

# Community engagement in your ICES project

# Understanding equity-centered engagement



# What is community engagement?

Community engagement is established through meaningful and authentic relationships with communities, allowing people who live with inequities to influence health system priorities and inform decisions. These relationships, whether short or long-term, must consider community members as partners in research rather than 'service recipients', recognizing that community members know best about what they need to be healthy and the solutions to address inequities.

When engaging with racialized or immigrant communities, an equity-based approach is essential. Researchers should reflect on the unintended biases and structures of power that exists, distort findings, perpetuate status quo, and ultimately harms communities.

# **When** and **why** should I engage communities in ICES research?

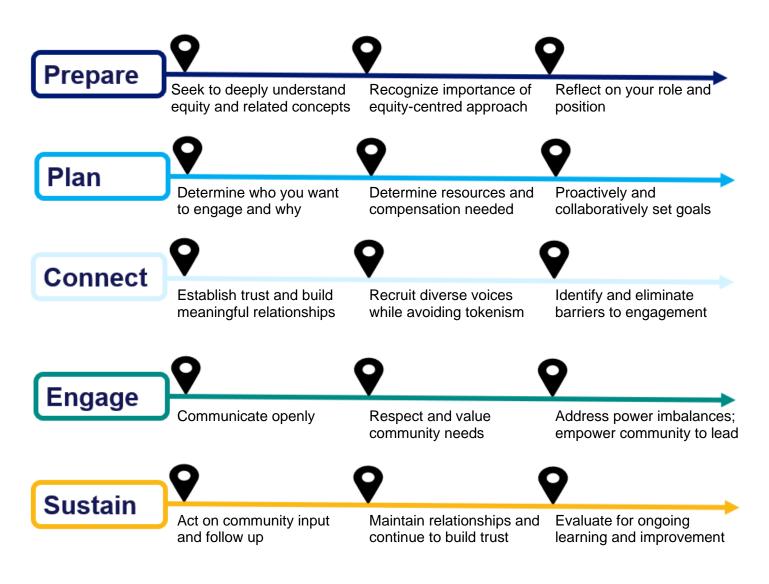
Authentic community engagement in research can lead to findings that generate mutual benefit for researchers and communities that take into account a bigger picture than the use of data alone. However, not all ICES studies are conducive to community engagement, and it is worth emphasizing the importance of conducting this work not to simply "check a box", but to meaningfully engage and understand how data can be appropriated used, interpreted, and disseminated.

Any project using race and related data should consider if there are opportunities to engage with communities directly on project planning, interpretation, or dissemination. An integrated knowledge translation approach is one that incorporates knowledge users throughout the research processes, whereas an end-of-grant approach may involve communities primarily during dissemination. Ideally, communities should be integrated throughout the research process in some way, however, engagement approaches can look different depending on the project (e.g., focus groups, an advisory council, surveys, town halls, etc.). In addition, studies should consider whether their results have direct impacts to certain communities and whether race or related data are the primary exposure of interest (in which case, engagement is strongly recommended). If this is not the case, but race or related data is still included as part of the baseline characteristics or analysis, researchers should consider explaining why they chose to include these variables and the potential impacts of racism and social determinants of health on the corresponding results.

Undertaking community engagement requires adequate time, resources, budget, and planning to execute appropriately and, when possible, adequate funding should be allocated for community engagement from the onset of a grant submission. Members of the community engaged in the research project should be adequately compensated for their time and researchers should take steps to establish genuine relationships. Without these considerations in place, the engagement may be misperceived as tokenism or could cause harm. If your project does not have the funding or resources to undertake community engagement adequately, consider other ways you can engage with communities during the dissemination phase. There is no one-size-fits all approach to community engagement, and project teams are encouraged to connect with the Public Engagement and Knowledge Translation (PEKT) team to determine when and why community engagement might be appropriate for their study.

# How can I meaningfully engage communities?

This tool was modified from a tool from <u>McMaster<sup>1</sup></u> and informed by a framework from <u>Ontario Health<sup>2</sup></u>. The resources included are not exhaustive but, rather, are intended as a starting point.



<sup>&</sup>lt;sup>1</sup> Haq U, Dhamanaskar R, Tripp L, Rodgers J, Abelson J. Supporting equity-centred engagement: A step-by-step guide with tailored resources. Public and Patient Engagement Collaborative. Hamilton, Canada: McMaster University. Published 2023. Accessed May 25, 2023. <u>https://ppe.mcmaster.ca/resources/equity-centred-engagement/</u>

<sup>&</sup>lt;sup>2</sup> Ontario Health, Cancer Care Ontario. Equity in Egagement Framework. Public and Patient Engagement Collaborative; McMaster University. Published 2023. Accessed May 25, 2023. <u>https://www.ccohealth.ca/en/what-we-do/person-centred-care/equity-engagement</u>

## Prepare

#### Seek to deeply understand equity and related concepts

Before planning for community engagement in an ICES research project, consider refreshing your fundamental understanding of "equity" and other related key concepts. Communication of these concepts at a nuanced level should also be considered as part of grant applications and publications when applicable.

#### Supporting resources

National Collaborating Centre for Determinants of Health

Centre de collaboration nationale des déterminants de la santé



#### **Glossary of essential health equity terms**

This search-optimized web glossary explains the nuances of 32 fundamental equity-related terms.



Key principles and terms for communication This brief guide shows examples of non-stigmatizing language.

#### Recognize the importance of an equity-centred approach

Communities may have lived through decades of structural inequities with real impact on health outcomes. Early in your project preparation and planning, reflect on how these structural inequities influence data and consider (and discuss with community) which outcomes should be meaningfully analyzed.

Supporting resources



#### Community engagement for health equity

This guide introduces authentic community engagement and its essential role in public health.



#### Engaging communities in your data collection initiative

This brief article emphasizes the role of community engagement when working with sociodemographic data.

#### Reflect on your role and position

Research as an institution tends to reinforce power dynamics, where academics drive priorities. Research teams must be proactive and creative in how they dismantle this power structure and restore the community voice by reflecting on their own implicit biases or assumptions that may influence their project.

Supporting resources



#### The urgency of intersectionality

In this 20-minute video, Dr. Kimberlé Crenshaw introduces how multiple "intersecting" forms of oppression create compounding experiences of marginalization.



#### Privilege and critical allyship

In this 5-minute video, Dr. Stephanie Nixon explains how social structures produce both unearned advantage and disadvantage. <u>Self-reflection</u> is encouraged.

#### Determine who you want to engage and why

Due to the importance of authentic and genuine relationships with community partners, ICES does not facilitate connections between community partners and researchers. However, the <u>PEKT office</u> can help you to consider potential avenues to find partners, including the ICES public mailing list. Consider existing relationships you have that may serve as a starting point, including at your institution or through other researchers. Often these relationships start organically or through word of mouth. Recruitment calls through posters at community organizations, community health centres, social media, and word of mouth via leaders in the community can also be effective.

Supporting resources

POLICY Politiques de Santé Micromonation de la fami Community Knowledge for Equity in Healthcare

This brief article encourages a shift from engaging "patients" to engaging a "community".

#### Determine resources and compensation needed

Define what level of community engagement you are looking for and set clear expectations regarding timeline, budget, and other constraints. Expense reimbursement as well as additional compensation validate the contributions, time, and effort of community partners to your project and are strongly encouraged when budget allows. The type of compensation should ideally be determined in collaboration with your partners based on their needs and preference: an hourly wage, a quartetly lump sum, a one-time honoria, or other in-kind offerings (e.g., courses, training, or gift cards).

Though there is no standardized amount for how much to compensate partners, it should be no less than the regional <u>living wage</u> and may often range from \$20-50/hr.

Supporting resources



#### Budgeting for public engagement

This brief article outlines and explains budget items for consideration. See also an accompanying <u>budget template</u>.



#### **Budget estimates for ICES**

This ICES guide offersestimates for travel reimbursement, venues, interpreters, etc.

#### Proactively and collaboratively set goals

When working with community, co-design of a shared mandate and realistic goals is important from the onset. Engage community in an interactive process (e.g., a consensus building exercise) rather than passive feedback (e.g., one-way communication via email) and discuss with the community their desitre to share (or defer) final decision-making power.

Supporting resources



<u>Co-designing engagement to promote health equity</u> This article outlines key points for co-designing research processes and goals.

# Connect

#### Establish trust and build meaningful relationships

Build relationships and establish informal dialogue with community groups to build trust. Conversation about community should happen with the community, in the community. Let go of the "neutral research expert" hat when you connect with community. Be upfront and honest about your motivation for this work, how it fits in your professional agenda, your fears and uncertainties. Acknowledge that you do not have all the answers.

Develop a clear, honest, and representative agreement with community partners and organizations. Be transparent about the deadlines and institutional pressures you have as well as the benefits and costs for each party so that community partners can make an informed choice.

#### Supporting resources

Facilitators Barriers

Balancing power dynamics This brief checklist outlines some "do's & don'ts" for relationship-building.



How do you start working with a community? This Q&A describes concrete actions to address common challenges.

#### Recruit diverse voices while avoiding tokenism

Consider how recruitment practices may perpetuate colonialism and favor those with certain privileges, access channels, and knowledge. Actively connect with communities and community networks to get the right people involved. Recruit multiple community members to avoid tokenism and to avoid undue pressure on one individual to represent the values of a whole community. Use an intersectional approach to ensure that diverse identities are at the table.

Supporting resources

CIHR IRSC

Tokenism: seeing it, fixing it

This article describes examples of tokenism and offers suggestions to address/avoid.

#### Identify and eliminate barriers to engagement

Reflect on hidden costs to communities incurred by engaging with you. Lower barriers to engagement (e.g., complicated or long forms may automatically exclude those with a lower level of education, and online only forms may exclude those without a computer or mobile device). Reflect on risk for reliving trauma for participants and how to minimize that.

Carefully plan with your community partners the engagement activities in terms of location, time, and recruitment strategies to account for a variety of needs and capabilities. Offer multiple modes of engagement to suit different comfort and accessibility levels with virtual, hybrid, and in-person formats.

Supporting resources

Ontario Chi

#### **Recruiting for diversity**

This guide provides concrete actions that can reduce barriers to recruitment and engagement.

## Engage

#### Communicate openly

It is important for research teams to communicate at every step of the process so that community partners can fully understand and meaningfully contribute to discussions on the research approaches, methods and limitations. Create space for respectful exchange with your partners and to get feedback on how the research is going, how the relationships are evolving, and how they are feeling.

#### Supporting resources



#### Respect and value the community and their needs

Consider different approaches to engaging with community partners that allow a variety of ways to contribute (e.g., written feedback, large group discussions, small group discussions, in-person or online). Carefully consider potential barriers to participation and how these can be addressed so all partners can contribute equally. Include checkpoints to revisit the process, how the relationship is evolving, and discuss challenges or the need for change.

#### Supporting resources

#### Flipping orthodoxies to design inclusive meetings

This template prompts planners to challenge status-quo practices and assumptions.

#### Address power imbalances and empower community to lead

In discussions with community partners, be willing to share authority and power and provide options for how community partners can shape the research (e.g., how the study is set up, how data is interpreted, etc.). Clearly lay out who is acting as the Principal Investigator and if there is a possibility for a community partner to act as one too. Discuss contractual agreement; rights to access, use, and share data and findings; compensation; and research costs. When faced with one community member advocating for an issue that is not agreed upon by other members, consider using consensus building approaches.

#### Supporting resources



MAKING

#### **Co-creation for power-sharing**

This prompts planners to consider where power can be shared with community.



#### Partnering with community-based organizations

This article describes how to share power to foster successful relationships.

# **Sustain**

#### Act on community input and follow up

Decide with community how to communicate data and metrics respectfully and to avoid harm, knowing that numbers are often an incomplete picture of what is happening at a community-level. Invite co-ownership in contextualizing and sharing results, including co-authorship of products beyond academic papers that can be more widely accessible (e.g., infographics, webinars for communities, etc.).

Provide frequent updates and report back the outcomes by demonstrating how the feedback were used and how it led to action. Demonstrate small wins and progress to maintain energy and enthusiasm.

Not all recommendations by community may be applicable or possible for an ICES research project (e.g., a desire for more socioeconomic data is often restricted by the data we have available). It is important to communicate the reasons for why certain feedback could not be incorporated and potential alternatives.

Supporting resources



<u>A Manifesto for ethical research in the downtown Eastside</u> This guide describes community expectations for reciprocity.

#### Maintain relationships and continue to build trust

Maintaining relationships involves follow-through on commitments and potentially sustaining communication beyond an initial engagement (as applicable and desired by the community and research team). Make sure to clearly describe in reports, papers, and to the community partners themselves how their input was used to inform the project.

Supporting resources



National Collaborating Centre for Determinants of Health Centre de collaboration nationale des déterminants de la santé Community engagement for health equity

This 7-minute video describes best practices for building authentic relationships.

#### Evaluate for ongoing learning and improvement

Consider evaluating your engagement annually or at the end of the project to determine what worked well and what lessons can be learned. Both anonymous surveys, informal discussion, and self- or group-reflection can be used as methods of evaluation.

Supporting resources

BMJ Journals	Engagement indicators for health system improvement
BMJ Open	This article describes co-development of indicators to measure engagement. Figure 2 summarizes the indicators.