Changemark
RESEARCH + EVALUATION

Shared Purpose

A Community Guide to Ethical Research Partnerships

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Table Of Contents

Shared Purpose: A Community Guide to Ethical Research Partnerships

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Special Thanks

This guide wouldn't have been possible without the support of so many people. Huge thanks to **Elder Sandy Lambert** for sharing his wisdom and decades of experience in Indigenous health research—his guidance really grounded this work in a deeper way.

Thanks also to **Matt Bonn** and **Isabelle Boisvert** for making sure the guide speaks to the real, day-to-day lives of people who use drugs.

Thank you to **Kilala Lelum Health Centre's Research Committee Members** for generously sharing their Research Charter with us. The time, care, and community guidance that went into creating such a thoughtful document is evident. Having the chance to draw from this Charter is truly a gift. It sets a strong example and paves the way for other community organizations to engage in research in a good way.

And a special shout-out to **Tara Taylor** for recognizing how important this project was from the very beginning and backing us to get it done.

Acknowledgement of Territory

With gratitude, we reaffirm that Changemark is located on the stolen land of the xʷməθkwəy̓əm (Musqueam), Sḵwx̱wú7mesh Úxwumixw (Squamish), and səl̓íl̓wətaɬ (Tsleil-Waututh) Nations. With humility and gratitude, our work also takes place on sovereign Indigenous lands and traditional territories across Turtle Island.

Changemark recognizes that an acknowledgement of territory is not enough but is an important social justice and decolonial practice that promotes Indigenous visibility and serves as a reminder that we are on settled Indigenous Land. We give our thanks to the Peoples of these territories for their ongoing stewardship of the land since Time Immemorial and keeping it healthy and strong for future generations.

Special Remembrance

We would like to take a moment to acknowledge and remember all the lives lost to the toxic drug supply. As community members and trusted allies, this is the heart of why we do this work. These are preventable deaths and they demand that we continue striving to improve lifesaving services through ethical, evidence-based practices.

There are many individuals to whom we could dedicate this section, but we would like to offer special remembrance to two extraordinary advocates: **Alexandra de Kiewit** and **Raffi Balian**.

Alexandra was a person who used IV drugs and a central figure in harm reduction and drug user advocacy, not only in Montreal, Quebec but across Canada and internationally. She was kind, caring, and deeply compassionate. As a co-founder of the Canadian Association of People Who Use Drugs and a leader in the HIV/AIDS movement, Alexandra's impact was profound. She will never be forgotten.

Raffi was also a person who used IV drugs and a tireless advocate for drug policy reform. He co-founded the Canadian Drug Policy Coalition and worked at South Riverdale Community Health Centre, where he played a pivotal role in the development of supervised consumption services in Toronto, Ontario. He too, was known for his kindness, empathy, and unwavering commitment to the community.

Both Alexandra and Raffi paved the way for people who use drugs to lead, to shape research, and to drive meaningful change. We dedicate this document to them, with gratitude, love, and respect.

Disclaimer

This document is intended as a reference to support community based organizations' work with researchers. Not all guidance will apply to every relationship, situation, or organization. Please use what feels relevant and helpful to you.

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Comments, Suggestions or Training

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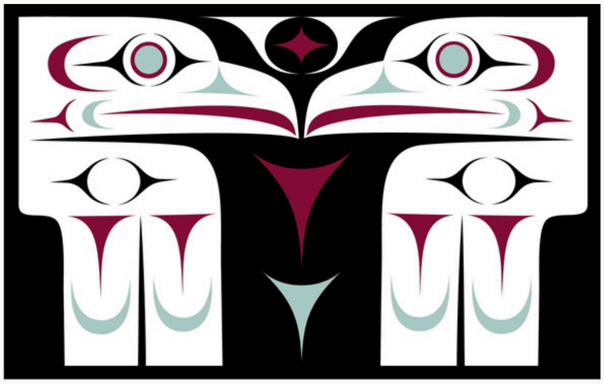


The Raven's design represents change, they bring an imminent and constant change as gatekeepers of the dark void. Raven's carry messages from the ancestors in the spirit world and raven medicine helps bring light to people on earth.

- Words and logo by Margaret August, Coast Salish Artist

Introduction

Who This Guide is For

We've drawn inspiration from the powerful work of peers and community members in Vancouver's Downtown Eastside (DTES), who wrote *Research 101: A Manifesto for Ethical Research*. But while that document was written for researchers, this one is written for **you**—organizational leaders and managers, as well as frontline teams, peer workers, people with lived and living experience and people who live and breathe this work.

Why This Guide Exists

Community organizations—especially those working in harm reduction, housing, peer support, and mental health—are no strangers to research. Studies are often conducted in the spaces you operate, involving the people you support, the services you deliver, or the networks you help build.

Research can be a force for good. It can unlock funding opportunities, shift policy, amplify public narratives, and help validate what community members and frontline workers have long known through lived and professional experience. When done well, it creates space for learning and change that's grounded in trust, respect, and real-world expertise.

But research isn't always done well. Too often, it's shaped by institutional priorities or academic timelines, and enters communities through top-down requests. You may be asked to give input on decisions that have already been made, lend credibility to a project that doesn't align with your values, or recruit participants for studies that offer little benefit—or even risk harm—to your community.

This dynamic is especially familiar to communities historically impacted by colonialism, racism, and systemic surveillance. For many, research has not been a tool for justice and to create social change, but a source of misrepresentation, extraction, and ongoing harm. These patterns have often created distrust and skepticism when it comes to the word "research".

This guide exists to begin changing that conversation.This guide is here to support you so that if you decide to engage in a research project, you have the tools to approach the decision clearly, confidently, and in line with your values and priorities.

How to Use This Guide

Research projects unfold in stages—funding, design, ethics board approval, recruitment, data collection, data analysis, and eventually, sharing results. But for community organizations, it's critical to think through all of these stages **before** agreeing to take part, even if you're being brought in after things have already started.

This guide is designed to help you do just that. It walks through the major aspects of a research partnership:

- How and when you're involved
- What role your organization plays
- Who benefits from the work
- How information is collected, shared, and used
- How findings are returned to the community

Even if you're approached late—after funding is secured or data collection has begun—you still have a right to ask questions, negotiate your terms, and say no. Understanding the full research pathway helps you avoid being sidelined and ensures your time, knowledge, and relationships are respected from the start.

Whether you formalize expectations through a Community Research Agreement or just want to feel more confident having these conversations, this guide offers tools to shape partnerships on your own terms.

CHAPTER 1:

Start with the Relationship

First and foremost, research partnerships are relationships. Like any relationship, they take time to build and not every partnership will be the right fit.

Before getting into logistics or signing anything, take time to get to know the researcher or research team. Strong partnerships are built on trust, mutual respect, and shared understanding, not just timelines and outputs. Rushing into a project can cause more harm than good, especially when community relationships, staff time, and lived experience are at stake.

Start with a conversation, not a commitment.

You can also ask to speak with other organizations they've worked with or review their previous research. Good researchers expect to be vetted. You wouldn't hire a new team member without checking their references—the same goes for researchers. Transparency and accountability are part of ethical research.

These early conversations help clarify expectations and values. They also give you space to assess whether this is a relationship you want to pursue. You can appreciate a research team's good intentions while still deciding that the project isn't the right fit for your organization.

Community Wisdom

Before agreeing to a research partnership, it's completely reasonable—and wise—to take time to learn about who you're working with. Try:

ASKING FOR REFERENCES

Ask for references from other organizations they've partnered with.

REVIEWING PUBLICATIONS

Review previous publications to see how they've represented the community in their work.

MEETING INFORMALLY

Meet informally over coffee, at an event, or through mutual connections.

Ask things like:

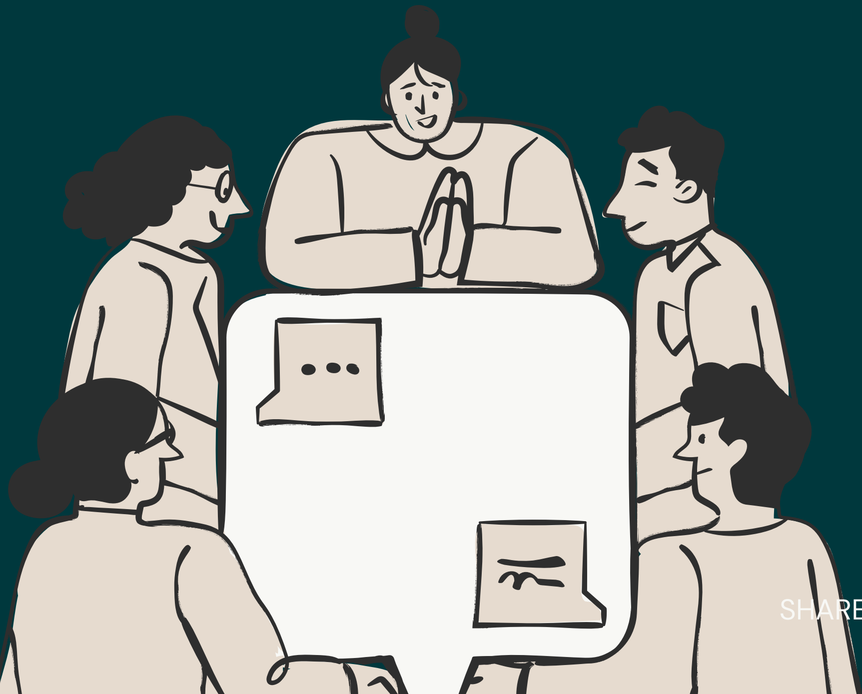
- What brought you to this work? Why do you want to work with us specifically?
- Who is this research for, and what is it trying to change or improve?
- What do you hope our community will gain from this?
- What stage is the project at? Can we help shape the direction?
- Who is funding this work? Who stands to benefit?
- What do you know about our community—or the communities we work with?
- Have you partnered with community organizations before? What did those partnerships look like?
- What is your experience with community-based or participatory research?
- How are you planning to give back? What does reciprocity look like to you?
- How are you prepared to follow any cultural or community protocols that may apply?
- How will you build trust with staff, clients, and Elders or community leaders?

CHAPTER 2:

Defining Your Role + Setting Expectations

Before agreeing to support a research project, **take time to understand what role your organization is being asked – or would like – to play.** Are you being asked to share knowledge, support participant recruitment, provide services or space, or participate as research "subjects" (or better named "participants")? Are you being asked to be part of the research design or simply to help implement an existing plan?

Understanding what's being asked of you helps ensure that your involvement is informed and intention. Not every role will be a good fit, and not every request is reasonable. The clearer you are upfront, the better positioned you are to make the right decision.



Here are some typical roles community organizations are asked to take on, with examples of what each might look like:

Research participant or subject

Your organization's services, programs, or practices are being studied as part of the research. This could mean your staff or community members are being asked to take part in interviews, focus groups, or surveys.

Example: A study evaluating the impact of Elder and Knowledge Holder care in primary care settings conducts interviews with staff and members at a local Indigenous Health Cooperative to learn more about how the program was developed, delivered, and its impact. In this case, the *organization* is a research participant.

This may also include situations where you're asked to help deliver a new intervention being studied, such as running a new program/service or integrating an evidence-informed approach into your existing services.

Example: A research group is studying a new train-the-trainer program for overdose response to stimulants and asks your organization to run the program with your staff as part of the study. Your team delivers the training while researchers evaluate the outcomes for staff and clients who participate. In this case, your organization is both implementing the program and participating in the research.

Recruitment or outreach support

You're helping connect researchers with participants. This might mean conducting outreach, sharing posters, facilitating warm hand-offs to the research team, or co-hosting information sessions.

Example: Your team is at a local drop-in centre and is providing recruitment support for a clinical trial of a treatment that is taking place at another site.

Knowledge holder or advisor

You're invited to share your insights to shape the research design, develop questions, or interpret findings. This might involve sitting on an advisory group or offering input at key points in the study.

You are invited to join an advisory committee to help shape a study on cannabis as a harm reduction tool for people who use opioids. You review and guide development of the intervention, survey or interview questions, share knowledge about the population's needs, and help interpret early findings.

Site or Space Provider

Your organization is asked to host the research project or activities, offering a place to conduct interviews or surveys, or allowing researchers to observe programs.

A drug checking site is used as a space to host one-on-one interviews with people who use drugs for a study about community perceptions of trends in the unregulated drug supply.

Community Wisdom

Most research projects have a Project Advisory Committee that helps guide decisions about the research process, findings, and knowledge sharing. As a community partner, you have the right to sit on or ask who sits on this committee—or to recommend someone from your organization such as a peer worker, Elder, Knowledge Holder, or program lead, depending on the perspectives needed.

For projects involving Indigenous communities, at least two Indigenous people should sit on any advisory group to avoid tokenism and support shared leadership. If a research team says they have Indigenous representation, **ask who is involved, how often they meet, and whether you can speak with a member** to understand the relationship.

If no advisory group exists, you can suggest forming one to help build trust and accountability.

Communications or Dissemination Partner

You’re helping to share the research findings by co-hosting a forum, sharing updates with your network, or co-authoring materials.

EVENT

After a study on prescribed alternatives to the toxic drug supply ends, the researchers ask if you'd be willing to co-host a local event where results are shared with service users and community leaders.

Things to Watch Out For

Each of these roles carries different responsibilities, risks, and demands on your time, space, and relationships. Consider the following points to guide early conversations and clarify expectations:

Table 1. Benefits and risks by research partner role

Role	Potential Benefits	Potential Risks
Research Participant	• Highlights your work • May improve services or support funding • Access to new/innovative programs • Supports advocacy • Meaningful ways for clients/staff to share their stories	• Risk of being misrepresented • Findings framed out of context • Retraumatization without adequate support • Risks to trust/confidentiality if not trauma-informed
Recruitment and Outreach Support	• Helps clients contribute their voice • May create paid opportunities for participants	• Staff burden if under-resourced • Clients may feel pressured or confused

Role	Potential Benefits	Potential Risks
Knowledge Holder or Advisor	• Direct influence on design and findings • Opportunity to reflect community priorities • Possibility for sustained collaboration or recognition	• Input may be ignored • Time-consuming and potentially tokenistic
Site or Space Provider	• Convenient for participants • Showcases your work • Demonstrates collaboration • Supports community staff in protecting service users	• Can disrupt services or workflow • Privacy/confidentiality concerns • Potentially compromises trusted space
Communications and Dissemination Partner	• Ensures findings are shared accessibly • Showcases your organization’s role • Helps reach decision-makers	• Risk of disagreement on how results are framed • Potential reputational harm • Time demands may not be acknowledged or supported

Power and Decision-Making: Who Holds the Power?

At its core, research is a relationship – and like any relationship, it’s shaped by power. Who holds it? Who shares it? How is it protected?

If you’re being asked to join a project, don’t just clarify your role. **Clarify what power comes with it.** What decisions will you help make? What happens if you disagree with the research direction or how findings are used? Who responds to concerns, and how?

Some organizations are brought in late or treated as token partners. Others are deeply involved from the start. Understanding where you stand, what research stage you are at, and what influence you have helps ensure your participation is both meaningful and fair.

The Spectrum of Community Involvement in Research

To help navigate this, we've adapted a version of the IAP2 Spectrum of Public Participation, a tool originally developed to guide how organizations engage the public in decision-making. See page 15 (the next page).

Here, we use it to illustrate common levels of community involvement in research projects. This framework helps clarify:
- Your role in the project
- The typical decision-making power tied to that role
- The promise researchers should make to your organization

Note: One level isn't better than another—they're just different. Not every organization has the capacity or desire to be deeply involved in shaping a research project, and that's okay. Nor does it always make sense based on your organization's area of expertise. For example, in a clinical trial of a new medication, it may be most appropriate for your organization to be engaged at the Involve level—supporting aspects like recruitment or eligibility screening—without being pulled into regulatory matters or daily operations. What matters most is that you are involved at the level you are most comfortable with.

Questions to Ask Early On:

Decision-Making: What kinds of decisions will we have input on, and how will that input be used?

Disagreements: What happens if we don't agree with how our community is being represented or how the research being conducted? Can we pause or revise the process?

Review Rights: Will we be able to review materials (like interview guides, consent forms, publications, or presentations) before they're shared publicly or approved?

Changes to the Project: Can we revisit or renegotiate parts of the project as it unfolds if it's not working for our staff or participants?

Table 2. Spectrum of research engagement

Level of Enagement	Goal	Decision-Making Power	Promise to Your Organization	Example
Inform	To provide you with clear, timely, and accessible information about the research	None	You will be kept informed of key details, such as timelines, goals, and results.	Researchers are tracking changes in the unregulated drug supply in several regions. They send your organization monthly bulletins with summary data and alerts about emerging substances.
Consult	To gather your input on aspects of the study that affect your organization or community	Low	Your feedback will be considered when shaping aspects like recruitment strategies, tools, or timelines—but final decisions rest with the research team.	Researchers designing a survey on youth vaping ask your team to review and suggest edits to make the language more accessible for your clients. They thank you and incorporate some changes, but the final survey is theirs.
Involve	To include your organization in shaping how the research is designed, delivered, and how results are interpreted or disseminated.	Moderate	Your knowledge and perspectives will influence decisions on study design, data collection, and how findings are interpreted and shared.	You're invited to sit on the advisory committee for a study evaluating cannabis use for self-management of withdrawal symptoms from opioids. Your team helps shape interview guides and later joins a debrief to discuss preliminary results.

Table 2. Spectrum of research engagement

Level of Enagement	Goal	Decision-Making Power	Promise to Your Organization	Example
Collaborate	To partner with you throughout the process as co-creators of the research project.	Shared	You will co-lead major project elements, participate in decision-making, and your priorities will shape the direction and outcomes of the study.	Your organization co-develops and runs a stimulant overdose response train-the-trainer as part of a multi-site RCT. You're involved in designing the training, hiring peer facilitators, interpreting results, and co-presenting findings.
Empower	To support your leadership and self-determination in guiding the research process	High	The research will reflect your terms, leadership, and protocols. Your approval is required for major decisions, and benefits will flow back to your community.	An Indigenous Health Cooperative invites researchers to support a Model of Care evaluation. Community leaders co-design the research questions, oversee data collection, and own the data. Researchers act as facilitators and translators of findings only with community approval.

Building the Relationship Around Shared Accountability

Strong partnerships are grounded in clear communication and shared accountability. Ideally, the process for raising concerns or resolving disagreements should be discussed **early on—not just when problems arise.** This includes talking about how decisions will be made, what happens when there's a conflict, and how community voices will be honoured throughout the process.

Some research teams will suggest signing a formal agreement, which can work well—but it's not the only way to build accountability. In some contexts, especially when working with Indigenous communities, requiring signatures can be inappropriate or activating (i.e. triggering). Instead, consider creating a written understanding that reflects both parties' values, expectations, and responsibilities. This might take the form of:

- A shared letter of agreement or partnership
- A memorandum of understanding (MOU)
- A verbal or ceremony-based agreement, with shared notes or documentation
- A relational protocol, co-developed with Elders or Knowledge Holders

Whatever form it takes, the goal is to create something that you can refer back to-a shared anchor to revisit commitments, align expectations, and resolve issues together.

Watch for These Red Flags:

- You're told decisions have already been made and can't be changed.
- Researchers ask for feedback but don't follow up or incorporate it.
- There's no clear point of contact or process for raising concerns.
- You're not given time to review materials before they're shared externally with institutions, funders, or at conferences
- Advisory roles feel like a checkbox, rather than a space for collaborative leadership .

Fair Compensation: Your Time Isn't Free

Community time and expertise should never be treated as a freebie. Once you've discussed your role and expectations with the research team, make sure there's compensation that reflects the scope of your involvement. **If your team is contributing time, space, insight, or emotional labour, that contribution needs to be resourced.**

Here are some key areas where compensation should be considered:

- **Staff time:** This includes coordination, communication, recruitment, or translating research activities into community contexts. This is foundational - not optional. It also includes any adaptations needed to make the research fit your settings, time spent in meetings, reviewing materials, helping with logistics, or making changes to staff responsibilities to support the study.

- **Emotional labour:** Research can surface grief, trauma, or activating content—for participants and staff alike. When that happens, it often falls to frontline workers to provide support. This takes time, care and can require staff to step back from research activities. Compensation should account for both formal and informal support before and after a study visit, like debriefing with a participant or offering comfort when researchers aren't equipped to do so. It's essential, relational work that should be planned for and recognized.

- **In-kind contributions:** Things like lending space, equipment, or helping researchers connect through long-standing community relationships are all valuable and often invisible forms of support. They should be acknowledged, tracked, and compensated where possible.

- **Overhead and admin:** Most institutions budget 10–15% of direct research costs to cover admin. So should you. This helps cover things like reporting, human resources, staff support, and infrastructure that make your involvement possible.

Community Wisdom

There's no one-size-fits-all rate—but your time and energy should never come at a loss. Use tools and benchmarks (like those from CAPUD, CCSA, or PEEP) to help guide discussions. See the Additional Resources section.

- Factor in local cost of living, inflation, experience, and the emotional impact of the work
- Rates should reflect responsibility and expertise
- The people doing the work should help decide what's fair
- Funds should be paid directly to those doing the work

- **Cultural or relational protocols**: Budget for ceremony, honoraria for Elders or Knowledge Holders, and time for community preparation or consensus-building. These are core elements of ethical research with many communities.
- **Capacity-building**: If possible, ask for funds to support training, mentorship, or hiring community members into paid roles. This builds leadership and skills beyond the project itself and empowers community members directly affected by the research.

If the project budget isn't finalized, push for a dedicated line item to support your role. Better yet, ask to co-create the budget so you can ensure costs are realistic and aligned with your community's priorities.

Community Wisdom

If there's unspent money at the end of a grant, ask for it to be redirected to your organization, especially if you provided time or space beyond what was budgeted. Extra funds can support thank-you honoraria, knowledge mobilization efforts, or resources for future community-led work.

CHAPTER 3:

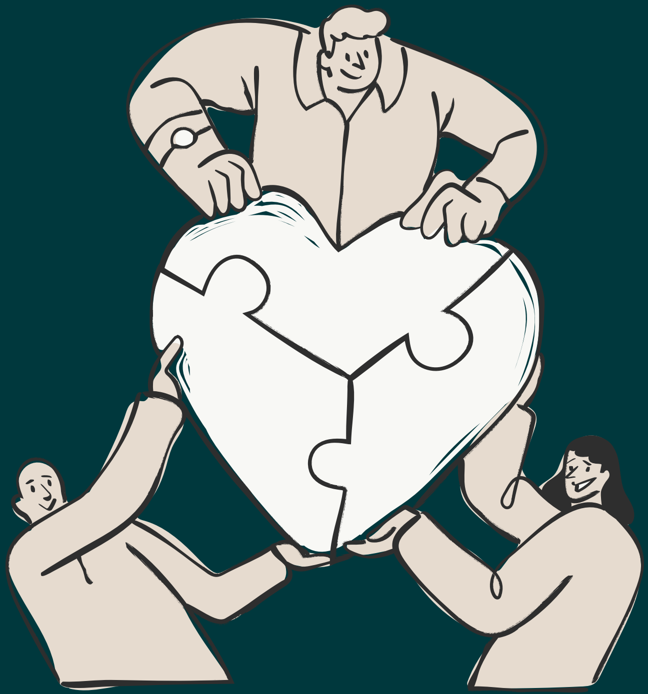
Ethics: Whose Ethics?

Most academic research projects require approval from a Research Ethics Board (REB) or similar oversight body. These boards are meant to protect participants, but they don't always consider what's ethical from a *community* perspective.

Many REBs:

- Focus on individual risks, not community or cultural harms.
- Prioritize academic definitions of harm, like confidentiality, over emotional, spiritual, or relational risks.
- Lack experience with harm reduction, peer-led, trauma-informed, or community-driven approaches.
- Use frameworks rooted in colonial and institutional worldviews, often misaligned with the lived/living experiences, values, and knowledge systems of the communities involved.

Just because a project has ethics approval doesn't mean it's ethical for your community.



Community organizations, especially those working with people who use drugs, are unhoused, or are Indigenous, are often most impacted by gaps in institutional ethics. A project might technically follow the rules but still cause harm, retraumatize participants, or violate community values.

What REBs Might Miss

- **Relational responsibility:** How will the researcher show up in community, build trust, uphold relationships, and follow through on commitments?
- **Reciprocity:** Will your community benefit from taking part? Will the research findings be returned to participants in a way that's accessible, relevant, and useful?
- **Plain language:** Are consent forms, surveys, questionnaires and information sheets actually accessible across different levels of literacy, language, or cultural context?
- **Accessibility:** Do the research methods promote meaningful participation? Are there supports in place like transportation, food, flexible timing, or childcare?
- **Wider consequences:** Could the findings be used, intentionally or not, to stigmatize, criminalize, or harm participants? How might others outside the research team misuse the results?
- **Relevance:** Is this research meaningful enough to justify your community's time and energy? Who decided it mattered, and why?
- **Accountability:** What happens if someone feels harmed, misrepresented, or excluded? Who can they turn to, and how will it be made right?

In many communities, what affects one person ripples through many. Research should honour that. Participants aren't just individuals—they're knowledge holders, caregivers, leaders. Their stories deserve long-term care, not extraction.

Community Wisdom

Even though Research Ethics Boards may not always get it right, but they can still be a resource if something feels off. If your organization or participants feel ethical commitments aren't being followed, you can contact the REB directly. This may lead to:

- A pause on the project while concerns are reviewed
- A requirement for the research team to change their approach or revise materials
- Follow-up from the REB to ensure risks are being addressed

What You Deserve to Know and Name

At a minimum, your organization has the right to:

1. **Review the REB submission** and ask for a plain-language version.
2. **Ask how risks will be managed**, including reputational, emotional, cultural, and safety risks for staff and participants.
3. **Name what ethical care looks like in your context** and follow up with the research team to ensure it is integrated into the process.
4. **Request trauma-informed supports** like peer support, Elders, or counsellors if the research may surface grief, trauma, or activating content.
5. **Demand a transition plan** for any interventions. For example, what happens when the research ends? Will participants lose access?
6. **Request "member checking"** - a chance for participants to shape or review how their stories are presented (see next section for more details).
7. **Ensure informed consent is ongoing**, not just a checkbox at the start.
8. **Contact the REB if something feels off.** The researcher should provide an REB number (usually starting with "H") and a phone number to call. That code identifies the specific project to the ethics board.

Community Wisdom

If possible, consider forming a Community Research Review Committee—a small group of staff, peers, Elders, or community members who help assess research requests based on your organization's values.

Even a simple intake process or values-based checklist can make a big difference. It gives you a way to:

- Decide whether a project aligns with your community's priorities
- Reflect your ways of knowing and ethical standards
- Name concerns or conditions before committing to participate

See the Toolbox for sample tools including:

- Terms of Reference for a Community Research Review Committee
- Research Application Form
- Research Application Form Review Checklist

CHAPTER 4:

Data Collection, Access, + Ownership

Research is built on trust. When someone agrees to participate in a study, by sharing their story, completing a survey, or providing a biological sample, they're extending trust that their information will be handled with care, respect, and purpose. That trust must be protected at every stage. Too often, this hasn't happened. Researchers have come in, gathered what they needed, and left, extracting data without giving anything back. In the process, they've reinforced hierarchies, treated academic knowledge as more valuable than lived or living experience, and failed to represent communities accurately or respectfully.

While some practices have improved, these patterns are not just part of the past—they still happen today. This section outlines key points in the data collection journey, from recruitment and data collection to storage, access, and analysis, and offers guidance on what to ask, watch for, and advocate for at each stage.

Recruitment: Who is Being Asked to Participate and How?

Recruitment refers to how participants are identified and invited to join the research. It's not just about checking eligibility boxes or handing out flyers. It's a deeply human process, shaped by trust, communication, and power dynamics between the person asking and the person being asked.

Recruitment strategies generally fall into two categories:

- **Passive recruitment**: sharing information publicly and waiting for people to express interest (e.g., flyers, social media, notices).

- **Active recruitment**: doing outreach, where either research or site staff, people with lived and living experience, or providers directly approach potential participants.

Both can be appropriate, but active recruitment has more potential for perceived pressure—especially if the person doing the outreach holds any kind of real or perceived power (e.g., a housing worker, nurse, or prescriber). Still, active recruitment is often more effective for reaching people who are underserved or disconnected from formal care systems. This is especially true when recruitment is peer-led or grounded in trusted community spaces.

That's why it's so important for your organization to shape how recruitment is done. Whether it's deciding where recruitment happens, when, by whom, or in what way, your input ensures the approach is grounded in trust and humility.

Organizational Involvement Matters

When community organizations help shape recruitment and engagement strategies, it leads to better participation in research projects and reduces loss to follow up during the project. Your team brings valuable, on-the-ground knowledge about what makes people feel safe, interested, and willing to engage.

What Makes Recruitment Work

As community organizations, you understand what makes people feel safe, curious, and ready to engage. Here are areas where your guidance is essential:

- **Timing -** You know when people are most and least available—like avoiding cheque week, shelter turnover times, or cultural ceremonies. These rhythms matter.

- **Location -** You can identify spaces that feel safe and comfortable, such as drop-ins, harm reduction sites, healing spaces, or supportive housing, not just clinics or offices.

- **Language and Framing –** You can help shape materials that feel approachable and relevant, steering away from overly clinical, academic, or jargon language.
- **Access Supports –** You know what makes participation possible—transportation passes, snacks, water, harm reduction supplies, or childcare.
- **Trusted Recruiters –** You can identify who should do active recruitment or outreach. Often, it's people with lived and living experience, Elders, or outreach workers who already hold trust and understand local dynamics.
- **Time and Flexibility –** You understand that people may need multiple conversations, gentle check-ins, or long-term relationship-building before agreeing to participate. That timeline needs to be honoured.

Researchers may ask your organization to help recruit by distributing flyers, doing outreach, or sharing information. But that doesn't mean you need to agree to everything.

If your organization has built trust with community members, your involvement carries weight. Misusing that trust or rushing recruitment can damage relationships that took years to build.

Recruitment also takes real time, labour, and emotional energy, especially for staff and peers who are deeply embedded in community. Even in higher-trust settings, it may take multiple conversations and reassurances before someone agrees to participate. That needs to be reflected in research timelines, budgets, and staffing plans from the start.

Questions to Ask About Recruitment

Use these prompts to guide your organization's conversations with researchers:

Who is doing the recruitment, and how? What relationships or reputations do they carry?

Who is eligible to participate, and what are they being asked to do?

Why this community, this moment, this topic? Who benefits?

What supports are in place to prevent retraumatization, coercion, or risk?

Is the recruitment strategy inclusive of people who don't use formal services?

Community Wisdom

Below is some common recruitment lingo decoded:

- **Passive recruitment**: Posters, flyers, or social media announcements. No direct contact is made.
- **Active recruitment**: Direct outreach to individuals or groups.
- **Street outreach**: Approaching people in public or community settings, usually led outreach workers or peers.
- **Peer outreach**: Recruitment by people with lived and living experience.
- **Referrals**: Participation invitations from service providers—such as harm reduction programs, housing teams, or clinics.
- **Snowball sampling**: Asking participants to refer others in their network.
- **Respondent-Driven Sampling (RDS)**: A structured, coupon-based system leveraging social networks of people with lived and living experience, people who use drugs, or other marginalized groups.

Data Collection: What Information Will Be Collected and Why?

Once someone agrees to participate, the next step is gathering their information through surveys, interviews, storytelling, administrative data, biological samples or other methods. It might seem straightforward on paper, but this stage can carry deep emotional, cultural, and spiritual weight.

For participants, it's not just about "providing data"—it's sharing lived experience and personal stories. That deserves care.

Community-based organizations are often best positioned to assess whether data collection plans are appropriate, respectful, and safe. You know what your community has already shared, what they've been asked before, and what they're tired of being asked again.

Honouring the Space: Building Trust and Participant Safety

Before any information is collected, the setting must support participants' emotional, physical, cultural, and spiritual safety of participants. Researchers may be focused on logistics and timelines. You're focused on people.

Questions to guide the research team:

Who will collect the data? Are they trained in trauma-informed interviewing, cultural safety, and anti-racism? Have they worked with this community before?

What supports will be in place? Consider food, child care, ceremony, traditional medicines, harm reduction, or quiet spaces to ensure safety and comfort.

Are Peer researchers, Elders, or Knowledge Holders involved? If so, how will their time and wisdom be supported and compensated?

Is the method inclusive and accessible? Are researchers entering spaces where people already feel safe? Do they know how to explain the research in plain, culturally relevant language?

Community Wisdom

When researchers are looking to recruit participants, community staff can play a big role in ensuring they're doing it in an accessible way. If you're helping a team communicate their study, try encouraging them to:

- Understand their own study clearly – What are they really trying to learn?
- Break it down into 1–3 simple points that feel relevant and clear to the community.

For example: "They're looking to hear from people who use drugs, especially folks who inject. The goal is to improve services in the community or to get your input so they can bring it up to policy makers".

Community Wisdom

Even when research occurs outside Indigenous communities, cultural safety must remain a priority. You can hold researchers accountable by:

- Ensuring access to Elders, Knowledge Holders, ceremony, medicines, or cultural wellness teams when requested.
- Encouraging long-term relationships with cultural teams, not one-off or transactional engagement.
- Advocating to follow local protocols for compensating Elders and Knowledge Holders fairly.
- Promoting wellness tools that let Indigenous participants express their goals, needs, and experiences in their own words

The Research Methods: Gathering Information with Care

The way data is gathered shapes how people are seen. Some methods strip away context. Others make room for full stories.

It’s also important to understand why certain data is being collected. What questions are researchers trying to answer? How will the information be used? Without clarity, it’s hard to ensure data collection is ethical or justifiable.

You can ask researchers:

- What methods will be used and why?
- How do these reflect the values, realities, or cultural practices of our community?
- Will participants help shape how their story is told or interpreted (e.g., by reviewing transcripts or summaries)?
- What happens if someone feels misrepresented or harmed by how their story is used? What processes are in place?
- What training or preparation will those conducting data collection activities receive?
- Are people with lived and living experience, Elders, or Knowledge Holders involved in shaping or facilitating the data collection process?

A Note on Informed Consent

Consent is more than a signature. It’s a process. Participants need to fully understand what they’re agreeing to—not just once, but at every stage. That means:

- Using plain language in the consent form and in discussions about it.
- Giving participants a copy of their consent form.
- Re-visiting consent before follow-ups.
- Offering verbal consent options for those with literacy barriers or those who prefer conversation.
- Having someone not related to the study available to read or translate the consent form and act as a neutral support.
- Being thoughtful when working with people who may intoxicated or otherwise unable to fully consent.

Community Wisdom

Sometimes, participants realize partway through that something doesn’t feel right—maybe they feel misrepresented or unsafe, or maybe the research isn’t what they expected.

When this happens, there needs to be a clear path to raise concerns, one that’s safe, supportive, and easy to navigate.

Community-based organizations can support participants by:

- Acting as a point of contact for concerns
- Bridging communication between participants and researchers.
- Escalating concerns to the Research Ethics Board (REB), if needed.
- Ensuring there’s clear paths for participants to pause or withdraw from the study.
- Offering support beyond a phone number – walking people through what happens if they speak up, and offering trusted contacts.

Ensuring Researchers Are Prepared

Before any data is gathered, researchers must be prepared. Not just with tools, but with the training to engage community respectfully. Preparation may include knowledge and/or training on:

- Cultural safety and anti-racism
- Trauma-informed interviewing
- OCAP® principles (Ownership, Control, Access, Possession) – applicable to First Nations communities1
- TCPS2 ethics guidelines – especially Chapter 9 (Research Involving the First Nations, Inuit and Métis Peoples of Canada)

Additional preparation may include:

- **Cultural context:** Understanding local strengths, diversity, and challenges.
- **Community protocols:** How to engage Elders, observe ceremonies, and respect local practices.
- **Harm reduction:** Using nonjudgmental, respectful language around substance use, trauma, housing, and health.
- **Organization orientation:** Understanding what your organization does and how it serves the community.

This kind of preparation should be planned with your organization to ensure researchers have the relevant training to engage community.

Data Storage, Access, and Management: Who Can See the Data?

When community members share their stories, they're extending trust. That information reflects identity, history, struggle, and strength. Your organization has the right to help shape what happens next – how data is stored, who accesses it, and how it is used.

What Is a Data Sharing Agreement?

A Data Sharing Agreement (DSA) is a formal document that outlining:

- Who owns the data
- Who can access and analyze it
- How the data will be stored and protected
- How results will be shared and published
- What will happen to the data when the project ends

Think of a DSA as a tool to protect participants and ensure your organization has a say. A good DSA should be negotiated **before** any data collection begins. But even if your organization is brought in later, it's not too late to ask for one.

What Should a DSA Include?

A strong DSA outlines:

- **Ownership and control** – Who makes decisions about the data?
- **Access rights** – What your organization can access and when?
- **Confidentiality and privacy** – How personal and sensitive information is protected.
- **Review rights** – The ability to review and respond to findings.
- **Acknowledgment** –How your organization and the community will be credited.
- **Limitations on use** –Conditions for reusing the data in future studies.
- **Destruction or return of data** – What happens to the data after the project ends.

Community Wisdom

If a researcher tells you "the university owns the data", you still have options:

- Negotiate a Data Sharing Agreement (DSA) to outline access, use, and shared control.
- Request co-ownership or custodianship, especially if you're supporting recruitment, or the subject of the research.
- Invoke OCAP® principles for First Nations communities.
- Ask for clarity: Who decides how the data is used? How will your community be acknowledged or included?

Bottom line: University ownership isn't a wall. There are workarounds and precedents for community access, especially when ethical research practices demand it.

Indigenous Data Governance

If your organization is Indigenous-led or serves Indigenous people, you request that researchers:

Protect Indigenous Knowledge and teachings. You can ask that:

- Stories, teachings, or oral histories shared through the project remain the intellectual property of the Knowledge Holders or community.
- These teachings are not shared, published, copied, or stored without fee, prior, and informed consent by the original Knowledge Holder or steward.
- Any disputes around use or interpretation of cultural knowledge be resolved with guidance from the appropriate Elders or community authorities.

Follow community-specific protocols when working with Métis people.

Uphold OCAP® principles for First Nations:

- **Ownership** – First Nations communities own the data collected about them
- **Control** – Communities decide how their data is used
- **Access** – Communities must have access to their own data
- **Possession** – Communities should hold the data, physically and digitally

Use of the National Inuit Strategy on Research when working with Inuit people.

Data Analysis: Interpreting the Findings

Once the data is collected, researchers move into the analysis phase where key themes, patterns, and insights start to take shape. This is where meaning is made. As a community-based organization, you play an important role in making sure that the analysis is accurate, meaningful, and grounded in lived realities—not just abstract data points.

How CBOs Can Contribute

CBOs can:

- Offer local context to explain why certain patterns may be emerging.
- Highlight community strengths and structural barriers that affect interpretation.
- Flag misinterpretations or missing nuances.
- Support involvement of people with lived or living experience in the analysis process.

These contributions strengthen the research's credibility and relevance.

What to Expect During Data Analysis

Analysis may involve:

- Identifying common themes in qualitative data.
- Spotting trends or patterns in quantitative data.
- Connecting findings to the original research questions.
- Interpreting what the data means and why it matters

Strong analysis explains not just *what* is happening, but *why*, how it differs across communities, and what systems shape it. It should also reflect multiple ways of knowing, not only academic expertise. Your knowledge is vital—you can answer questions researchers can't, or that would take them far longer. Early insights help ensure research leads to real community benefit.

For Research Involving Indigenous Communities

When Indigenous participants are involved, analysis must be co-led by Indigenous team members and grounded in Indigenous worldviews. Researchers should:

- Involve an Indigenous co-lead in analysis design.
- Engage Indigenous analysts or data stewards for identity-linked data.
- Invite and compensate Elders/Knowledge Holders to reflect on findings.
- Validate meaning through member checking with Indigenous partners.
- Handle identity data with care:
  - Avoid grouping First Nations, Métis, and Inuit together.
  - Recognize "Two-Spirit" as a distinct gender option.
  - Use narrative methods for small samples.
  - Distinguish on- and off-reserve experiences.

What is “Member Checking”?

Member checking is when researchers share early findings with participants or community partners to verify accuracy, add context, and improve how stories are represented.

Why it matters:
People with lived and living experience often see things others miss. They help decode language, understand local dynamics, and offer insights that make findings more useful and truer to the community.

What it can involve:

- Reviewing draft themes, quotes, or summaries.
- Clarifying meaning or context.
- Flagging misinterpretations.

You Might Be Asked to:

- Review a sample of findings (usually 20%).
- Answer questions like:
- “Does this reflect what you hear/see in the community?”
- “What does this quote or theme mean to you?”
- “Is anything missing or misrepresented?”

How it’s done:

- Through a group session, one-on-one conversation, or feedback form.
- Facilitated by the research team—ideally with peer or community support.
- Done in person or virtually.

What should happen after:

- You are fairly compensated for your time and expertise.
- Feedback is documented and integrated.
- Researchers revise or explain their interpretations.
- You’re shown how your input shaped the final results.
- Your contributions are acknowledged.

If researchers don’t invite this kind of input, you can ask for it! But ideally, it should be discussed at the beginning of the project. You might also ask when you’ll be brought into the process and how long it will take to see results—will it be in 3 months? 6 months? A year? 4 years? Make sure your role in shaping analysis, framing, and language is part of early agreements so you’re not left out later.

CHAPTER 5:

Returning Results to the Community and Beyond

The work isn't done after data collection and analysis. For many communities, the real harm comes from being forgotten once the study ends. Too often, results are presented at conferences or in journals long before they're shared back with the people who made the research possible. This breaks trust and undermines good practice.

A values-based approach requires follow-through. Returning findings in a meaningful way is part of reciprocity. Researchers should ask how the community wants to receive the findings, who they should be shared with, and in what formats. They should also consider what matters to the audience and tailor language and materials so that everyone can understand and engage with the results.

Ways to Share Findings Back with the Community

There are many ways to bring findings back to community:

- **Small group gatherings or talking circles** to review key themes and invite feedback.
- **Drop-in style presentations** at trusted spaces like Friendship Centres. Overdose Prevention sites.
- **Printed or visual summaries**, such as zines, posters, or infographics, distributed in familiar settings.
- **Workshops or peer-led sessions** co-facilitated by people with lived or living experience.
- **Community feasts or shared meals**, where findings are shared alongside food that reflects local culture.
- **Art-based formats** like murals, digital storytelling, poetry, or exhibits that bring findings to life in accessible, expressive ways.
- **Audio and video recordings** that can be shared in-person, online or through community hubs.

It's Not on You: What to Expect from Researchers

As a CBO, you shouldn't be expected to carry the weight of returning findings. That responsibility belongs to the research team. While you may choose to collaborate, guide, or offer suggestions, you're not expected to lead this work or fill in the gaps.

You can hold researchers accountable to:

☑ **Plan logistics**, like booking welcoming, accessible venues and covering costs for honoraria, food, and transportation.

☑ **Organize cultural and emotional supports** such as Peer Workers, Elders, or cultural wellness staff.

☑ **Use clear, jargon-free language** so people can understand the findings.

☑ **Co-present with people with lived and living experience**, Elders, or community members where appropriate.

☑ **Highlight strengths** and resilience, not just challenges.

☑ **Create space for dialogue**, allowing people to ask questions, offer feedback, and add context.

☑ **Translate materials** into locally relevant languages and formats.

Your Role as a CBO in Sharing Research Findings

Your role is to offer guidance on what will work and what won't. That might include:

- **Suggesting trusted spaces**: Comfortable, safe venues like drop-ins or community hubs.
- **Recommending food**: Meals that are culturally appropriate and, when possible, locally sourced.
- **Advising on recognition:** Honoraria amounts, gifting, or other meaningful forms of appreciation.
- **Suggesting thoughtful gifts**: practical items (e.g., transit passes, water bottles, lighters, umbrellas), or fund things like snacks or swag.
- **Helping promote participation:** Emphasizing that this isn't just a presentation, it's a chance to shape what happens next.
- **Timing and accessibility**: Offering input on session length, local scheduling conflicts, and best days/times.
- **Encouraging participation:** Helping the team build a conversational, interactive format.

Sharing Results Far and Wide

Returning findings to the community is essential but it shouldn't stop there. Sharing results more broadly can amplify impact, influence systems, and reach people with the power to drive change.

Common Dissemination Methods

After community feedback has been gathered, researchers may share findings via:

- Conferences (local, national, international)
- Academic journals
- Public media (e.g., op-eds, blog posts, Indigenous-led outlets)
- Visual and digital formats (infographics, short videos, podcasts, social media)
- Policy briefs and reports aimed at decision-makers and funders

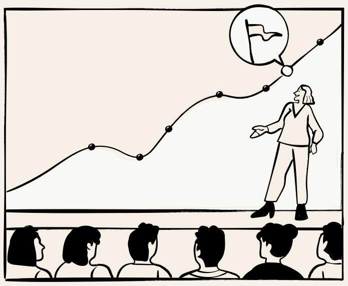
Community Wisdom

Findings are often shared at conferences or meetings before being formally published. This is common—but community partners are often left out.

You should expect to be notified of any presentations, reports, or publications involving your organization or data. This gives you the opportunity to:

- Review and fact-check key messages
- Raise concerns
- Request to be credited or included in presenting

Whether you choose to participate directly or not, being consulted and acknowledged matters.



Your Role in Broader Dissemination

CBOs can help ensure dissemination is accurate, community-rooted, and reaches the right people. You can:

- **Review materials** before publication or presentation to ensure respectful framing.
- **Request updates** about all products or events involving your organization or community.
- **Help shape strategy**, suggesting formats and audiences that reflect your values and goals.
- **Nominate co-authors or speakers**, including staff, peer researchers, or community members.
- **Guide framing and tone**, ensuring community strengths and solutions are centered, not just needs or deficits.

Community Wisdom

In academic publishing, first authorship typically goes to the person or team that played the largest role in designing the project, collecting or analyzing data, and writing the manuscript.

If your organization was central to the research, such as leading recruitment, shaping the research questions, acting as the main site, or contributing to analysis, it may be appropriate to request co–first authorship, especially when your role was foundational.

Even if co–first authorship isn't appropriate, you still have the right to:

- Be included as a co-author or in the acknowledgements section if your organization helped shape or support the research in a meaningful way.
- Review and provide input on how your organization and community are described in any publications.
- Have early conversations about authorship so expectations and roles are clear and fair from the start.

Academic publishing is one way that research impact is measured—and it can influence future funding, recognition, and credibility. Your knowledge, labour, and relationships matter. They deserve to be recognized in the final product.

CHAPTER 6:

Formalizing the Relationship

Setting the Terms of Engagement

If you decide to move forward with a research partnership, it's important to set clear expectations in writing. A Community Research Partnership Agreement, Memorandum of Understanding (MOU), or Terms of Reference (ToR) are great tools to protect your team, promote transparency, and make sure everyone is on the same page.

This document should reflect *your* values, needs, and realities—not just the researcher's template. Don't hesitate to propose additions or edits that reflect community's protocols, principles, or concerns. These agreements are meant to be negotiated.

A Community Research Partnership Agreement outlines roles, responsibilities, timelines, and boundaries. It serves as a reference point if expectations shirt or tensions emerge.

What to Include in a Research Partnership Agreement

1. **Values and ethics** –Guiding principles like mutual respect, accountability, anti-racism, and decolonial practices.
2. **Staff Roles and responsibilities** – What your organization *is* and *is not* responsible for, such as recruitment, intervention delivery, or data collection.
3. **Cultural Protocols** – Involvement of Elders or Knowledge Holders, ceremonies, teachings, or local customs.
4. **Emotional support** – Plans for participant and staff wellbeing when sensitive topics arise.
5. **Workload and Operational Impacts –** What happens if the research starts interfering with regular program operations or asks more of the staff than was originally agreed to?
6. **Compensation and cost coverage** – Who covers what costs, when payments are made, and how in-kind contributions are recognized.
7. **Communication protocols** – Who the main points of contact are and how often check-ins will occur.
8. **Use of space** – Whether the research team will use your facilities, and how it might affect client flow
9. **Data responsibilities** – Your organization's role in collection, analysis, capacity building, and review timelines.
10. **Data access** – What data you'll have access to, and under what conditions. Link to a Data Sharing Agreement if applicable.
11. **Dissemination** - How findings will be shared with the community. Whether co-authorship or co-presentation opportunities will be offered.
12. **Exit clause** – Conditions for pausing or ending the agreement if the partnership no longer aligns.

A Note on Hesitations Around Signing

Some organizations or Nations may choose not to sign formal agreements due to historic breaches of trust. Others may prefer verbal or relational commitments.

This choice should be respected.

Even without a signature, you can collaboratively develop a written document outlining shared values, expectations, and protocols. It helps ensure accountability and transparency for both sides and provides something to refer back to.

CHAPTER 7:

Saying No (Or Not Yet)

You are allowed to say no.

Whether it's a full stop "no", a "not right now," or a "yes, but not like this," community-based organizations have every right to decline, delay, or renegotiate research requests. You don't owe researchers your time, trust, or data.

Sometimes, the timing just isn't right. Maybe your team is overextended, community priorities have shifted, or you need stronger commitments from researchers before proceeding. These are all valid reasons to pause or walk away.

Community Wisdom

Saying no isn't a missed opportunity – it's leadership. It creates space for better-aligned, respectful partnerships. In a research landscape where extractive practices still happen, setting boundaries protects your staff, clients, and values. When you do say yes, it should be on your terms.

Setting Boundaries: Some Language You Can Use

> **We'd like to revisit this conversation when capacity allows.**

> **We're not in a position to take on a research partnership at this time.**

> **We're open to collaboration, but only if these conditions are met...**

> **We've decided not to move forward with this project, and we appreciate your understanding**

Not sure where you stand?
Use the *Red Flags, Green Flags & Negotiation Tips* tool on page 51 to help assess.

Final Thoughts

Community organizations and people with lived and living experience are not sidekicks to research, you are the reason it matters. Ethical, relevant, and impactful research must be shaped by the people and places it aims to benefit. But too often, research is rushed, extractive, or disconnected from community realities.

Strong research partnerships start with relationships, not methods. They require trust, transparency, and shared purpose and power. They move at the speed of care, not just funding. You are under no obligation to open your doors. If you choose to, it should be because the process respects your time, reflects your values, and supports your community's self-determination.

At its best, research can amplify local knowledge, support advocacy, and create meaningful change—but only if the process is done right.

Six Principles to Guide You

1. **RESPECT:** For the cultural, emotional, and intellectual contributions of community members.
2. **RECIPROCITY:** Ensuring real benefit flows back to those who contribute.
3. **RESPONSIBILITY:** To uphold commitments, prevent harm, and honor protocols.
4. **RELEVANCE:** To your community's needs, strengths, and priorities.
5. **RELATIONAL ACCOUNTABILITY:** Rooted in trust, care, and long-term connection
6. **REPRESENTATION:** That reflects lived realities—not deficit-based narratives.

You have the right to ask hard questions, set boundaries, and shape the terms. Ethical research starts with your leadership. If you choose to say yes, let it be on your terms—and in service of what matters most to your community.

Glossary of Terms

Activating
A term used instead of "triggering" to describe when something causes a strong emotional or physical response, often linked to past trauma.

Advisory Committee
A group of people who provide guidance, advice, and community perspective on a project or study.

Anti-Racism
Taking action to recognize, challenge, and change policies, practices, and attitudes that create racial inequality.

Biological Samples
Parts of the body or substances from it (like blood, hair, urine, or saliva) that are collected for research.

CAPUD
The Canadian Association of People Who Use Drugs—a national group that advocates for the rights and voices of people who use drugs.

CCSA
The Canadian Centre on Substance Use and Addiction—a national organization that provides research and policy advice on substance use.

Ceremony
A traditional practice, gathering, or ritual that holds cultural or spiritual meaning in Indigenous communities.

Coercion
When someone feels pressured or forced into participating in research without fully free choice.

Community-Based Organization (CBO)
A nonprofit or grassroots group that provides services or advocacy within a community.

Community Research Partnership Agreement
A written agreement between a community and researchers that sets out shared values, roles, and responsibilities, ensuring the community leads and benefits from the work.

Community Research Review Committee
A local or community-based group that reviews research projects to ensure they reflect community priorities, values, and safety.

Cultural Safety
Providing services and research in a way that respects and supports people's cultural identity, and challenges power imbalances, discrimination, and racism.

Cultural Wellness Team
A group that supports health and healing using cultural approaches, often led by Elders, Knowledge Holders, or traditional healers.

Data Analysis
Looking at and interpreting the information collected to find patterns, answers, or insights.

Data Collection
The process of gathering information for a study (for example, through interviews, surveys, medical tests, or observations).

Design (Research Design)
The plan for how a research study will be carried out, including who is involved and what methods are used.

Dissemination
Sharing research findings with others, such as through reports, presentations, or community events.

Elder
A respected member of an Indigenous community who holds cultural knowledge and wisdom, often guiding decisions and practices.

Ethics Board Approval
Formal permission from a Research Ethics Board to carry out a study. This ensures the project is ethical and protects participants.

First Nations
Indigenous Peoples in Canada who are neither Métis nor Inuit, with unique Nations, cultures, and histories.

Friendship Centre
Community hubs in towns and cities that provide services, cultural programming, and supports for Indigenous Peoples.

Funding
Money provided to support a research project.

Inuit
Inuit are Indigenous Peoples in Canada who primarily live in Inuit Nunangat, the homeland encompassing four regions: Inuvialuit Settlement Region (Northwest Territories), Nunavut, Nunavik (Northern Quebec), and Nunatsiavut (Northern Labrador). Inuit are a distinct people with their own culture, language (Inuktut), and history.

Intellectual Property (IP)
Ideas, inventions, or creative work that someone owns the rights to. In research, this might include data, written work, tools, or technology.

Indigenous Communities
First Nations, Métis, and Inuit people, each with their own cultures, traditions, and governance systems.

Indigenous Health Cooperative
An organization led by Indigenous communities that provides health services rooted in Indigenous values, traditions, and self-determination.

Knowledge Holder
A person recognized in Indigenous communities as carrying important traditional or cultural knowledge, which may or may not overlap with being an Elder.

Memorandum of Understanding (MOU)
An agreement between groups that outlines roles, responsibilities, and terms of working together, but is usually not legally binding.

Métis
People of mixed Indigenous and European ancestry in Canada, with a distinct culture, identity, and history.

OCAP®
Principles that guide how First Nations data is handled: Ownership, Control, Access, and Possession. These ensure communities have authority over their own information.

PEEP
The Peer Engagement and Evaluation Project, led by the BC Centre for Disease Control. It builds networks of people with lived experience to strengthen harm reduction services, improve peer engagement, and guide health authorities in best practices.

Peer Reviewed
A process where experts in the same field check a study or article before it's published to make sure it is accurate, fair, and high quality.

Recruitment
The process of finding and inviting people to take part in a study.

Research Design and Methodology
The blueprint for a study, including the questions asked, how participants are chosen, and what methods are used to collect and analyze data.

Research Ethics Board (REB)
A committee that reviews research studies to make sure they are safe, ethical, and respectful for participants. (Similar to Institutional Review Boards, or IRBs, in the U.S.)

Retraumatization
When research or interactions cause someone to relive or feel the effects of a past trauma.

TCPS-2
Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2nd edition). Canada's main rules for conducting ethical research.

Terms of Reference (ToR) / Charter of Rights
A document that explains the purpose, roles, responsibilities, and decision-making process for a group or committee.

Tokenize
In research, this means breaking down data (like interview transcripts or survey responses) into smaller pieces (words, phrases, or codes) so they can be analyzed.

Traditional Medicines
Healing practices, remedies, and medicines used in Indigenous communities, based on cultural knowledge and traditions.

Toolbox

Practical tools and templates for building stronger research partnerships

Table Of Contents

Red Flags, Green Flags + Negotiation Tips

Red Flags: When to Proceed with Caution Be cautious if:	**Green Flags: Signs of a Strong Respectful Partnership** Feel confident moving forward when:
⚠️Researchers won't sign a Data Sharing Agreement (DSA)	🟢Researchers collaborate on and agree to a Data Sharing Agreement that reflects your priorities and rights
⚠️ There's no compensation for your time or space	🟢 Your organization is compensated fairly for your time, space, and contributions
⚠️ Participant compensation is low, delayed, or issued through stigmatizing means (like gift cards instead of cash)	🟢 Participants receive timely, adequate, and respectful compensation (e.g., cash, e-transfer, or culturally appropriate alternatives)
⚠️ You have no input into recruitment or data collection design	🟢 You are actively involved in designing recruitment and data collection to ensure relevance and respect
⚠️ Researchers will not commit to sharing findings with your organizations or community for review before they are published or made public.	🟢 Researchers commit to returning findings to your organization and community before public release
⚠️The project timeline feels rushed and unrealistic	🟢 The project allows for a reasonable timeline with space for review, input, and adaptation
⚠️ You're pressured to sign on quickly	🟢 You are given ample time to consider and discuss the opportunity before committing `
⚠️No clear plan exists for sharing results back	🟢 There's a co-developed plan for sharing findings back in community-accessible formats
⚠️ Researchers treat community engagement as a checkbox	🟢 Researchers approach engagement as a relational, ongoing partnership, not just a funding requirement

Your Rights and Negotiation Points

You Have the Right To:	You Have the Right To: You Are Not Automatically Entitled To (But Can and Should Negotiate For):
- A clearly defined role and expectations	- A role in REB submissions (e.g., being listed as a collaborator, reviewing and providing feedback on submission)
- Receive fair compensation for staff time and contributions	- Funding tied to research participation
- Provide input into recruitment strategies and methods	- Access to technical or academic-level data
- Shape early data analysis	- Access or ownership of research data including raw data
- Data Access and Ownership through a DSA	- Influence over final interpretations
- Review and correct findings before publication	- Shaping dissemination strategies - Being notified of upcoming conference presentations or abstract submissions - Present or co-present at conferences
- Access to plain-language results	- Accessible and user-friendly knowledge products from the study
- Public acknowledgment and recognition including how you want to be acknowledged (i.e., where, name, etc.)	- Co-Authorship on publications or inclusion in acknowledgement sections
- Sustained Partnership and reciprocal relationships	- Follow-up partnership opportunities (pilots, grants)

Sample Community-Research Partnership Agreement

This Agreement is entered into on this ___ day of __________, 20__, by and between:

Community / Organization/ Indigenous Nation:

Name:
____
Representative:
____
Role/Title:
____

Ally Organization / Research Partner:

Name:
____
Representative:
____
Role/Title:
____

Purpose and Shared Vision

This Agreement affirms a shared commitment to co-create knowledge in a way that honour and reflect the priorities. knowledge systems, governance, laws, and lived realities of the communities involved. The partners agree to work together in a good way, respecting the sovereignty, leadership, and needs of the [insert community, organization, Indigenous Nation] in all aspects of the work.

Guiding Principles

This partnership is rooted in the following shared principles:

- Community self-determination and leadership in research matters
- Respect for diverse worldviews, cultures, and knowledge systems including Indigenous ways of knowing.
- The OCAP® principles (Ownership, Control, Access, and Possession) and community-specific protocols when working with First Nations, Métis and Inuit data.
- Community ownership and control over their stories, data and contributions.
- Relational accountability, reciprocity, and trust.
- Transparency, honesty, and open dialogue.
- Equitable sharing of knowledge, recognition, and benefits.

Scope of Work

The partners will co-develop and implement research activities that reflect the community's priorities and knowledge systems, such as:

- Community-led research design and approval processes.
- Knowledge gathering in ways that honour community protocols, cultural practices, and governance.
- Shared data analysis, meaning-making, and interpretation.
- Story-sharing and knowledge mobilization that benefits the community.
- Community capacity building, mentorship, and opportunities for leadership.

Shared Responsibilities

Responsibilities of the Community/Organization/ Indigenous Nation:

- Provide direction, leadership, and guidance on all research activities.
- Identify community protocols, values, and practices (including cultural) to be respected.
- Appoint community members to lead or co-lead the project.
- Review and approve all knowledge products before they are shared externally.

Responsibilities of the Ally Organization / Research Partner:

- Follow the direction of the [insert community, organization, Indigenous Nation] throughout the project.
- Ensure that research practices align with [insert community, organization, Indigenous Nation] protocols or laws, ethics, and priorities.
- Share all project information openly and in ways accessible to [insert community, organization, Indigenous Nation].
- Create opportunities for community leadership, training, and meaningful participation.

Data Sovereignty and Governance

All data and knowledge gathered in this partnership belong to the [insert community, organization, Indigenous Nation]. Data will be cared for according to community protocols and governance structures, and in alignment with OCAP® and Indigenous data sovereignty principles if applicable.

Cultural Protocols and Sacred Knowledge

The partners acknowledge that some knowledge is sacred and not for public sharing. [Insert community, organization, Indigenous Nation] protocols will guide what, how, and with whom knowledge is shared.

Knowledge Sharing and Benefits

Knowledge will be shared in ways that are meaningful and useful to the community first. All knowledge-sharing activities will be reviewed and approved by [insert community, organization, Indigenous Nation] before being shared with broader audiences.

Honouring Relationships and Addressing Conflicts

The partners agree to resolve differences through respectful dialogue, guided by the values of kindness, honesty, and humility. When needed, trusted community members may help mediate conversations.

Agreement Term and Renewal

This Agreement will remain in place for the duration of the project [insert duration], and can be amended at any time by mutual agreement to reflect the evolving relationship and shared priorities.

Signatories

Signed on behalf of the Community/Organization/Indigenous Nation:

Signature:
____
Name:
____
Role/Title:
____
Date:
____

Signed on behalf of the Ally Organization / Research Partner:

Signature:
____
Name:
____
Role/Title:
____
Date:
____

Example Charter for a Community Research Review Committee – Kilala Lelum Health and Wellness Cooperative

This sample charter is shared with the permission of Kílala Lelum Health and Wellness Cooperative and is provided here as an example of how one Indigenous-led organization has structured their research governance. It may serve as inspiration or a reference for communities developing their own research review committees.

1. BACKGROUND

[Insert name of organization] is a non-profit Indigenous Health organization that has been operating in Vancouver's inner city since 2018. The Kílala Lelum Health Centre offers an inter-professional team based primary care home that includes a partnership of services between traditional Indigenous Elders/Healers and primary care providers. The mandate of Kílala Lelum is to provide culturally safe and effective care to patients/members of all nations. Specifically, Kílala Lelum has the mandate to enact the Truth and Reconciliation Commission Calls to Action in Health (Health Actions 19-23) which includes establishing measurable goals to identify and close the gaps in health outcomes for Indigenous Peoples and to recognize, respect, and address the distinct health needs of the Métis, Inuit, First Nations, and off-reserve Aboriginal Peoples. To this end, the Kílala Lelum acknowledges its mandate to participate in research that aims to promote health equity and promote Indigenous Peoples health and wellness.

The purpose of this Charter is to guide the Kílala Lelum Research Committee to (a) promote research that aligns with the philosophy, values and broader mandate of the Kílala Lelum and (b) communicate with potential research partners [VC1] with respect to the processes of research conducted at Kílala Lelum.

Kílala Lelum 3-Year Research Vision Statement (2024- 2027):
The 3-Year Vision is to be engaged in innovative research that reflects the needs of and provides benefits to our urban Indigenous and non-Indigenous members, the wider community of Indigenous people living in the vicinity and beyond, and for Kílala Lelum to be recognized as a model organization in Canada for conducting community-based, culturally safe, equity oriented, participatory research in inner-city healthcare.

2. GUIDING PRINCIPLES

Research conducted at Kílala Lelum must comply with the CIHR (2007[1]) ethical considerations for research involving Indigenous people in Canada, and Chapter 9 of the Tri-council Policy Statement on Research involving the First Nations, Inuit and Métis Peoples of Canada (2010[2]). As outlined in this policy, Indigenous Peoples and their communities retain their inherent rights to any cultural knowledge, sacred knowledge, and cultural practices and traditions, which are shared with the researcher (Article 7). Community and individual concerns over, and claims to, intellectual property should be explicitly acknowledged and addressed in the negotiation with the community prior to starting any research project. Expectations regarding intellectual property rights of all parties involved in the research should be stated in the research agreement (Article 8). Researchers should also recognize and respect the rights and proprietary interests of individuals and the community in data and biological samples generated or taken in the course of the research (Article 12.1).

In addition to conforming to these policies, researchers should be familiar with the ethical principles that have been developed specific to research conducted in the Downtown EastSide as outlined in the Manifesto for Ethical Research in the Downtown Eastside[3]. Specifically, Kílala Lelum supports research that is informed by the following principles:

- Place-Based: Place matters. Research that is grounded in the histories, cultures, and relationships of the Downtown Eastside and broader K’emk’emeláy̓ (Vancouver) holds deep relevance. Projects are encouraged to honour Host Nations—xʷməθkʷəy̓əm, Sḵwx̱wú7mesh, and səlilwətaɬ—and to reflect the specificity of community-defined priorities, land-based practices, and local knowledges.

- Indigenous Data Sovereignty: Data is relational and powerful. Kílala Lelum upholds Indigenous Peoples’ inherent rights to govern data through the First Nations principles of OCAP®, the Métis-specific principles of OCAS, the Inuit Qaujimajatuqangit principles, and other Indigenous research and data governance frameworks. Research agreements are co-developed and clarify how data is stored, accessed, interpreted, and shared—always centring Indigenous ownership, control, and stewardship.

- Ceremony and Cultural Protocol: Research may be guided by cultural protocol and ceremony, as directed by Elders or Knowledge Holders. Ceremony can support safety, clarity, and connection across all phases of the work. Researchers are invited to engage with humility, consent, and openness to teachings.

- Reflexivity and Self-Location: Research begins with self-awareness. Researchers are encouraged to reflect on their positionality, assumptions, and potential biases—recognizing how these shape relationships and the research itself. Sharing a self-location statement and being open to course correction are acts of accountability and growth.

- Healing-Centred and Strengths and Desire-Based Framing: Research honours Indigenous strength, resilience, and cultural resurgence. Projects are encouraged to move away from deficit narratives and the pathologization of Indigenous experiences, and toward stories of survivance, wellness, and community-led solutions. A desire-based lens focuses on narratives of hope, possibility, and agency, and what communities are dreaming, building, and reclaiming for the future.

- Ethics Beyond Compliance: Ethics is much more than a checklist. Research at Kílala Lelum honours relational ethics, spiritual care, and community accountability. Institutional frameworks (e.g., TCPS-2) are respected, but so too are the ethical teachings and protocols held by Indigenous communities.

- Knowledge as Medicine: Stories and teachings are sacred. Research honours knowledge as a living medicine that must be treated with care and consent. Sharing knowledge in ways that foster healing, continuity, and community benefit is an act of service.

- Relational Accountability: Research is rooted in relationships. Trust, transparency, and reciprocity shape every phase of the work. This includes meaningful engagement with advisory committees, regular reporting to Kílala Lelum, and inclusive, culturally grounded knowledge sharing. Researchers are invited to continually ask: How am I showing up for those who are showing up for me?

The committee will meet quarterly and at the call of the chair.

These principles will be considered by reviewing any proposed research using the following key questions[4]:

- What are the unique benefits of proposing research at Kilia Lelum?
- What kinds of learning opportunities are the researcher/team willing to engage in?
- What are the potential hidden costs and resource requirements that ought to be anticipated?
- How will the researcher/team address the individual and group conflicts and/or anxieties that can sometimes arise when conducting research with decolonizing intentions?

3. GOALS, OBJECTIVES, AND ACTIVITIES

Goals	Objectives	Activities
1. Research conducted with Kílala Lelum reflects the needs of the DTES community and is conducted in accordance with the Principles of Research outlined in section 2.	That all research conducted with Kílala Lelum be first approved by the Kílala Lelum Research Committee, and progress/challenges will be reviewed at quarterly committee meetings.	All parties interested in conducting research with Kílala Lelum will complete the pre-application checklist and request form (see appendix) and pay a non-refundable sliding scale administration processing fee.
2. That the outcomes of research conducted at Kílala Lelum be appropriately cataloged and made accessible to the DTES community	That all final outcomes of research be collected by the Kílala Lelum research committee and archived on the Kílala Lelum website.	Upon completion of the research process at Kílala Lelum a "final report" (in the form of a poster, manuscript or report) will be submitted to the Kílala Lelum Research Committee Coordinator and will be posted in the "research" section of the Kílala Lelum website, at the discretion of the research committee. Knowledge translation and exchange activities must be completed within a reasonable time frame.

4. RESEARCH COMMITTEE COMPOSITION

The Kilala Lelum Research Committee shall be composed of a specific balance of members to ensure objective input and adequate community representation. The committee will strive to include community members, Elders, clinical staff, have Board and Member representation, as well as experienced researchers. Researchers with active studies in process or proposed at Kílala Lelum will be asked to declare a conflict of interest to facilitate arm's length review processes. The committee will be led by a "Committee Chair" and be supported by a staff person in the role of "Research Coordinator".

A "consensus" model of decision-making will be employed by the committee. Any committee member's concerns need to be addressed before an approval is granted. Any committee member will recuse themselves if there are conflicts of interest.

Upon submission of the pre-application checklist, the Research Committee Coordinator and Committee Chair will confer as to whether the application:

1. Does not require an application (is not research, is research conducted elsewhere that requires limited involvement of KL membership and staff).
2. Requires an application which can be reviewed by the committee by email.
3. Requires an application and attendance at a committee meeting.

Researchers will be notified of the need for an application and meeting attendance. When approval is granted, it will be provisional pending Institutional Board ethics approval. The letter of approval will be issued by the Committee Chair following consensus approval.

Monitoring Ongoing Research

The Research Committee strives to monitor active research projects to promote sharing of knowledge between research teams and to help with problem solving. Active research groups will be invited to meet with the Research Committee bi-annually. In accordance with CIHR ethical considerations for research involving Indigenous people in Canada and Chapter 9 of the Tri-council Policy statement, Kilala Lelum (KL) identifies the following key areas as points of discussion on evaluating a research project’s active status.

Consent Procedure: How, when and where participants are approached, and by who. Challenges will be reviewed, and potential solutions discussed.

Privacy & confidentiality: Reviewing current practices related to a participant’s personal identification.

Recognizing Elders and Knowledge Keepers: An important aspect of Indigenous-focused research is ensuring research is in partnership with community goals and values, and as such, requires on-going consultation with community Elders or Knowledge Keepers.

Customs & Codes of Practice: Researchers will be asked to share their on-going experience with participants, community members, and other stakeholders.

Conflict of interests

Kilala Lelum has a role in stewarding community-based, Indigenous health research and promoting investigations that are in line with our guiding principles. Purposefully, the Research Committee (RC) membership is composed of diverse individuals with roles as investigators, consultants, practitioners, community- and board members at KL, other allied health services, and research groups. As such, KL recognizes that conflicts of interest (COIs) will arise in activities or situations that place an individual or institution in real, potential, or perceived conflicts between the tasks or responsibilities related to research, personal, intra- and inter-institutional, and other interests (enter TCPS 2 citation here). Committee members have the responsibility of being transparent, forthcoming, and consistent in reporting COI information ranging from, but not limited to, personal or professional relationships to financial interests, activities, and other affiliations related to prospective projects. This requires committee members to be aware of their own potential for real or perceived COIs. The diversity of research interests necessitates COIs be assessed on a case-by-case basis through honest and open communication between committee members when reviewing each prospective project.

5. FUNDING

Those parties conducting research with Kilala Lelum will pay a sliding scale research application processing fee.

Private donations to KL will also be utilized to support the RC activities.

6. RESEARCH COMMITTEE MEMBERSHIP

Committee Role	Committee Member(s)	Email Address
Committee Chair	Name	Email
Board Representatives	Name	Email
Research Committee Coordinator	Name	Email
By virtue of her office (exofficio)	Name	Email
Elder	Name	Email
Peer Representative	Name	Email
Members at Large	Name	Email

7. CURRENT, PROPOSED AND PAST RESEARCH AT KILALA LELUM

Previous, Current & Proposed Projects

8. RESEARCH CHARTER ADDENDUMS

Research_Charter_Addendums.docx
Honorarium Payment Policy

1]Canadian Institutes of Health Research. (2007). CI7dHR guidelines for health research involving Aboriginal people. Ottawa, ON: Canadian Institutes of Health Research.

[2]Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Canada. (2010). Tri-Council Policy Statement: Ethical conduct for research involving humans.http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9/

[3]https://open.library.ubc.ca/cIRcle/collections/ubccommunityandpartnerspublicati/52387/items/1.0377565

[4] Adapted from: Elwood, J., Andreotti, V., & Stein, S. (2019). *Toward Braiding* Handout 1. (2019). Guelph, ON: Musagetes Foundation. https://decolonialfuturesnet.files.wordpress.com/2019/02/towards-braiding-handout-1.pdf

Sample Research Application Form

Application Form

Use this template form to help researchers clearly communicate their intentions, plans, and expectations before any partnership begins. You can provide it directly or adapt it as part of your own review process with your Community Research Review Committee.

Section 1: Contact and Project Information

Researcher Applicant Name:	
Email:	
Phone:	
Title of Proposed Research Project:	
Date of Submission:	
Proposed Start Date:	

Section 2: Pre-Application Checklist

1. Please check all that apply so that we understand the scope of your request:

- ☐ To post notices or posters about a research project conducted at other locations, inviting insert your organization name] **staff** who wish to participate.
- ☐ To post notices or posters about a research project conducted at other locations, inviting [insert your organization name] **clients/service users/members** who wish to participate.
- ☐ To invite [insert your organization name] **staff** to participate in your proposed study.
- ☐ To invite [insert your organization name] **clients/service users/members** to participate in your proposed study.
- ☐ To invite [insert your organization name] **clients/service users/members** to participate in your proposed study.
- ☐ To consult with [insert organization] **staff or people with lived/living experience** about any aspect of the proposed research process.
- ☐ To consult with [insert organization] **staff or people with lived/living experience** about research processes in general.

2. Do you hold research funding to conduct this research? (please specify source(s) and duration of each):

3. Are you a student proposing a research study? If yes, please specify the program and supervisor/supervisory committee members.

Section 3: Summary of Proposed Research Project

Project Title:	
Name of Principal Investigator: *Please attach a copy of their CV or resume) Name(s) of Co-Principal and Co-Investigators:	
Institutional Affiliation and Position:	
Summary of research proposal including objectives and research methods (max 500 words). Please ensure to include details about: • Recruitment strategies and resources allocated for this phase • What kind of data you aim to collect • Will you link to pre-existing datasets? If yes, which ones? • Desired project outcomes and/or anticipated wellness impacts • Knowledge mobilization plans	
Which Research Ethics Board has approved ethics for this project and/or will process an ethics application? Please include: • Ethical Review Board Approval Date: • Contact Information (REB #):	

Section 4: Supporting Documents

Required: Most recent draft of proposal/project summary, a copy of ethics approval certificate. **Please insert attachment as objects here or attach them in the email.*	
Required: Existing letters of support, email chains with partners or collaborators, agreements/contracts, consent forms, interview guides, slide decks from presentations, etc. **If the researcher is not able to send these documents at an early phase, request a protocol summary.*	

Section 5: Project Scope

What is the geographic scope of the project?	☐ Community-level (i.e., specific neighbourhood, Nation, or small population) ☐ Municipal (i.e., one or more municipalities or cities within a region) ☐ Provincial (i.e., spans across regions with a single province or territory) ☐ National (i.e., applies to multiple provinces or territories across Canada) ☐ International (i.e., involves more than one country). ☐ Other – Specify:
Where will the project take place? Which communities, if any, are involved in this project?	

Section 6: Roles and Responsibilities

What is being requested of our organization? Provide details and/or requirements regarding collaboration with our organization.	
Please provide a detailed description of the expected resources required from our organization including, but not limited to: • Office space • Staff time • Research advising • Knowledge exchange and/or translation tools • Communications for participant recruitment Include how those costs will be covered including plans for in-kind contributions.	
Is our organization being asked to guide outreach, recruitment, engagement and/or retention processes? If yes, please provide details.	
Please provide any additional information that may be helpful for our organization's operations review of the project.	

Section 7: Organizational Criteria

How will this project benefit [insert organization] clients/service users/members/ staff or other community members? What are the expected positive outcomes for participants? (be as specific as possible)	

Why is this research important now, and how will it add value to the current context or evidence base?	
If the study includes a service or intervention, what happens to participants when the study ends?	
What experience do members of your team have working with communities like ours?	
How does the project adhere to the principles of meaningful community engagement?	
How does your project integrate trauma-informed, cultural safety and humility approaches?	
How will the knowledge being generated through the project be shared back with our organization and the communit(ies) involved?	

Section 8: Alignment with Guiding Principles

Please describe how your project reflects our organization's research principles and provide brief responses to the key questions listed below. Each response should be no more than 250 words.

Note the research principles listed here are examples only. Your organization should work internally, and/or with a community research committee, to define the research principles that matter most to you.

Equitable:	
Action-oriented:	
Participatory:	
Relational:	
Reciprocity:	
Accountability:	

Key questions:

- What are the unique benefits of proposing research at [insert your organization]?
- What kinds of learning opportunities are the researcher/team willing to engage in?
- What are the potential hidden costs and resource requirements that should be anticipated when engaging with [insert organization] in research endeavors?
- How will the researchers/team address tensions, concerns, or conflicts that may arise when working with communities who have been historically excluded, persecuted, surveilled, discriminated against, or harmed by research?

Section 9: References

Please provide 3 references, with at least one being from a past community partner, collaborator or ally.

Reference 1:
Name:
Email:
Phone Number:
Relationship:

Reference 2:
Name:
Email:
Phone Number:
Relationship:

Reference 3:
Name:
Email:
Phone Number:
Relationship:

Application Scoring

Use this checklist to help evaluate whether a proposed research project is a good fit for your organization and community. Each question can be scored on a scale from 1 to 5 where:

- **1 = Not addressed or major concerns**
- **2 = Minimally addressed, significant gaps remain**
- **3 = Somewhat addressed, needs improvement**
- **4 = Mostly addressed, minor issues remain**
- **5 = Fully addressed, clear and appropriate**

Section 2: Pre-Application

Question	Score (1-5)	Comments
Is the scope of the request clearly defined (e.g., recruitment, consultation, on-site research)?		
Has the researcher indicated whether they hold research funding and specified the source?		
If applicable, has the researcher disclosed student status and supervisory committee details?		

Section 3: Project Summary and Supporting Documents

Question	Score (1-5)	Comments
Is the project title and PI/CV information complete?		
Are co-investigators and institutional affiliations clearly stated?		
Is the research summary complete with sufficient detail on the research objectives?		

Question	Score (1-5)	Comments
Are recruitment strategies and resources adequately described?		
Are data collection methods adequately described?		
Is the type of data and use of pre-existing datasets clearly outlined?		
Are project outcomes and result will be communicated back to your organization/community/Nation?		
Is Research Ethics Board approval included or pending with clear explanation?		

Section 4: Roles and Resources

Question	Score (1-5)	Comments
Are the expectations of our organization clearly stated and realistic?		
Are staff, peers, or clients being asked to take on roles that are appropriate and well-supported?		
Have resource needs (e.g., space, staff time, communication support) been clearly identified?		

Question	Score (1-5)	Comments
Is there a sufficient plan for covering costs related to the organization's involvement?		

Section 5: Community Engagement, Ethics and Safety

Question	Score (1-5)	Comments
Are all required documents (proposal, ethics certificate, etc.) attached and complete?		
Are additional relevant materials (e.g., letters of support, consent forms) included?		
Has the applicant shown understanding of the needs and values of our organization and community (e.g., trauma-informed care, cultural safety, anti-stigma practices)?		
Does the project reflect principles of meaningful engagement and community leadership?		
Are safety, privacy, and emotional/cultural supports clearly addressed?		
If the study includes an intervention or service, is there a plan for what happens when the research ends?		

Section 6: Guiding Principles and Accountability

Question	Score (1-5)	Comments
Has the applicant described how the project aligns with our organization's core research principles, and values (e.g., relational, reciprocal, accountable)?		
Are responses to the key questions clear, thoughtful, and grounded in real-world understanding of our organization's role?		
Does the researcher acknowledge power dynamics and offer concrete steps to support equity and shared decision-making?		
Are community voices clearly reflected in the proposed process (e.g., co-design, interpretation, authorship)?		

Section 7: Knowledge Sharing and Follow-Up

Question	Score (1-5)	Comments
Is there a clear plan to bring findings back to our organization and the community in plain language and accessible formats?		
Will our organization and/or participants have a chance to review findings before they are published or publicly shared?		

Question	Score (1-5)	Comments
Are there opportunities for co-authorship, acknowledgement, or continued collaboration?		
Has the researcher described how they plan to stay connected after the project ends (e.g., through ongoing resource co-creation, knowledge sharing, or next steps)?		

Section 8: References and Reputation

Question	Score (1-5)	Comments
Has the researcher provided three references, including at least one from a community organization?		
Do the references speak to the researcher's accountability, respect for community processes, and ability to follow through?		
Does the researcher's past work demonstrate trustworthiness and relevance to the community?		
Are references diverse in type (e.g., academic, peer, community-based) and credible?		

Interpreting the Total Score

Across all eight (8) sections, the maximum total score is 135. Use the table below to guide your response:

Score Range	Interpretation	Suggested Action
165–185	**Strong fit.** The project aligns well with your organization's values and priorities.	✅ Proceed with partnership
120–164	**Moderate fit.** The project shows potential but requires some revisions or conditions.	✏️ Request changes before proceeding
Below 120	**High concern.** Major issues or misalignment present.	⚠️ Consider declining or renegotiating

Sample Data Sharing Agreement

Between [Research Institution] and [Community Organization]

1. Purpose

This agreement sets out the principles and processes for respectfully and responsibly sharing data collected as part of the [Project Name] research project. This partnership is grounded in mutual trust, transparency, and a commitment to support the health, well-being, and sovereignty of the community.

2. Parties to the Agreement

Researcher(s): [Lead Researcher Name], [Institution Name], [Department]
Community Organization/Nation: [Community Organization Name], [Representative Name/Position]

Both parties acknowledge and respect the rights, ownership, and interests of the community in the data collected during the project.

3. Scope of Data Shared

The data covered by this agreement includes:
- [Specify types of data: e.g., interviews, surveys, program statistics, health data (de-identified), narratives, etc.]
- Timeframe of data collection: [Dates]
- Any limitations on use: [Specify if applicable]

4. Principles of Data Sharing

The parties agree to the following principles:
- Respect for Ownership and Control: Community members and organizations retain ownership over their own data and stories.
- Collaborative Use: Data will only be used for the agreed-upon purposes and in ways that benefit the community.
- Transparency: Both parties will communicate openly about how data is used, shared, and interpreted.
- Confidentiality and Privacy: Data containing personal or sensitive information will be protected and shared only in ways that comply with privacy laws and the values of the community.

5. Use of Data

The shared data may be used for:
✓ Collaborative analysis and interpretation
✓ Joint presentations and publications (with prior approval)
✓ Program development, planning, or service improvement for the community
✓ Any other mutually agreed purposes

6. Data Access and Storage

Data will be securely stored by [Researcher Institution] and [Community Organization] according to their respective data security protocols.

Access to raw data will be limited to individuals named in this agreement unless otherwise approved in writing by both parties.

7. Publication and Knowledge Sharing

Community partners will be offered co-authorship or acknowledgement in all publications and presentations.

Community members will be consulted before data is shared publicly.

Findings will be shared in accessible formats with the community.

8. Duration of Agreement

This agreement is effective from [Start Date] to [End Date], or until completion of the project and all related data activities.

9. Dispute Resolution

If disagreements arise regarding data sharing, both parties commit to dialogue and resolution through respectful conversation and, if needed, involvement of a neutral mediator agreed upon by both parties.

10. Amendment and Termination

This agreement may be amended by mutual consent, in writing. Either party may terminate the agreement with [30] days' written notice, ensuring that any outstanding responsibilities regarding data are fulfilled in good faith.

11. Signatures

Signed on behalf of the Community/Organization/Indigenous Nation:	***Signed on behalf of the Ally Organization / Research Partner:***
Signature: ____________________________	Signature: ____________________________
Name: ____________________________	Name: ____________________________
Role/Title: ____________________________	Role/Title: ____________________________
Organization: ____________________________	Organization: ____________________________
Date: ____________________________	Date: ____________________________

Sample Research Complaint Pathway Tool

This tool offers a starting point for creating clear, accessible guidance on where and how to raise concerns related to research participation and/or partnerships. Whether you're a community partner, a research participant, or someone supporting others involved in research, it can be difficult to know who to contact if something goes wrong or simply doesn't feel right.

Every collaborative research process should include a transparent pathway for filing concerns or complaints, tailored to the local context and shared early on. This sample version is based on research conducted with University of British Columbia and regulatory bodies in British Columbia, but it can be adapted to reflect your local jurisdictions and project.

EXAMPLE BC POCKET CARD: Research Gone Wrong? Here's Who You Can Call

Concern	Who to Contact
Concerns about your rights or experiences as a research participant	**UBC Research Participant Complaint Line** 604-822-8598 or 1-877-822-8598 RSIL@ors.ubc.ca
Broader ethical or study misconduct concerns	**UBC Office of Research Ethics** Director: Jean Ruiz Phone: 604-827-5310 Email: jean.ruiz@ubc.ca
Ethics violations or research misconduct in federally funded research	**Secretariat on Responsible Conduct of Research (SRCR) – National Oversight** https://ethics.gc.ca secretariat@srcr-scrr.gc.ca Web: SRCR – Submit a Complaint
Clinical trial harm or misconduct	**Health Canada Clinical Trial Compliance** clinical.trials-bioequivalence@hc-sc.gc.ca
Harm from a doctor, nurse, or social worker in a research setting	**Their Professional Regulatory College** (e.g., College of Physicians, Nurses or Social Work).
Research misconduct or scholarly integrity (e.g., plagiarism, data falsification, fabrication, unauthorized data use)	**UBC Vice-President Research:** research.integrity@ubc.ca

Concern	Who to Contact
Privacy breach (personal data was used without your permission):	**Privacy Commissioner of Canada:** https://www.priv.gc.ca
Discrimination or identity-related harm (related to race, gender, disability):	**BC Human Rights Tribunal** https://www.bchrt.bc.ca
Indigenous People who experience a privacy breach or research misconduct can also contact:	**First Nations Information Governance Centre** https://fnigc.ca info@fnigc.ca **Also consider notifying:** Your Nation or Governing Council (band council, Métis regional body, Inuit Tapiriit Kanatami (ITK)) to initiate a formal complaint and demand public accountability.

Honoraria / Pay Benchmarks Resources

There's no universal rate for compensating your involvement in a research project. You can and should negotiate based on the type of contribution, local cost of living, and experience of the person involved. Below are some resources to serve as a guide:

- Guidelines for Partnering with People with Lived and Living Experience of Substance Use and Their Families and Friends
- Hear Us, See Us, Respect Us: Respecting the expertise of people who use drugs
- Peer Payment Standards for Short-term engagements

Language Matters

Choosing the right words isn't just about being polite, it's about power, respect, and accuracy. These resources can help you advocate for language that reflects your community's values, avoids stigma, and ensures your voice is represented clearly and meaningfully in research:

- Overcoming Stigma Through Language: A Primer
- Language Guide For Working With People Who Use Drugs
- Respectful Language And Stigma Regarding People Who Use Substances
- Words Matter! Language Statement & Reference Guide - INPUD
- Guiding Principles For Breaking Down Drug-related Stigma In Academic Writing

Library

Below is a curated library of additional tools and guides to help community-based organizations navigate research partnerships.

CSF Community-Engaged Research Manual for Agencies

Read this if you want a deep dive into how research works in academic settings and how to advocate for your role as a community partner.

A comprehensive, plain-language manual created by UCSF Clinical and Translational Science Institute's Community engagement program designed to help community-based organizations (CBOs) assess, negotiate, and participate in academic research partnerships. Note, this resource is not tailored specifically to research involving people who use substances and marginalized communities. Nonetheless, it covers how to assess potential partners, steps in the research process, and ethical and logistical considerations such as informed consent, IRB approval (equivalent to REB), budgeting, and data sharing. It also includes tools for managing expectations, sustaining partnerships, and navigating bureaucratic systems.

Condensed version: guide_for_cbos.pdf
Appendices: Memorandum of Understanding Template

FNHA Data and Research Intake Form

Read this if your organization works with First Nations communities in BC and may be involved in research or is asked to support or participate in a research project.

This intake form is a required step for researchers seeking to engage with the First Nations Health Authority (FNHA). It ensures that research proposals align with the First Nations Health Authority's (FNHA) values, including OCAP® principles, cultural safety, and community-driven priorities. The form collects detailed information about the research project, including objectives, methodologies, community involvement, data management plans, and anticipated benefits to the communities involved. Submitting this form initiates a review process by FNHA to assess the proposal's alignment with ethical standards and community interests.

FNHA Research, Ethics, and Data Access Framework

Read this if you are working with First Nations communities and want to ensure your research practices align with Indigenous principles.

Developed by the First Nations Health Authority, this framework lays out a values-based approach to research and knowledge exchange with BC First Nations communities. It is rooted in Indigenous worldviews and principles such as OCAP®, Two-Eyed Seeing, and relational accountability. The document sets out seven directives—including community-driven, Nation-based decision-making and cultural safety—and offers specific competencies, goals, and indicators for conducting ethical, useful, and transformative health research. It guides researchers and institutions in aligning with First Nations priorities and ensuring respect for traditional knowledge and governance structures.

Appendices: Indicators, goals, and competencies matrix.

IPFCC Guide – Engaging Underserved Urban Communities in Research

Read this if you want practical strategies for initiating or proactively building equitable research partnerships in underserved urban communities.

This guide was created for a PCORI-funded project led by Smart from the Start, aimed at supporting underserved communities in Boston and Washington, DC. It offers strategies for community organizations to proactively engage researchers and assert their role in shaping research priorities, and includes advice on early relationship-building, budgeting for engagement, and evaluating partnership outcomes.

Appendices: Community member profiles and engagement examples

NIHMS Community Partnership Guide for Engaging with Academic Researchers

Use this guide if you need help deciding if and how your organization will participate or partner in a research project and what your organization's role should be in each aspect of the project.

Developed by the Institute for Translational Health Sciences and Seattle Children's, this peer-reviewed guide aims to empower community-based organizations to partner effectively with academic research teams in research projects that involve their community. It provides a three-step process: screening incoming research requests using a seven-question checklist, selecting levels of engagement across key domains (involvement, governance, budgeting, dissemination), and formalizing terms via a customizable MOU.

Appendices: Screening tools and MOU template

Research 101: A Manifest for Ethical Research in the Downtown Eastside

Read this if your organization works with or supports communities that have been over-researched or misrepresented, and you want to advocate for ethical, community-led research practices.

This manifesto was co-created by peer workers and community members in Vancouver's Downtown Eastside (DTES). It offers a community-driven framework for ethical research, emphasizing transparency, mutual benefit, and the active involvement of community members throughout the research process. The manifesto serves as a guide for both community organizations and researchers to foster equitable partnerships and to challenge exploitative research practices.

Tufts CTSI - Tools for Research Partnerships

Read this if you want a short and practical guide to reflect on the current state of a research partnership or to start building one.

This resource outlines key considerations when preparing for research collaboration through a comprehensive list of questions to guide toward best practice. It is a helpful tool for internal team discussions or early-stage partner meetings.

Tufts CTSI - Steps to Building Research Partnerships
Read this if you're just starting a new partnership and want a clear roadmap of what to do and when.

This one-pager breaks down the key steps of partnership development, from exploring shared goals and building trust to establishing shared decision-making processes. Ideal for setting the tone and scope of a new collaboration.

Tufts-CTSI - Self-Assessment Tool for Community-Engaged Research
Read this if you want to assess your organization's readiness to engage in research partnerships.

A brief, self-reflective checklist designed for community-based organizations to consider internal capacity, interest, and fit before engaging in collaborative research. Great for early conversations with staff, leadership, or potential partners.

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