

CONDUCTING COMMUNITY-BASED RESEARCH WITH POPULATIONS LIVING WITH VULNERABLE CONDITIONS: AN EXAMINATION OF CHALLENGES, CONSIDERATIONS, AND BEST PRACTICES

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EXECUTIVE SUMMARY

Including populations living with vulnerable conditions in research has the potential to positively influence their health and well-being and increase research quality and relevance. Participation for these populations can be fraught with feelings of mistrust, disrespect, and stigma. Further, they often have multiple barriers to overcome that may impede engagement such as poor health, poverty, and complex cultural/language difficulties. Thus, creating collaborative, respectful, and positive research environments is essential. Three interrelated studies aimed to understand how key informants, families living with vulnerable conditions, and community-based stakeholders believe researchers and community partners could best work with populations living with vulnerable conditions when conducting community-based research (CBR).

Study 1: Interviews with Key Informants

The purpose of these interviews was to explore the challenges key informants (e.g., researchers, community partners) faced when engaging vulnerable populations during various phases of CBR and to provide a rich local understanding of the positive “best” practices used when conducting CBR with populations living with vulnerable conditions within Alberta. Interviews were conducted with 14 researchers, community partners, government policy-makers, program funders, project coordinators, program planners, and school board employees experienced in working in the areas of children and youth, education, and health. Involvement in CBR ranged from 5–30 years and with populations living with vulnerable conditions from 5–30 years. Cross-case analyses were used to analyze the data.

Key informants experienced several challenges: participant language/literacy barriers, building trusting relationships, participation accessibility, families’ crises, cultural protocols, research process, engagement/recruitment, offering incentives, and knowledge mobilization. Key informants discussed positive practices they used when conducting CBR: invest time in building trusting, long-term relationships; accommodate participants’ needs; ensure rigour throughout the research process; be prepared to participate—equally, honestly, and deeply; make research relevant to participants; work

Study 2 Participant Demographics

- 48% Canadian-non Aboriginal, 40% New Canadian, 12% Aboriginal
- 76% employed
- 56% of families did not have a co-parent living in the household
- 32% had one child, 20% had two children, 28% had three children, 20% had four or more children
- 40% married; 36% separated, divorced, or widowed; 20% single, never married; 4% living with a partner
- 16% were junior high graduates, 44% were high school graduates, 40% were postsecondary graduates

with a community liaison/broker who knows population well; and tailor honorariums to participant groups.

Study 2: Interviews with Families Living with Vulnerable Conditions

We aimed to understand how families living with vulnerable conditions believe researchers and community partners could best work with them when conducting CBR. All 25 participants had previously taken part in a longitudinal CBR project entitled Families First Edmonton. We conducted telephone interviews, asking participants about participation challenges, considerations, and recommended practices. Data was analyzed using cross-case analyses.

Participants discussed participation challenges, including lack of time, research question content and format, others' perceptions/discrimination/stigma, participation accessibility, and language barriers. Participants suggested that researchers and community partners consider increasing ease of access to opportunities, including programs and services, understanding families' individual needs, getting to know participants, and making participating enjoyable. Positive practices that families believed were helpful in involving and keeping families engaged in research included: benefits of participating, establishing and maintaining rapport with participants, making research participation accessible to families, advertising opportunities to families, and acknowledging research experiences and protocols.

Study 3: Concept Mapping with CBR Stakeholders

This study aimed to understand how positive practices used when conducting CBR with populations living with vulnerable conditions relate with one another and learn how often practices are used and how effective they are for CBR stakeholders. We used group concept mapping, where stakeholders brainstorm ideas, determine how ideas are related, and rate ideas on relevant dimensions. Their input

formed a framework to organize thinking about positive practices to use when conducting CBR with populations living with vulnerable conditions.

Data collection was conducted in two phases. First, participants generated statements online, describing positive practices to use when conducting CBR with populations living with vulnerable conditions. Participants also responded to an open-ended question about the challenges they experienced when conducting CBR. Second, using Concept Systems Global software, participants viewed the list of 72 statements generated in the first phase and were asked to sort the statements for similarity into piles and then assign a label to each pile. Participants then rated the statements on frequency of use and perceived effectiveness.

In the statement generation phase, 37 researchers, community partners, and policy-makers in health, human services, children and youth, and education, had, on average, 13.8 years experience conducting CBR and, on average, 12.7 years experience conducting CBR with populations living with vulnerable conditions. They conducted CBR most often with people living with poverty; newcomers and refugees; aboriginal populations; and children and youth. In the sorting and rating phase, participants included 26 researchers, policy-makers, program planners, and community partners with, on average, 10 years experience conducting CBR. They conducted CBR most often with people living with poverty; children and youth/children and youth in care; First Nations, Métis Inuit, and/or indigenous peoples; people with health issues; and newcomers, immigrants, and/or refugees.

CBR stakeholders noted several challenges: lack of time, high mobility of some participants, building trusting relationships and breaking down suspicions and mistrust, language and cultural barriers, ethics protocols and consent, low literacy levels, and meeting participants' basic needs. During concept mapping of positive practices, 7 clusters emerged: ethical practices, participant supports, social accountability, community involvement, language competence, financial compensation, and project viability. Practices within the Ethical Practices cluster were rated highest on frequency of use and highest on perceived effectiveness.

Over all three phases of this research, participants emphasized the importance for researchers to build trusting, respectful relationships with their participants; understand and accommodate participants' needs (e.g., culture, language, literacy level); and ensure participants benefit from taking part in research (e.g., honorariums, incentives, new knowledge).

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