. When data owned by one party is in the possession of another, there is a risk of breach or misuse."

## **BREAK-OUT DISCUSSION**

### THINK OF YOUR RESEARCH PROJECT...

What ethical challenges might you face in the different phases of research?

How would the principles we just covered help you to address these challenges?



# NEXT STEPS



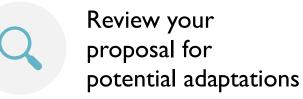
## **NEXT STEPS**



Provide workshop evaluation feedback



Check the project webpage for workshop slides





Discuss ethics with your teams and with others (Slack)

Next Workshop: February 26 at IPM (Eastern) Implementing Research: Collecting and Analyzing Qualitative and Quantitative Data





# COACHES' CORNER

OPTIONAL INDIVIDUALIZED SUPPORT

