A Toolkit to Guide Equity-Centred Community Engagement in Research

Checklists

ICES Data Discovery Better Health

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SickKids

Prepare

Take action!

Reflect on your readiness.

The goal of the 'prepare' phase is to understand your positionality, power and assumptions to prepare you to start relationships with humility, transparency and an awareness of how research can reinforce inequities. You may find it helpful to use these prompts for self-reflection and to guide discussions with your project team.

You may find it helpful to use existing tools that support early reflection on roles, power and readiness before beginning relationship-building with community members. The Designing and Assessing Inclusive and Systematic Co-Production (DAISY) Framework offers guided prompts to help you think through decision-making, compensation and how roles will be shared in an equitable way. The Guidance for Reporting Involvement of Patients and the Public (GRIPP2) checklist, although originally created as a reporting tool, can also be used during planning to clarify your purpose and the level of involvement community members will have in shaping the research. These tools are useful activities to complete early in the process to support transparency and intentional engagement.

Checklist

Your role and readiness

- [ ] I understand what community engagement *is not* (i.e., asking for letters of support).
- [ ] I understand what community engagement *is* (i.e., shared decision-making, relationship building).
- [ ] I can clearly explain why I want to engage (not "because the grant requires it").
- [ ] I understand that meaningful community engagement requires time and ongoing relationship-building.

Positionality (power and privilege)

- [ ] I have reflected on my identity, privileges and lived experience (what I assume, what I don't know).
- [ ] I recognize that community members may have valid mistrust based on past harm from research.
- [ ] I can name how power currently sits (institutional authority, control over budget/data/timelines).

Team preparedness

- [ ] Our team agrees on why community engagement is needed (not one person advocating for it alone).
- [ ] We have discussed how we will deal with discomfort or pushback.
- [ ] If community engagement shifts our research plan, we are ready to change direction.

Plan

Take action!

Document your project scope, roles, budget & expectations.

The goal of the 'plan' phase is that expectations, influence, timelines and compensation are explicit and equitable. Use these prompts to help you and community members co-design how you will work together.

A fillable and printable Engagement Planning Worksheet is available to support researchers in preparing and planning for community engagement. Completing the worksheet is a helpful activity to think through decisions, timelines and roles before reaching out to community members.

Checklist

Who and why

- [ ] The community group(s) are clearly defined (not broad terms such as "vulnerable populations" but specific groups, like "high school youth advocating for mental health supports").
- [ ] We can explain what decisions community members have opportunities to influence (i.e., refining research questions, interpreting results).

Resources and compensation

- [ ] We have budgeted for honoraria for partners that is aligned with living wage.
- [ ] We have additional budget for supports that may be needed by partners: transportation, childcare, food, accomodations, translation, supplying technology like internet modems or laptops or others as needed.
- [ ] We have decided how and when community members will be compensated, and we have a dedicated individual on the team (or in our institution) to assist with the process.

Engagement design (how decisions will be made)

- [ ] We discussed and agreed on decision-making (consensus? vote? shared leadership?).
- [ ] We have co-developed expectations: time commitment, deliverables, flexible participation.

Boundaries and non-negotiables (transparency)

- [ ] We have identified what is fixed (ethics restrictions, data access).
- [ ] We have identified what is flexible (methods, interpretation, dissemination).

Connect

Take action!

Plan for building relationships.

The goal of the 'connect phase' is to build trust and rapport before discussing tasks or deliverables related to the research project. Trust is established through repeated, consistent and relational interactions. Discuss these prompts with your project team and use them to help guide a written engagement plan that considers how you will start building meaningful relationships. Revisit the prompts periodically to reflect on whether these relationships are being fostered and nurtured appropriately.

When we spoke with members of the ICES Public Advisory Council, they had the following tip for researchers who are connecting with community members: "Can we get to know you a little bit? Why are you interested in this issue? What got you here? Are you involved in the community outside of research? Just share with us a little, your personal or professional story and who you are outside of the 'alphabet of titles'. Walk with us, beside us." – The ICES Public Advisory Council

Checklist

Building connection

- [ ] We met people where they are (their space, their events, their communities).
- [ ] We opened space for conversation about their priorities, not just our project.
- [ ] We shared why this matters to us personally (not only professionally).

Accessibility and inclusion

- [ ] Meeting formats and times were set based on community members' preferences (not our convenience).
- [ ] We planned for accessibility: interpreters, American Sign Language, plain language, mobility needs, etc.
- [ ] All communication was jargon-free and provided in advance.

Psychological safety

- [ ] We acknowledged any potentially triggering topics and offered opt-outs.
- [ ] We provided mental health supports or debrief options.
- [ ] We explicitly stated: "You do not have to share personal experiences to be a member of this team."
- [ ] We explained what decisions they will influence (i.e., refining research questions, interpreting results).

Engage

Take action!

Build inclusion into your engagement plan

The goal during 'Engage' is to ensure community members feel heard, valued and encouraged to lead. Discuss these prompts with your project team and use them to help guide a written engagement plan that considers key best practices.

When we spoke with members of the ICES Public Advisory Council, they had the following tip for researchers who are engaging with community members: "If there is a delay during the research process, let us know. Don't wait 365 days to come back to me. There was a research group [I was part of] that met very infrequently, like once a year. I don't remember any circle back of our feedback and then I think the project ended without anyone telling us. Bad communication!" – The ICES Public Advisory Council.

You may also find it helpful to draw on existing tools that support co-design, shared decision-making and transparency throughout the engagement process. The Patient-Centered Outcomes Research Institute PCORI Engagement Plan Worksheet offers guided prompts to help teams identify roles, determine how decisions will be made and assess whether engagement is meaningful and reciprocal.

Checklist

Onboarding and supporting full participation

- [ ] We held a kick-off meeting and co-created a community agreement and/or terms of reference; and pre-determined preferred communication methods between meetings (text, email, WhatsApp).
- [ ] We provided orientation that was written in plain language and conducive to the language and literacy needs of the group (e.g., online platform tutorial, outlining stages of research, a glossary of terms, etc.).
- [ ] We assessed the needs and values of our partners and if necessary, have found opportunities for them to build further leadership capacity in areas relevant to the work (e.g., facilitation training, peer mentorship, etc.)

Transparency and sharing decision-making

- [ ] We built in power-sharing if desired by the group or certain members (e.g., rotation of meeting facilitation, shared agenda setting, transparency around decision-making).
- [ ] We have been clear on the roles and responsibilities of everyone on the team, so there are no surprises or misinterpretations.
- [ ] We check in regularly on process, not just assigned tasks ("How are we working together?").
- [ ] Our decision-making processes were clear and transparent.

Documenting, reflecting and closing the feedback loop

- [ ] We have documented key decisions and contributions and shared back with the group.
- [ ] Feedback loop was explicitly acknowledged and acted on: "You said _____, we adjusted _____."
- [ ] We reflected together on what is working and what needs to change.

Sustain

Take action!

Discuss the future of relationships.

The goal of the 'sustain' phase is to maintain relationships responsibly and/or close the project respectfully to make sure that the benefits flow back to community, not just to researchers. Use these prompts to guide a conversation with community members about their goals and priorities beyond the project.

As you move through the stages of your research study, it can be helpful to use tools that prompt intentional closure and support the continuation of relationships beyond the formal end of the work. The Sustaining the Work or Initiative Tookit from the Community Tool Box at the University of Kansas offers practical guidance on how to wrap up partnerships respectfully, including discussing whether and how the relationship will continue.

Checklist

Reciprocity and return of benefits

- [ ] We shared findings with community members in usable formats (e.g., plain-language summaries, infographics, presentations to the community, etc.).
- [ ] We offered community members opportunities for future involvement (e.g., conference co-presentations, letters of support, skill development opportunities, etc.).

Closure with care

- [ ] We held a final meeting to confirm what was completed and what remained outstanding.
- [ ] We fulfilled all of our commitments to community members, with no unpaid labour or unaddressed promises (e.g., payments were processed and follow-ups were completed).
- [ ] We asked community members whether they wished to stay connected and how they preferred to maintain contact.

Shared future planning

- [ ] We used community members' input to inform next steps or future research priorities.

Evaluate

Take action!

Evaluate your experience & impact

The goal when evaluating is to measure the quality and impact of engagement, including how people experienced it, whether power shifted and how relationships changed over time (not just 'whether' activities occurred). Use these prompts to reflect with community members and the broader project team on what is important to evaluate and how to plan your evaluation process.

Checklist

Co-create the evaluation

- [ ] Community members helped define what "success" meant.
- [ ] Community members helped select the evaluation tools.
- [ ] We evaluated process, experience and impact, not only outputs.

Continuous learning

- [ ] We evaluated at multiple stages (beginning, mid-point, end), not only at the conclusion.
- [ ] We discussed findings collaboratively with community members and the approach was adjusted based on what we learned.
- [ ] We chose evaluation methods that reflected the project context and included approaches such as interviews, focus groups, surveys and other ways of gathering feedback.
- [ ] Community members helped decide what should be evaluated and how, measures of success reflected their priorities and perspectives.

Sharing the findings

- [ ] We shared results back to community members before sharing with academic audiences.
- [ ] We shared results in accessible formats (e.g., visuals, stories, audio, culturally relevant approaches, etc.).

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