

SFU

CERi

COMMUNITY-ENGAGED RESEARCH



PIPPS

Pacific Institute on Pathogens,
Pandemics and Society

COMMUNITY-ENGAGED RESEARCH DURING HEALTH CRISES:

Engaging with civil society organizations

October 2023



About PIPPS and CERi

Pacific Institute on Pathogens, Pandemics, and Society (PIPPS)

PIPPS is an interdisciplinary research institute based at Simon Fraser University’s (SFU) Burnaby campus focused on strengthening British Columbia’s (BC) capability to prevent, prepare for, and respond to major infectious disease events.

PIPPS is a research and training platform that brings together BC scientists, educators, trainees and public health institutions with leading national and international experts. This project has been developed under the Health and Social Inequities PIPPS theme, which conducts research on the interactions between systemic causes and the effects of health crises to inform equity-based pandemic preparedness, responses, and recovery.

SFU Community Engaged Research Initiative (CERi)

CERi is a university-wide strategic initiative that aims to enhance and support ethical research engagements in and with community. CERi’s office is situated at 312 Main in the heart of Vancouver’s Downtown Eastside and offers programs such as the Graduate Fellowship Program, the Community Engaged Research Funding Program, Community Scholars Program, and Researchers in Residence, among others. CERi promotes principles of participation, cooperation, social transformation, and knowledge translation to lift up and strengthen the capacity of SFU’s researchers and students, to engage respectfully and ethically with community members.



Contents

+ Glossary	4
+ Acknowledgments	5
+ Introduction	6
+ CER and health crises	
+ What is Community-Engaged Research (CER)	7
+ Priority populations in health crises	8
+ Civil society organizations (CSOs)	10
+ CER considerations during health crises	12
+ Relationship building during health crises	14
+ Lessons learned - reflecting on the COVID-19 pandemic	15
+ Community-engaged research ethical principles during health crises	16
+ Tools for doing CER in Health Crises	
+ Tool #1: Participation continuum	22
+ Tool #2: Developing guiding values - facilitation guide	24
+ Tool #3: Terms of reference template	26
+ Tool #4: Considerations for planning engagement with civil society organizations during health crises	28
+ Tool #5: Data sharing agreement	32
+ Tool #6: Authorship guidelines template	36
+ Tool #7: Community research agreement	38
+ Further learning	40
+ References	41

Glossary

TERM	DEFINITION
Community-Engaged Research (CER)	A research paradigm that emphasizes ethical engagement practices, and prioritizes the involvement/goals of communities and community members that are most affected by the issues being researched. CER aims to generate respectful, collaborative partnerships between community, community based organizations, and researchers.
Priority population	Groups at a heightened risk of socially produced health inequities (Wieland et al., 2020).
Civil society organization (CSO)	Socially driven, not-for-profit agencies that operate separately from government and business (United Nations, n.d.).
Health crises	Situations in which health consequences have the potential to overwhelm routine community capabilities to address them (Nelson, 2007).
Health equity	“The absence of unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically, or geographically” (Public Health Canada, 2018).
Health inequities	“Differences in health status [due to] the distribution of health resources between population groups, arising from the social conditions in which people are born, grow, live, work, and, age” (WHO, 2018).
Health inequalities	“Differences in health status or in the distribution of health determinants between different population groups. This can be attributed to the unequal distribution of the social and economic factors that influence health (e.g., income, employment, social supports) and exposure to societal conditions and environments largely beyond the control of the individuals concerned” (Public Health Canada, 2018).
Terms of reference	A document used to define the purpose and structure of a project, including roles, responsibilities, timeframe, and objectives.

Acknowledgments

Acknowledgement of place

The authors acknowledge that our work takes place on the traditional and unceded territories of the Musqueam, Squamish, Tsleil-Waututh, Katzie, Kwikwetlem, Qayqayt, Kwantlen, Semiahmoo, and Tsawwassen nations. Our work is deeply rooted in the goal of generating systemic change, which requires us to examine the history of the land that we are on today, support the people who are stewards of this land, and commit ourselves to stand in solidarity with Indigenous communities. Indigenous scholars have long been engaged in knowledge creation and knowledge sharing that identifies a spirit of “relational accountability” (Wilson, 2001), in which knowledge is shared with all of creation, including the land. We take this teaching to heart as we do the work of community-engaged research.

Handbook authors

Simran Purewal, PIPPS

Julia Smith, PIPPS

Muhammad Haaris Tiwana, PIPPS

Kari Grain, CERi

Tara Mahoney, CERi

Funder

We would like to thank the Canadian Institutes for Health Research and Health Research BC for financing this handbook

Community-engaged research roundtable contributors

On July 6th, 2023, we convened a group of community-engaged researchers at SFU to discuss their experiences conducting community-engaged research during the COVID-19 pandemic. Their invaluable contributions and insights informed our lessons learned (p. 15). We thank all the contributors for participating in the roundtable:

- + Alice Mūrage
- + Angel Kennedy
- + Dr. Evelyn Encalada Grez
- + Jason Proulx
- + Dr. Kalysha Closson
- + Dr. Kelley Lee
- + Dr. Maya Gislason
- + Dr. Paola Ardiles Gamboa
- + Dr. Stefanie Machado
- + Moreno Zanotto

Suggested citation

Purewal, S.K., Smith, J., Tiwana, M.H., Grain, K., & Mahoney, T. (2023). Community-Engaged Research During Health Crises: Engaging with Civil Society Organizations.

Introduction

Purpose of handbook

Community-engaged research (CER) is crucial in health crises, such as the COVID-19 pandemic. Community engagement can provide insights into how priority populations are experiencing the crisis and can help to identify community needs. In turn, this can guide interventions to reduce health and social inequities exacerbated during crises. Engagement with civil society organizations (CSOs) can also help researchers conduct community-driven research with priority populations. In this handbook, CSOs refer specifically to non-profit organizations and community groups that operate separately from governments and businesses, at local, national, or international levels (Lee, 2010).

This handbook has been developed to provide guidance to researchers who aim to ethically engage with CSOs during health crises, especially crises caused by infectious diseases (e.g., COVID-19, H1N1). The book contains CER considerations and practical tools for researchers to support engagements with CSOs. We focus on engaging with CSOs to reach priority populations, as CSOs are trusted leaders embedded within the communities they serve.

Intended audience

This handbook will be useful for researchers (e.g., academics, graduate students, health authorities public health institutions and community-based researchers) interested in conducting community-engaged research with CSOs during health crises.

Building on existing work

We have collated existing information for conducting research with CSOs and tailored tools to the context of health crises, in which traditional forms of research (e.g., in-person interviews, focus groups) may be hindered by necessary public health measures, such as physical distancing. Our work has been informed by promising practices for CER and lessons learned from various health crises, including, but not limited to, the mpox outbreak, the Ebola outbreak, the H1N1 pandemic, and the COVID-19 pandemic.

This handbook also builds on existing work from SFU CERi:

- SFU CERi Community Resource Handbook: A Guide to Community-Engaged Research (2021) (Mahoney et al., 2021)
- SFU CERi - Community-Engaged Research in Times of Crisis: A Continuing Conversation: A recorded panel sharing experiences and reporting on a series of media-centred community-engaged projects that were part of the *Field Stories: CER in Times of Crisis Symposium*.
- Community-Engaged Research Ethical Principles (Grain, 2020)

Community-Engaged Research (CER)

CER “creates space for community, community members, and community-based organizations [CSOs] to work in collaborative partnerships with academic researchers” (Kantamneni, 2019). It centres on the equitable involvement of all partners involved in the research (UC Riverside, n.d.). CER projects collect information to address a particular question emerging from community interest (Mahoney et al., 2021).

CER methods are wide-ranging. They prioritize methods that meet the needs of community partners, as members of the research team. CER methods draw on both conventional research (e.g., semi-structured interviews, surveys, focus groups) and participatory methods, such as (Mahoney et al., 2021):

- Digital storytelling
- Photovoice
- Community mapping

Conducting CER has several benefits:

- Incorporates lived experiences and insights from community members throughout the research process (UC Riverside, n.d.)
- Facilitates knowledge sharing back to communities
- Enhances the study design and research process through community insight
- Informs the development of recommendations and interventions that are culturally and linguistically appropriate (Yale School of Medicine, n.d.)
- Fosters co-learning and capacity building among the research team, including all partners involved (Mahoney et al., 2021; Payan et al., 2022)

CER DURING THE COVID-19 PANDEMIC

The Canadian Myth: The exclusion of Internationally Trained Physicians

In April 2020, a grassroots social media campaign, *Trained to Save Lives*, was initiated to enable internationally trained physicians (ITPs) to contribute to British Columbia’s (BC) COVID-19 response. Subsequently, a partnership was formed between SFU researchers (Dr. Evelyn Encalada Grez, Dr. Paola Ardiles, and Simran Purewal), RADIUS SFU, and the Canadian on Paper Society for Immigrant Physician Equality to conduct research on this community-driven topic. With the support of a community advisory committee, the team conducted virtual interviews to explore barriers in the medical licensing process. Read the report, including the study’s findings and recommendations, here.

Priority populations in health crises

Health crises are situations in which “health consequences have the potential to overwhelm routine community capabilities to address them” (Nelson, 2007). Processes of globalization, such as the increase in human mobility and urbanization, have facilitated the spread of infectious diseases on a global scale (Labonté et al., 2011). As a result, there is increased research and policy attention on the globalization of infectious diseases and how to limit their spread (Colizza & Vespignani, 2010). Planetary and One Health research further suggest that infectious disease events will continue to be complicated by the effects of climate change including extreme weather and disasters, such as heatwaves and flooding (Public Health Ontario, n.d.).

Preparedness for, and responses to health crises requires a multi-disciplinary approach involving several sectors, including government agencies, public health institutions, research institutions, and CSOs (Nelson, 2007). Coordination and collaboration among these structures underpin the management of health crises (Public Health Ontario, n.d.).

During health crises, resources are stretched thin, priorities must be decided on an immediate time scale, and the needs of distinct population groups are neglected as general public health interventions take precedence (Wingate et al., 2007). Yet, as exemplified by the COVID-19 pandemic, health crises disproportionately affect **priority populations**, which are groups at a heightened risk of socially produced health inequities (Wieland et al., 2020; Sudbury Health Unit, 2016). **Health inequities** refer to “differences in health status [due to] the distribution of health resources between population groups, arising from the social conditions in which people are born, grow, live, work, and age” (WHO, 2018). Where priority populations and

their needs are not identified at the outset of the health crisis, health inequities are exacerbated (WHO, 2020).

Priority populations often have less access to preparedness, planning, and recovery resources in crises (Ringle et al., 2011). Responding to health crises requires identifying groups that are at the greatest risk of experiencing health inequities (Michener et al., 2020). This typically involves collaborating with local advocacy, service, and health-related CSOs serving priority populations (Ringle et al., 2011). In the context of health crises caused by infectious diseases, characteristics used to identify priority populations are (Public Health Ontario, 2015):

SOCIO-DEMOGRAPHICS

e.g., gender, ethnicity, age

MEDICAL FACTORS

e.g., mental health status, disabilities, higher risk of severe complications from infectious diseases, immunosuppression (CDC, 2018)

BEHAVIOURAL FACTORS

e.g., attitudes, stigma, health risk behaviours, protective factors

GEOGRAPHICAL FACTORS

e.g., remote, rural, urban or suburban locations

BURDEN OF DISEASE

e.g., incidence and prevalence

ACCESS TO HEALTH AND SOCIAL SERVICE

e.g., underserved communities who face barriers to care, such as cost, linguistic barriers, and/or limited access to specialized services

Throughout the COVID-19 pandemic, priority populations included a wide range of groups including racialized people, Indigenous communities, people with mental health issues, people experiencing housing insecurity or homelessness, people with disabilities, those with multiple chronic conditions, people in rural or remote communities, people with low-income, and im/migrants (Evidence Synthesis Network, n.d.). They experienced a disproportionate burden of COVID-19 morbidity and mortality, and inequitable social impacts, in part, due to the rapid implementation and removal of public health measures (Ismail et al., 2021).



CER DURING THE COVID-19 PANDEMIC

Health and well-being of indigenous women living with HIV

Dr. Angela Kaida, Professor in the Faculty of Health Sciences at SFU, and the CHIWOS-PAW BC research team are leading a collaborative strengths-based research study in partnership with people with lived experiences, Elders, and researchers to understand how Indigenous women living with HIV on the Coast Salish Territories understand their health through traditional ways of knowing. In the early stages of the pandemic, they faced challenges in engaging with participants and within the team itself. To overcome barriers, they adapted their study from town hall and focus group discussions to one-on-one meetings to align with public health guidelines. Members also had improved internet and tech support as the team engaged with the telecom sector to provide necessary resources and connection services.

Civil Society Organizations (CSOs)

What are CSOs?

CSOs are socially-driven, not-for-profit agencies which operate separately from government and business (United Nations, n.d.). They can include community groups, volunteer-driven organizations, faith-based organizations, and non-governmental organizations. These organizations have several functions, like advocating for community members, advancing collective goals, providing health and social services, and influencing the actions of decision-makers. CSOs often act as intermediaries between policymakers and community members by facilitating dialogue and engagement opportunities (Kanthor et al., 2014).

CSOs, as per the information provided by the United Nations (n.d.), may be organized at the local, national,

or international level. They engage with diverse missions, priorities, and populations of priority. Some CSOs' notable contributions during past health crises included (Government of Canada, 2022):

- Promoting inclusive and sustainable social change
- Mobilizing the voices of communities that have been marginalized
- Challenging societal norms and practices that have harmful and indirect effects on priority populations
- Brokering connections between government entities and community members
- Responding to health crises through advocacy, service delivery, and direct relief
- Building trust and social cohesion among community members

CER DURING THE COVID-19 PANDEMIC

Sustainable business adaptation during COVID-19

During the pandemic, Dr. Tammara Soma, SFU Assistant Professor School of Research and Environmental Management, partnered with the National Zero Waste Council (BC) to investigate promising practices and innovative solutions aimed at supporting a green recovery from COVID-19. The team worked to identify existing local business networks and facilitate a peer-to-peer online exchange aimed at encouraging collaboration and sharing learning. The team highlighted case studies of 10 businesses that adapted to COVID-19 while prioritizing a sustainable local economy. By sharing their strategies and reflections, other businesses can learn how to align with public health orders and maintain their commitment to sustainability.

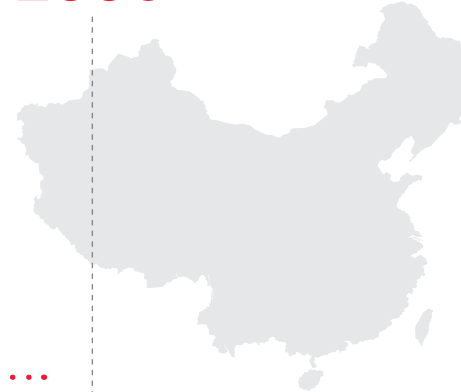
CSOs during previous health crises

Because CSOs have long-standing relations with the communities they serve, they have played a significant role in responding to previous health crises (Wingate et al., 2007).

CASE STUDY 1: SARS in China (Schwartz & Evans, 2007)

China obtained assistance from voluntary religious organizations (Buddhist, Daoist, Catholic, Protestant and Muslim groups) through financial support and volunteers. Other organizations that provided support included China's Family Planning Association, whose members participated in education, information dissemination, and survey work on the spread of SARS in rural areas of the Guangxi province. Members of the Huizeying Human Service Center of Beijing also helped medical workers and their families cope with the stress of their work combating SARS.

2003



CASE STUDY 2: Community-driven response in Toronto, Canada (Cassa, 2023)

During the COVID-19 pandemic, the South Asian Vaccine Engagement Collaborative initiative was created to increase COVID-19 testing, vaccine confidence, and access among South Asian communities in Toronto, Ontario. SAVEC worked with 12 South Asian agencies such as the Council of Agencies Serving South Asians (CASSA), Alliance for South Asian AIDS Prevention, Bangladeshi-Canadian Community Services, and community leaders in the city of Toronto, experts, in collaboration with media outlets to develop agile, population-specific, and culturally responsive strategies.

2020



CASE STUDY 3: Mpox outbreak in Europe (WHO European Region, 2022a; WHO European Region, 2022b)

To control the spread of mpox across Europe, the World Health Organization (WHO) encouraged community-engaged responses. They advised forming working partnerships with CSOs such as the National Minority AIDS Council, the Love Tank CIC, and others that had direct and trusted relationships with affected populations. Queer Health and PrEPster, projects emerging from The Love Tank, streamed live information sessions to inform their followers about mpox and translated how to reduce risk, prevent transmission and seek care in multiple languages. These CSOs worked as community advocates and trusted messengers to address disinformation.

2022



Community-engaged research considerations during health crises

Amid health crises such as the COVID-19 pandemic, the ability to conduct conventional research methods, like in-person focus groups, is often impeded by necessary public health and preventative measures (e.g., physical distancing, self-isolation). Past health crises provide an opportunity to reflect on the benefits and challenges of conducting CER during health crises.

Benefits

- Greater potential to conduct research with impact aimed at reducing social and health inequities (Michener et al., 2020)
- CER partnerships broaden the reach to priority populations through CSOs, which have the organizational and technical capacity to engage with population groups (Wieland et al., 2021)
- Health crises magnify existing inequities, which can be addressed through community-university partnerships (Corbin et al., 2021)
- Can result in mutually beneficial partnerships among researchers and community partners (Dillard et al., 2022)

Challenges

- Lack of time due to increased workload and demand for services (Du Mont et al., 2022)
- Relationship building may be hindered by public health mandates (Payán et al., 2022)
- CSOs may not have the infrastructure required to conduct CER (Scripps, n.d.)
- Privacy, security, and confidentiality concerns associated with conducting research remotely (Beyond the Toolkit, n.d.)

Key considerations

Engaging with CSOs is crucial to improving health outcomes during crises (Michener et al., 2020). Conducting CER requires researchers to be adaptable, innovative, and flexible. Key considerations for CER during health crises include:

Learning

- Reframe health crises as “community problems” as opposed to just “public health problems” to consider the direct and indirect effects on priority populations (Michener et al., 2020)
 - Demonstrate how research partnerships can help address CSOs’ needs; projects should be driven by community-identified needs (Michener et al., 2020)
- (Tool #4)**
- Learn about the assets of the community partner and community members (Scripps, n.d.)
 - Community assets are wide-ranging and may include (University of Kansas, n.d.):
 - Prominent community leaders and local champions
 - Physical structures or places (e.g., recreation and community centres, neighbourhood groups, libraries, social clubs, faith-based organizations)
 - Community services
 - Local businesses

Reflexivity

- Create opportunities for your community partner to share feedback in a low-barrier and safe environment (Barwise et al., 2022)
- Implement check-ins with the research team to understand how the health crisis is impacting them and their capacity to engage in the project
- Continuously analyze and monitor the evolving situation; be responsive to new and emerging needs (Corbin et al., 2021)
- Enter the partnership with transparency about your agenda and your community partner's agendas (Han et al., 2021)
- Reflect on the sub-groups unintentionally excluded from research due to a lack of digital connectivity (Salma & Giri, 2021) and explore other ways to engage with them

Reciprocity

- Discuss key insights and lessons learned throughout the entire partnership, not just toward project completion
- Share data and outputs on platforms that community members are familiar and comfortable with
- Prioritize capacity building during the partnership to ensure CSOs feel well prepared to initiate and continue community-driven research
- When possible, facilitate connections and mobilize local resources offered by other CSOs (Donnelley et al., 2021)

Level of engagement

When developing a research proposal, researchers and community partners must discuss the level of engagement they can commit to. During health crises, engagement level may change over time as CSOs experience increased service demands. To determine the appropriate level of engagement, consult with our **participation continuum (Tool #1)**.

CER DURING THE COVID-19 PANDEMIC

Impact of COVID-19 on families of children with autism: A community-engaged project

One group significantly impacted by the COVID-19 pandemic was families caring for children with autism. Researchers from SFU's Autism and Developmental Disorders Lab (ADDL) and the Social Attention Group in Education (SAGE) collaborated with Autism Community Training (ACT) to assess mental health, child and family functioning, quality of life and satisfaction with government support and services. They mobilized a survey co-created with ACT, which also included feedback from caregivers in this community. Their findings point to an urgent need for better supports that address the needs of parents who are struggling to care for their children under increasingly challenging circumstances.

+ Relationship building

Relationship building during health crises

Authentic and meaningful relationship building is paramount to conducting CER. To build relationships with CSOs during health crises, consider the following promising practices:

- Approach CSOs with recognition of the community's identified needs and priorities (Abara et al., 2014)
 - Before entering the partnership, become knowledgeable about the community's local context, including cultural factors, socioeconomic conditions, and inequities arising from the crisis (Minnesota Department of Health, 2015)
 - Prioritize flexibility. Be adaptive and responsive to CSOs changing needs in the crisis context.
- Acknowledge the significant contributions of CSOs, including their understanding of communities' realities and lived experiences (Donnelly et al., 2021)
- Enable bi-directional communication with CSOs using platforms they are comfortable with. Consider what the organization already uses and has expertise in (Plunk et al., 2022).
 - Identify digital connectivity needs and gaps among the team
 - Think about the effectiveness of the platforms used to communicate (Tindana et al., 2020). Which platforms should be used for different types of engagements (e.g., updates, feedback, discussions)? Are certain groups unintentionally overlooked by favouring one platform?
 - If the research team has collectively decided to introduce new platforms, provide technical support and/or training to enhance their understanding (Plunk et al., 2022).
- Prioritize regular communication on the identified platforms
- Document learning along the way in order to capture insights (Gonah, 2020) and inform future partnerships
- Maintain transparency about the team's time commitment, objectives, and funding (Han et al., 2021) (**Tool #2**)
- Share all necessary resources and information with your community partner
- Nurture and maintain trust by actively listening to CSOs and the communities they serve
- Co-develop and document guiding values to inform the collaboration (**Tool #3**)
- Strive for equal ownership throughout the entire research process, including the identification of research questions, data collection, and outputs (Donnelly et al., 2021) (**Tools #6 and #7**)



Lessons learned - reflecting on the COVID-19 pandemic

CSOs

CSOs' service delivery was significantly impacted by public health protections. Prior to the COVID-19 pandemic, organizations primarily served communities in person and offered physical spaces to foster social connections (Baggetta et al., 2022). Due to restrictions imposed by the pandemic, CSOs were forced to quickly adapt and engage with their constituents in alternate formats. They were faced with complex challenges, including:

- Limited access to resources and hindered staff capacity (Du Mot et al., 2022), while the need for services increased drastically
- Lack of specialized equipment and infrastructure required to engage with community members virtually
- Financial constraints due to depleting revenue streams and funding sources, like fundraising (Dayal, 2020)
- Changing constituents' priorities (e.g., greater need for immediate/ emergency needs)(Charitable, 2020)
- Restricted ability to collaborate with networks, including CER opportunities (Tindana et al., 2020)
 - Many researchers contacted CSOs with requests to participate in research or garner community feedback (Barwise et al., 2022)
 - The increased workload forced some staff to informally adopt additional roles, which presented challenges to committing to CER (Du Mont et al., 2022)

In spite of these challenges, CSOs remained committed to serving priority populations throughout the COVID-19 pandemic by:

- Building and maintaining trust among their constituents
- Shifting their service delivery to meet immediate needs (Suva et al., 2022)
- Filling gaps in healthcare provision and psychosocial supports, while advocating for the community's needs (Civicus, 2020)
- Prioritizing innovation, flexibility, and adaptability to respond to shifting needs (Civicus, 2020)
- Centring community engagement to promote preventative COVID-19 safety measures (UNICEF China, 2020)

Researchers

On July 6th, 2023, PIPPS hosted a roundtable discussion with community-engaged researchers at SFU. Researchers discussed the barriers encountered when conducting CER during the COVID-19 pandemic:

- Recruiting participants amid the shift to primarily online modes of engagement and attempting to overcome the systemic digital divide
- Ensuring psychological safety among all participants, as well as members of the research team
- The constantly shifting social, political, and health landscape, which directly and indirectly altered how research was conducted
- The pressure to perform and push constraints aside to deal with grant deadlines and outputs

Researchers also shared innovative strategies and successes experienced while conducting CER amid the health crisis:

- Creating time and space to have regular, informal check-ins with members of the research team to understand their needs and address barriers to engagement
- Leveraging new and emerging tools to meet accessibility needs, such as Zoom, REDCap, and virtual focus groups
- Breaking down geographical barriers to enhance the scope and reach of participants that researchers could not feasibly engage with prior to the pandemic
- An opportunity to engage with policymakers and advocate for priority populations, during a time in which diverse actors were willing to listen and make changes

Community-engaged research ethical principles during health crises

Overview

This set of principles builds on previously identified and distilled principles from a broad base of literature including community-led research ethics documents (e.g., Research 101: A Manifesto for Doing Research in the Downtown Eastside [Boilevin et. al, 2019]), Indigenous-led resources (e.g., Ethics in First Nations Research [Assembly of First Nations, 2009]), and a range of academic journal articles and literature reviews across disciplines, including research from the COVID-19 pandemic. The initial set was developed by Dr. Kari Grain with SFU CERi and in this current version, has been adapted to fit the context of health crises in collaboration with the Pacific Institute on Pathogens, Pandemics, and Society (PIPPS).

#1 Community participation during crises:

CER projects aim for high levels of community participation in various phases of research, including the identification of a research question, data collection, analysis, and knowledge mobilization. Community partners should be involved in leadership and collaboration to the extent that they desire, recognizing that during health crises, their capacity to engage may be hindered.

Tips and considerations:

Approach community partners as intellectual partners

In CER, Isler and Corbie-Smith (2012) note that “communities are not only research partners, but the originators of the intellectual research property

and as such should be recognized as co-leaders of the research processes through which their questions are answered” (p. 904). Additionally, it is important to learn about and embrace community assets identified by CSOs. During health crises, CSOs can provide important insights into supports available to community members and their needs.

Begin with a project that is community-driven

The priorities of the participating community must drive the choice of the study topic and its focus, which may be centred on meeting immediate needs in crises (Khodyakov et al., 2016, p.54).

Build a study design that integrates consistent attention to CSOs' capacity to engage as equal partners at every step

To ensure community partners feel supported and honoured in the partnership, embed regular check-ins throughout the entire process. (Edwards et al., 2020). Check-ins also provide an opportunity to connect about psychological safety amid the crisis.

#2 Community benefit:

CER projects should be oriented toward a primary goal of achieving community benefit, particularly during health crises.

Tips and considerations:

Aim for mutual benefit among all members of the research team

Research typically benefits university researchers through career advancement, a sense of fulfillment, and transformative learning. Less clear, at times, are the benefits that community members can or ought to receive. CER is designed with the foremost goal of benefitting community and valuing community collaborators' social capital (Boilevin et al., 2019; VanAuken, 2019). In health crises, mutual benefit must be prioritized at the outset of the partnership and revisited as the project progresses.

When CER projects engage with Indigenous communities, hold space for transparent conversations about how the research benefits will enhance the right of self-determination

"The right of self-determination of First Nations includes the jurisdiction and authority to make decisions about research in their communities. The benefits to the communities, to each region and to the national effort should be strengthened by the research. Research should facilitate First Nations communities in learning more about the health and well-being of their peoples, taking control and management of their health information and assist in the promotion of healthy lifestyles, practices and effective program planning" (FNIGC, 2011, p. 3).

Prioritize beneficence

CER should have demonstrable benefits to the community involved in research, especially priority populations experiencing inequities exacerbated by crises. The Belmont Report suggests that "beneficence" as a core ethical principle aims to maximize the benefits to those involved in research and diminish or eliminate the risks. "Research activities must result in tangible benefits to the participating community; investigators should be ready to address individual participants' needs uncovered in the course of research" (Khodyakov et al., 2016, p.54), paying attention to unique health and social risks and marginalization arising from crises.

#3 Ethical standards during health crises:

During health crises, ethical standards are often overlooked, with many institutions citing urgency as an excuse (Burgess et al., 2023). The COVID-19 pandemic, as well as other public health emergencies, highlighted complex ethical challenges, from research involvement to monitoring and surveillance (WHO, n.d.).

Tips and considerations

Research should be conducted only if it does not impede emergency response efforts

CSOs often engage directly with communities and provide critical services during health crises. As such, research should not be conducted if "it can be expected to take away personnel, equipment, facilities, and other resources from those required for outbreak response. In addition, resources allocated to research must not take away from routine health care and public health services" (WHO, 2021, p.2). The health and well-being of the entire research team take precedence during a crisis.

Address concerns related to research involvement

During public health crises, research participants are subject to heightened vulnerability, partially due to stigmatization and prejudice (Burgess et al., 2023). Some also fear the risk of infection, which may influence their ability to consent. Address these risks by asking

+ CER ethical principles

community partners their perceived and anticipated concerns; Assign additional importance and effort to the areas identified.

Be clear and consistent about boundaries

Academic researchers often become (or were already) friends and colleagues with community partners through CER projects. As in any relationship, it is vital to set explicit boundaries that simultaneously maintain trust with community members, and also address issues of power imbalances. It is the academic researcher's responsibility to ensure that community partners understand professional and relational boundaries. Additionally, the academic researcher should encourage community collaborators to discuss their own boundaries. Pay attention to how these boundaries are susceptible to being blurred during health crises, as people working remotely may have difficulties separating from work.

Ensure voluntary informed consent

The Belmont Report (1979) asserts that the consent process upholds "respect for persons" and protects autonomy. "Voluntary and informed consent" is also listed as one of the nine functions delineated in the United States federal regulations on the Human Subjects Protection Program (Ross et al., 2010).

Pay attention to informed consent considerations during health crises

In health crises, accessing consent materials may become challenging, and people might face additional barriers, such as language barriers for English-only documentation (Rothwell et al., 2021). Additionally, be mindful of the negative psychological and social impacts of the pandemic when assessing the capacity to provide voluntary informed consent (Newman et al., 2021).

#4 Power examination & active redistribution – recognizing your place in health crises:

Key to CER is the research team's attention to issues of power, privilege, and positionality, which may be heightened amid health crises. In addition to an examination of power, a CER team has the responsibility to commit to action that aims to redistribute unequal power.

Tips and considerations:

Examine researcher positionality before entering the partnership and throughout the project

University researchers should engage in ongoing critical reflection regarding their identity, biases, assumptions, and associated implications. CER requires that the researcher examines their own attitude and considers how power plays a role in the research processes, particularly as they approach CSOs as research partners during health crises (Wilson, Kenney & Dickson-Swift, 2018).

Consider the populations experiencing health and social inequities exacerbated by health crises

CER often takes up the goal of generating or enhancing empowerment for systematically marginalized individuals including refugees, rural populations, Indigenous people, and people with low income (Bacon et al., 2013; Boilevin, 2018; Chou & Frazier, 2019; Stoecker, 2012). During health crises, it may be important to broaden inclusion criteria and centre low-barrier methods of engagement to hear from diverse voices (McMaster University, n.d.).

Be accountable to your community partner

Practice and commit to accountability throughout the research process. This may involve informal engagement evaluations, whereby community partners have the opportunity to reflect on the partnership and raise any modifications required to enhance inclusivity (PCORI, 2021). Through engagement evaluations, partners also

have the opportunity to check in concerning their level of commitment and how this is influenced by the evolving nature of the crisis.

Take action in the redistribution of power

The redistribution of power involves “collaborative insider-professional researcher knowledge generation and application processes in projects of social change that aim to increase fairness, wellness, and self-determination” (Greenwood & Levin, 2003, p. 145). Aim to create safety among the entire research team, particularly in challenging times like health crises, so conflicts can be addressed in a respectful manner.

#5 Anonymity, confidentiality & privacy considerations of remote research:

CER projects prioritize the safety of the community identities and any sensitive data that they may share. New considerations have emerged with the proliferation of digital communication tools. Attention to anonymity, confidentiality and privacy in CER involve close collaboration with the community to understand and enact both institutional and community systems of protection, while also recognizing that individuals have the right to be identified if they choose to be through informed consent.

Tips and considerations:

Seek out and follow institutional (university-oriented) systems/procedures that are built to protect participants

Institutionally, there must be infrastructure in place to support confidentiality and privacy. These may be adapted to fit the context of public health crises. Ross and colleagues suggest that in any CER situation, “there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data” (Ross et al., 2010, p. 34). In institutional settings, research ethics boards require a detailed plan outlining how you will protect the

privacy and confidentiality of your participants; Part of this plan usually entails keeping electronic data encrypted in a password-protected computer, and any hard copies in a locked and secure area. While these systems are built to protect participants, recognize the limitations of these procedures and policies.

Seek out and follow community-based systems that are built to protect community members

Community organizations often develop their own systems and strategies for ensuring the protection and privacy of community members who they serve. Academic researchers should align their plans to the community organization or local culture in which the research is taking place, noting unique considerations spurred by necessary public health measures.

Good information management

As exemplified by the COVID-19 pandemic, misinformation and disinformation can be spread widely. To mitigate these risks among your research team, it is the academic researcher’s responsibility to maintain good information management (Burgess et al., 2023). This involves organizing records, ensuring team members can access data, and using appropriate technology to store and protect resources.

Be aware of additional risks associated with online communication tools

Online communication tools, like Zoom, may pose additional privacy and security challenges for team members, such as blurred boundaries and accessibility issues (Beyond the Toolkit, n.d.). Communicate the risks associated with video and audio data collected and implement safeguards to maintain privacy (Newman et al., 2021). Enable participants to remain off-camera and use pseudo-names. Additionally, provide alternate means, such as telephone calls, to support communities with low digital literacy or limited access to the internet.

+ CER ethical principles

#6 Attention to changing contexts:

Attention to changing context is vital at all stages of CER projects. It is especially important during health crises, where international and local contexts, as well as public health measures, may evolve rapidly. Since CER happens in and with community, factors such as history, culture, language, current events, and geography comprise the context in which the study occurs and inevitably influence all aspects of the research, including design, recruitment, and knowledge mobilization.

Tips and considerations:

Closely monitor the changing contexts and guidelines. Stay up to date on the local context, including public health and preventative measures, the growing knowledge base, and refer to credible information sources (Wanat et al., 2022). Keep a record of the changing contexts by sharing information and updates among the team.

Consider historical and social contexts

Review of contextual factors like historical background, cultural, socioeconomic and trust can help infer the partnership (Luger et al, 2020). This positions the academic researcher with a better understanding of the expectations, goals of engagement of the community partner, and the needs of the community.

Attend to the temporal location or “moment in time” in which research occurs

Current events, such as health crises, and temporal moments often have a tremendous impact on research. There is no more poignant example of this than the events of 2020 and the “double pandemic” arising out of COVID-19 and the enhanced attention on systemic anti-Black racism. Conducting CER during health crises means doing CER in a way that adapts to changing contexts and environments.

#7 Focus on relationships:

At the heart of CER is a focus on relationships – relationships between people, institutions, places, and knowledge. CER is an approach built on trusting and equitable relationships between researchers and communities.

Tips and considerations:

Emphasize relationship building over outputs

Focus on ways to build relationships with your community partners and how to support them during health crises. In CER, this should be prioritized over outputs to build authentic and meaningful partnerships (Duker, 2021).

Have plans to address conflict quickly and constructively

Relationships are bound to face moments of compromise, miscommunication, or even conflict. Acknowledge that these are likely to arise in challenging times, namely health crises. Regular meetings and transparent, honest communication can help to mitigate conflict. In the instance that conflicts arise, community-engaged researchers are encouraged to address them as soon as possible through open dialogue, mutual sharing, and an explicit plan for moving ahead.

Commit to adaptability

While project planning is vital to the success of a CER project, health crises may cause abrupt changes and delays. To foster trust and relationship building, be adaptable to meet shifting needs and priorities.

#8 Collaborative analysis and mobilization:

CER collaborations with the community do not stop once data has been collected. In fact, some of the most meaningful collaboration and fruitful insights happen at the stages of analysis (meaning-making) and dissemination (knowledge sharing). Analysis and dissemination should be carried out using frameworks and formats that make sense for the community.

Tips and considerations:

Discuss the capacity to engage in collaborative analysis

The First Nations Information Governance Centre (FNIGC) states that “as far as possible, fact-finding and analysis should be participatory, allowing communities to determine which aspects of health should be addressed and how” (2011, p. 4). Participants and/or community partners should have the opportunity to collaboratively make meaning of the data (Bacon et al., 2013; Grain et al., 2019; Kodyakov et al., 2016).

Actively facilitate collaborative analysis

Empower community partners through engaging discussions and interactive workshops to incorporate their insights in the analysis of data. When in-person analysis is not possible,

explore virtual tools to engage in collaborative analysis. If necessary, provide opportunities for team members to receive training on conducting analysis and explore ways to provide this training using low-barrier platforms.


Engage in collaborative decision-making on dissemination avenues and platforms

Discuss collaborative dissemination plans well in advance of data collection. Community partners should co-lead the plans for how the information will be shared, with whom it will be shared, and the platforms preferred by community members. Consider who will benefit the most from these findings amid the crisis context.




Tool #1: Participation continuum

Not all Community Engaged Research (CER) is created equal. Below is a continuum that illustrates ways a CER researcher can engage with community during health crises. It is intended to be adapted to fit the context, needs and capacity of your community partner.



	TRADITIONAL	CONSULTATION
Research, question, methods proposal and design	Researcher approaches CSO with research question and a research plan that includes methods of data collection. Open to community feedback but does not seek it.	Researcher approaches CSO with a general research question and plan and seeks advice/suggestions from community through consultations such as brief questionnaires shared with CSOs serving affected communities, ad-hoc meetings or focus groups with CSOs.
Ethics and consent procedures	Researcher only follows institutional ethics review board guidelines and ensures community informed consent.	Researcher prioritizes institutional ethics and informed consent procedures and also seeks/follows additional suggestions from community through virtual townhalls, meetings or online forums.
Recruitment, research and analysis	Researcher primarily leads recruitment and collection of data; Analyzes findings based on disciplinary or institutional standards/training.	Researcher leads plan for recruitment, carries out research with the team and analyzes data according to academic standards. Engages in member checks to confirm findings with the community.
Dissemination, sharing and mobilizing knowledge	Researcher makes a plan for knowledge mobilization and prioritizing academic publications, and shares that plan with community partners; Researcher makes recommendations to community and institutions based on findings.	Researcher checks with community for additional avenues and ideas of dissemination and knowledge sharing beyond papers and publications. CSO and researcher make/take up recommendations based on findings.

The continuum can be **adapted** to fit the context, needs and capacity of your community partner.



COLLABORATION	FULLY ENGAGED
<p>Researcher and CSO collaborate on development of a research question and mutually agreed-upon design/plan</p>	<p>Researcher and community enter a partnership and co-create a question for a research project/design; Community partners become co-leaders/co-researchers; Co-develop and MOU with roles and responsibilities, data ownership, and research plans; Formulate a plan that is reflexive and adaptive to changing contexts.</p>
<p>Researcher and community discuss shared ethics procedures and particular attention is paid to consent considerations during health crisis.</p>	<p>Community co-researchers set and share ethics and consent expectations of the local community with the university researcher/ research team. These are then integrated while implementing safeguards to ensure privacy and safety needs of participants. The primary researcher adopts measures to mitigate risks associated with participation.</p>
<p>Researcher and CSO partner for recruitment, and select community members get trained/ involved in research and analysis.</p>	<p>CSO collaborators/co-researchers participate in aspects of participant recruitment, conducting of the research, and analysis/ interpretation of data based on capacity, time commitment, and available resources; Active commitment to check-ins with community partner to understand needs and priorities throughout the project.</p>
<p>Early conversations lead to a shared plan for dissemination, sharing and future plans. Community partner leads local changes using data, and researcher advocated for changes using privilege and institutional connections.</p>	<p>At the onset, the entire team discusses plans for dissemination and knowledge sharing. CSO uses research, relationship with researcher and dissemination as avenues for desired change and to achieve goals; Equitable authorship on all outputs.</p>

+ Tool #2

Tool #2: Developing guiding values – facilitation guide

Guiding values must inform the work you do in collaboration with your community partner. During health crises, these may differ widely and thus, can influence how you work collectively. Developing guiding values will also help create safety among the research team (Beyond the Toolkit, n.d.). Existing guides about developing values primarily underscore contributions from the academic researcher’s perspective, with little input from community partners. To fill this gap, it is crucial to co-develop guiding values. This document serves as a facilitation guide to help you co-create guiding values with your community partner.

1. Define your shared vision, purpose, and goals for the project

- Consider the objective of the research project and your community partner’s mission and capacity within the health crisis context
- Have an open discussion about what motivated the research team to pursue this inquiry and the proposed benefit to the community, especially considering emergency response efforts
- Identify 2–3 goals you hope to achieve through this project

2. Schedule brainstorming session to develop guiding values

Schedule one hour to meet with your community partner. If possible, ensure the entire research team is available. To brainstorm guiding values, designate one member as the facilitator, who will encourage folks to contribute. Designate another member to track notes and ideas raised. Use low-barrier, virtual tools such as Google Jamboard, to aid the session. Ensure the research team is familiar with these tools in advance of the brainstorming session.

Provide adequate compensation/ honoraria to your community partner for their time (Grain, 2020).

Role of the facilitator

- Discuss clear objectives before the session
- Collaboratively set ground rules to help create a safe space for team members (includes reflecting on power dynamics within the team)



Guiding values must inform the work you do in collaboration with your community partner.

- Remind folks that the more ideas, the better
- Allow for different modes of participation to ensure equal contributions (e.g., chat features, calling in)
- Encourage members to build off each other's ideas
- Pose questions to the entire group, as opposed to individuals
- Keep the session on time and on track

Guiding questions

To facilitate the brainstorming session, the facilitator should pose the following questions to the team:

- What values should guide the work we do?
- Why are these values significant to the community organization and its members?
- How will these values inform our research collaboration?
- How will we check in with team members to protect our health and safety?
- How will we deal with conflicting viewpoints within the team?

Identify themes

At the end of the session, review the guiding values shared by team members. Then, group the values into common themes.

3. Document the guiding values

By the end of the meeting, ensure you have documented the guiding values in ways that work for the research team (e.g., in a shared online drive or any other encrypted platform).

4. Summarize what you heard

Once the guiding values have been documented, the academic researcher should summarize the themes identified and offer an opportunity for team members to share final inputs or insights (e.g., via email or a follow-up conversation).

5. Revisit the guiding values

The research team should revisit the guiding values on a routine basis, especially for long-term projects (i.e., 1 year +). This may involve reflecting on how these guiding values are shaping your work, relevance to the community within the crisis, and identifying any emerging areas to be addressed.

Tool #3: Terms of reference template

A terms of reference is a document used to define the purpose and structure of a project, including roles, responsibilities, timeframe, and objective. This template will help structure your research partnership and provide a form of accountability.

Project title:

Version no.

Project objective(s)

Briefly describe the objective(s) of the proposed research project.

Purpose:

This document serves as the guiding document for _____ project. The purpose(s) of the collaboration may include but are not limited to:

- **Providing feedback:** provide insights and feedback about the project
- **Advising:** project priorities, design, decision-making processes
- **Co-developing:** educational materials, research protocols, ethics
- **Sharing knowledge:** support knowledge dissemination and translation
- **Collaboration:** shared ownership of the research
- **Other:** _____ (e.g., participant recruitment, evaluation)

Activities

Use this section to capture the key activities involved in this collaboration.

Composition

Describe the makeup of the research team/ partnership and affiliations.

Term length

Insert the term length of the project (e.g., 1 year/ length of the project).

Anticipated time commitment

Based on discussions with your community partner(s), outline the anticipated time commitment per week or month. This may vary by member.

Methods of communication

Insert the team's preferred methods of communication.

This template will help structure your research partnership and provide **accountability**.

Team updates

How will updates be shared with the team?
Which platform(s) will be used to share updates?

Relevant resources

Clearly outline where members can access resources and knowledge sharing tools relevant to the research project (e.g., Dropbox, Google Drive).

Meetings

Outline the following:

- The mechanism used to schedule meetings (e.g., Doodle, Motion, Calendly)
- Proposed meeting dates and times
- Meeting platform (e.g., Zoom, phone)
- Notetaking: designated notetaker, when notes will be shared, where notes will be stored?

Ensure you have included alternatives for those who may not be able to attend in real-time. Is there an option to record meetings? How will agendas be co-created and shared with members?

Decision-making

Based on prior discussions, outline the process for decision-making.

Compensation

Include information about honoraria, compensation, and/or reimbursement. This should include compensation guidelines and the process for receiving compensation (e.g., e-transfer, cheques, and timeframe). Some indigenous peoples also are resistant to being tracked through financial payments.

Contact information

Insert the project's point-of-contact information.

Revision of terms of reference

Due to the evolving nature of health crises, this document will likely need to be revisited and revised. Outline the process and timeframe for revising the terms of reference.

Tool #4: Considerations for planning engagements with CSOs during health crises

Reflect on these considerations when planning engagements with CER amid health crises

- + **Identifying CSOs:** Tips for identifying community partners during health crises
- + **Identifying research priorities:** Guidance for conducting rapid needs assessments
- + **Communicating with CSOs:** Suggestions for communicating with CSOs
- + **Roles and responsibilities:** Considerations for mapping out roles and responsibilities
- + **Questions to consider:** Questions to consider prior to and during the CER project
- + **Knowledge mobilization:** Knowledge sharing guidelines and considerations

Identifying CSOs

During health crises, CSOs frequently receive requests for research collaborations, so consider the following questions before reaching out to potential community partners (Saleh et al., 2022):

- Why are you interested in engaging with this organization during this crisis?
- Is the research question timely and relevant to the community during this health crisis?
- How will the research benefit the CSO and community members amid the crisis?
- What resources do you anticipate needing from the CSO?
 - Does the organization have the resources required to undertake this research?
 - Have their resources been strained as a result of the crisis?

To identify potential community partners, you can employ a range of methods:

Lean into existing networks

If you (or a colleague) are already connected to a CSO, reach out to discuss potential research partnerships.

Identify community-engaged researchers within your institution

Look within your institution to identify researchers who have worked, or currently work with, community partners on research projects (Pasick et al., 2010).

Institutional partnerships

Does your institution have a community engagement office or institute? Does your institution already have partnerships with any local (or national) CSOs? Have any relationships been developed in response to the crisis? If so, reach out to these organizations to expand research opportunities.

Scan online directories of regional CSOs

Use online databases to identify established CSOs serving priority populations (Pasick et al., 2010). Larger directories will often highlight active CSOs, popular programs, and their public health responses during crises.

Attend events hosted by local CSOs (Scripps, n.d.)

During crises, many CSOs employ social media to maintain connections with the community. Use social media platforms to find and attend virtual events (e.g., webinars, roundtables, workshops) hosted by local CSOs.

Organize town hall forums

Arrange informal town hall-style gatherings (virtually or via phone) to hear from the community and grassroots organizations about emerging issues and their perspectives.

Identifying research priorities

To identify research priorities with CSOs, consider conducting a **needs assessment**; this involves investigating a research gap and exploring how the proposed project will contribute to filling the gap (Carleton University, n.d.). Needs assessments are used to gather information about social needs or issues among a priority population in order to decide which issues should be prioritized for action (Smart, 2019).

During health crises, needs assessments can be conducted rapidly, even with limited time, resources, and capacity. This requires reaching out to CSOs with the aim of understanding their immediate needs that can be supported by CER. Low-barrier and time-efficient assessment strategies include:

- Questionnaires disseminated to CSOs and their constituents via email or mail (Korteweg et al., 2010)
 - *Keep the number of questions to a minimum*
- Brief informational interviews with CSO staff (via virtual meeting platforms or phone calls)
- Virtual focus group discussions (Carleton University, n.d.)
- Online brainstorming tools/ discussion boards shared with local CSOs (e.g., Google Jamboard, MURAL) (Urban Institute, 2020)
- A rapid environmental scan of media outlets highlighting gaps and advocacy work during health crises

Communicating with CSOs

- At the outset, agree on key definitions and terms (Carleton University, n.d.). Avoid using jargon.
- Communication must flow freely throughout the entire project (Canadian Science Publishing, n.d.). Identify how communication channels will be maintained, allowing for remote connections.



+ Tool #4

- Explore the roles of **community mobilizers**: Members of the research team that can safely deploy technology to homes to be used for research and communication purposes, and provide training for technology as needed (Mitchell, 2021)
- Prioritize user-friendly platforms that the entire research team is already comfortable using. Consider platforms that CSOs may have pivoted to during the health crisis.
- Discuss potential barriers to using technology raised by your community partner (e.g., unfamiliar platforms, overuse of technology) (Adams et al., 2022).
- Provide updates in a timely manner (Carleton University, n.d.).
- Consider barriers that may impede communication, such as working conditions, digital connectivity, and caregiving responsibilities (Sayani et al., 2021). Have open discussions about how remote work may impede communication and be flexible in your solutions to these challenges.
- Determine which platforms are suitable based on the type of information being shared (Temple University, n.d.):
 - **Email**: for coordination and updates
 - **Online discussion boards** (e.g., MURAL, Miro, Google Jamboard): for gathering feedback and insights
 - **Telephone**: for brief conversations, questions, and check-ins
 - **Video conferencing tools** (e.g., Zoom): for lengthier, larger group discussions

Roles and responsibilities

When conceptualizing the project, discuss the roles and responsibilities of all members. While it is important to identify roles at the outset, be aware that responsibilities will likely change over time.

- Discuss time and capacity to dedicate to the project, acknowledging how the ongoing health crises may hinder the anticipated level of commitment
 - Ask how each member wants to be involved and revisit this question throughout the project (UBC, 2017)
- Ensure informed consent to participate is an ongoing process, paying attention to how the evolving nature of the health crises can influence how people participate (Mahoney et al., 2021)
- Define roles and decision-making processes with your community partner (PCORI, 2021)
 - Co-create role descriptions with your community partner based on their expertise, priorities, and desired level of contributions (Scripps, n.d.)
- Identify a point of contact when questions or issues arise to maintain open and consistent communication channels, even when conducting remote/off-site research
- Develop timelines collaboratively (Johns Hopkins University, n.d.)
 - Ensure all team members are aware of anticipated project timelines (Scripps, n.d.)
 - Consider how the health crisis may cause unintended delays to the project (e.g., becoming familiar with remote data collection tools)



When **conceptualizing** the project, discuss the roles and responsibilities of all members.

Questions to consider

Consider these questions when planning research engagements with CSOs:

- **Risks:** Are there any anticipated risks associated with participating in this research, particularly during the ongoing health crisis? If so, what measures are available to mitigate these risks? (Mahoney et al., 2021)
- **Data:** How will team members access the data? Who owns the data? (Mahoney et al., 2021) Can secondary data be used, if primary data collection methods are not feasible during the crisis?
- **Time:** How much time can you commit to this project on a weekly or monthly basis? Have you considered how your time commitment may be impacted by the health crisis?
- **Level of commitment:** What is your anticipated level of commitment for this project? How does this overlap with other commitments? Will CSOs' involvement hinder their community-based, frontline work?
- **Safety:** How do all members of the research team ensure physical and psychological safety for everyone involved? How can you commit to ensuring this project will not put people at risk during the crisis?
- **Resources:** What resources do you currently have to conduct this research? What resources will you require throughout the crisis? Will conducting research remotely require additional costs?
- **Contexts:** What are the regional cultural, political and historical circumstances of the community, as well as current social and health considerations. How might these considerations impact community agreement?"

(Tool #8)

Knowledge mobilization

Knowledge mobilization activities should be determined at the beginning of the project and in collaboration with your community partner.

- Bringing findings back to priority populations
 - Co-create knowledge-sharing ideas, strategies, and plans (Chicago Beyond, 2019). Prioritize user-friendly and remote platforms to support knowledge mobilization activities.
 - Involve other CSOs and community members who may benefit from the findings.
 - Identify creative ways of sharing findings, such as media engagements, videos, webinars, zines, virtual art galleries, podcasts, and community events (Scripps, n.d.). Consider other multimedia formats to share findings in engaging and accessible ways.
 - Develop simple, easy-to-read summaries of findings (Carleton University, n.d.). Highlight the most pertinent and relevant findings to be shared amid the crisis.
 - Consider the language needs of the community members you are hoping to reach, including their literacy levels.

Tool #5: Data sharing agreement

This tool serves as a template for data sharing agreements between researchers and civil society organizations (CSOs) to support community-engaged research (CER) projects during health crises. The agreement should be revisited throughout the partnership.

Purpose of the agreement

State the purpose of the data sharing agreement, including the objectives, scope, and duration of the research project.

Considerations

- How is data defined for the purpose of this project?
- What types of data will be used for this project?
- What data sources will be used for this project?
- Will the data include any personally identifiable information?

Definitions of data for this project

Articulate any definitions of data (e.g., documentation, qualitative data, quantitative data) relevant to the project.

Classifications of data

Review standard definitions of data classifications and determine appropriate storage formats/ locations:

CLASS	TYPE OF DATA	STORAGE/ LOCATION
Highly sensitive	Any data that may subject participants to any risks to themselves, their employment status or incur legal liability (Imperva)	
Sensitive	Documents containing confidential data (e.g., identifiers, raw data, audio recordings) (Imperva)	
Confidential	Potentially identifiable information (e.g., drafted proposals, human resources information) (University of Toronto)	
Internal	Data intended for internal/ partnership use only (e.g., emails, project work plans) (StrongDM)	
Unrestricted	Freely and publicly available information (e.g., conference abstracts, public communications)	

The data sharing agreement should be **revisited** throughout the partnership.

Data ownership

Strive to balance data openness and transparency with the need to protect privacy and confidentiality. Consider the benefits and feasibility of shared ownership of data throughout the research process. Review institutional requirements for data ownership, research ethics approval, and the data security and storage protocols of the community partner involved in the research. Pay attention to how these may be altered to fit the context of the health crisis.

Considerations

- Where will this data sharing agreement be stored?
- What are the data ownership and storing requirements for the institutional research ethics board and/or funder(s)?
- Have these been adapted to fit the context of the health crisis?
- How will the team become familiarized with the requirements and ensure compliance?
- What are the data security and storage protocols of the CSO?
- How will the team become familiarized with these protocols?
- How can we facilitate partial or fully shared ownership of the data?
- Are there any barriers to shared ownership imposed by the ongoing health crisis?
- Are there specific roles and responsibilities of those who own the data?

Access to data

Outline who has access to the data and the process for requesting access. Consider how data access will be ensured, especially if the team is conducting research remotely.

Considerations

- Are there any barriers to data access among the team imposed by the ongoing health crisis?
 - If so, what are the alternative channels or remote access solutions required to enable access?
- Who will coordinate access to the data?
- Can we enable data sharing and access among all members?
 - If not, what is the process for requesting access to data?
- What is a reasonable timeframe for data sharing among the team?
- If necessary, how will de-identified data be made available to the wider community or other organizations that may benefit from the data during the crisis?

Data storage

Identify where data will be stored. Justify the format of data storage, considering any risks or benefits associated with storing data while conducting research remotely/off-site. Prioritize storage sites that are approved by both the institution and CSO, enabling equitable access during health crises.

+ Tool #5

Considerations

- Where will data be stored (e.g., cloud-based platforms, secure servers)?
- Where will data be backed up?
- Where will documentation and metadata be stored?
- How can we protect data on the identified platform/ facility?
 - If the platform is password protected or encrypted, how will members gain access to this?
- Is the data storage platform accessible for all members of the research team, taking into account technological capabilities?
- Does the data storage platform allow for easy and protected access for research team members when conducting research remotely/ off-site?
- How will data breaches be reported?

Duration of data storage

Specify how long data will be stored. Justify the duration of the data storage based on potential future use, ethical guidelines, and legal obligations for your institution and the partner organization.

Considerations

- How long will the data be stored?
 - Why will the data be stored for this duration?
 - Does this storage duration account for delays imposed by the ongoing health crisis?
- What happens to the data upon termination of the agreement?
- How will data be archived and/or disposed of?

Duration of agreement

Specify the duration of this specific data sharing agreement. Note whether the agreement will be revised and, if applicable, the process for revising the agreement. Be flexible when revising, given the evolving nature of the health crisis.

Considerations

- How long will this agreement stand for?
- Will this agreement need to be revised or amended to accommodate the evolving nature of the context?
 - If so, what is the process for revising the agreement?

Data safeguards and security

Discuss data sources that may be deemed confidential and identify measures to protect confidential data, particularly any health-related data/information. Highlight specific measures to ensure the protection of data while conducting research remotely/ off-site. Consider how the transfer of data will be handled.

Considerations

- Will the data be anonymized?
 - If so, how will the data be anonymized?
- If necessary, what measures will be taken to de-identify the data?
- How will participants' privacy and confidential data be protected, particularly during health crises?
- How will sensitive data be handled?
- If necessary, how will data be transferred in ways that prevent unauthorized access or breaches?

Quality assurance

Implement procedures to ensure data quality assurance throughout the project.

Considerations

- Who will be involved in regular data checks?
- What is the process for validating and determining the accuracy of data?
 - How will this occur during remote engagements?
- Prior to analysis, what are the data cleaning protocols?

Considerations

- What is the process for sharing drafts among the research team?
 - How will drafts be shared?
 - How will feedback be solicited and received?
 - What is a reasonable timeframe for feedback, considering delays or disruptors associated with the ongoing health crisis?
- How can we implement open data-sharing principles, especially for findings that may support health crises planning, preparedness, and/or response?

Knowledge mobilization – Data considerations

Outline how data will be used and shared in knowledge mobilization initiatives, such as reports, lay-language briefs, and community-based events.



Tool #6: Authorship guidelines considerations

This tool provides considerations for authorship guidelines for external outputs, primarily peer-reviewed journals, from community-engaged research (CER) projects with civil society organizations (CSOs) during health crises.

Inclusion

Most often, authorship will align with contributions to the research project. In CER projects conducted amid health crises, contributions may vary widely throughout the entire research process. As such, contributions might not be solely based on the extent of the write-up, but should also consider lived experience and expertise shared by team members.

Standard academic definitions of contributions do not fully acknowledge collaborations with community. Furthermore, reviewers of peer-reviewed journals might not be familiar with the principles of community-engaged research.

Community-engaged research can occur along a continuum, especially during health crises. Consider the following criteria as a starting point for discussions about authorship:

- Contributions made to the research question of interest, study design and methods, or data collection, analysis, or interpretation of the data reported on
- Contributions to the draft or revisions of the output, considering expertise, insights, and feedback shared by team members

- Providing final approval of the version to be published
- Consenting to be accountable for the final output, ensuring that questions about the accuracy or integrity of any part of the work are appropriately examined and resolved.

Be mindful of journals that place limits on the number of authors on a paper. When possible, opt for journals that do not place such limits to ensure equitable inclusion of the research team.

Often, the intangible contributions and unconventional forms of expertise that community members/leaders possess, are not adequately acknowledged in the publication process. CER aims to uphold community expertise as valid knowledge, and therefore, even if a community contributor did not contribute to “writing” the piece, they may be equal contributors in terms of its development, the stories/examples involved, and/or the analysis of the problems/solutions that are elucidated through the research. Ensure that community contributors are acknowledged as co-authors in ways that align with early and frequent conversations with the authorship team.

Authorship order

At the outset of the project, come to consensus on authorship order and the nature of contributions. Note that authorship could look different depending on the paper or output. Team members must be involved in decisions about co-authorship. Discuss the following questions to determine authorship order:

- How has each team member contributed to the research?
- Who is leading, or primarily responsible for the publication?
- How will team members revise versions of the manuscript?
- Will the attributed authors have the time and capacity to respond to comments raised by editors and reviewers?

Typically, the primary author, making the largest contribution, will be listed first (as the first author). All other authors will be listed in descending order of contribution. If all other authors have contributed equally, after the first author, they will be listed in alphabetical order by last name.

Strive to implement an equitable publishing protocol. Support team members who may be marginalized by organizational hierarchy, gender, ill health, disability, occupational position, educational background and other relative positions of disadvantage, to achieve the position of first author on papers. Consider the impact of the ongoing health crisis on contributions.

Listing contributions

Where possible, individuals' contributions to the project/partnership should be described in the output.

Some journals may call for a **community involvement statement**, to understand how the community was engaged (Canadian Science Publishing, n.d.; Bordeaux et al., 2007):

- Why was a community-engaged research approach selected?
- How was a community-engaged approach undertaken during the health crisis?

- How was the community involved?
- In what stages was the community involved?
- How does the project benefit the community?
- How were findings communicated back to the community?

Drafts of manuscripts

All members of the research team must have ample opportunity to review and revise the drafted output before submission and/or dissemination. Be considerate of flexible timelines as the health crises may impede members' ability to review material. In addition, allow for co-ownership in all publications and outputs.

Acknowledgements

People who contribute to the project but do not qualify as authors (e.g., reviewers), based on the established criteria, should be acknowledged. Permission must be obtained from people who are acknowledged.

CER guiding principles

When determining authorship, prioritize the guiding principles of CER (Cheung et al., 2020; Mahoney et al., 2021):

- **Equity:** Have all contributors been appropriately attributed?
- **Fairness:** Have you provided opportunities to discuss inclusion, authorship order, drafts, and acknowledgements?
- **Accountability:** Do all partners have time and resources to commit to the outputs?
- **Respect:** How have discussions about inclusion, authorship order, drafts, and acknowledgements centred respect?
- **Community benefit:** How will you facilitate access to the output for community members?

Tool #7: Community research agreement

This tool provides a template for community research agreements during health crises, to be used in conjunction with the terms of reference (**Tool #3**). Decisions should be made in collaboration with the researcher and community partners.

Project title

1. Research question(s) of interest

State the research question(s) of interest relevant to this project.

2. Purpose and scope

Identify the purpose and scope of this project, including how the project was initiated, why the project emerged during the health crises, and the relevance to the community partner and members affected by the problem of interest.

3. Project goals

Outline the goals of the project, including any that may be pertinent to the ongoing health crisis.

4. Anticipated outcomes

Identify anticipated outcomes of the project, aligning with the goals and purpose of the project. Consider outcomes relevant to the ongoing crisis situation.

5. Roles of the academic researcher(s)

Highlight the roles of the academic researcher(s) in this project, acknowledging that they may change over the

course of the project and be influenced by the evolving nature of the crisis.

6. Roles of the community partner

Highlight the roles of the community partner in this project, acknowledging that they may change over the course of the project and be influenced by the evolving nature of the crisis.

7. Selected research methods

Provide an overview of the research methods (e.g., data collection, analysis), why they were selected, and how they will be conducted remotely/off-site.

8. Training required by members of the research team

Note if any training is required by members of the team (e.g., qualitative analysis, virtual tools/platforms, cultural sensitivity). Identify who will provide the training and the timeframe for training.

9. Anticipated benefits for community partners

Identify the anticipated benefits for community members involved in the research, including any foreseeable benefits amid the health crisis. Consider how the broader community may benefit from this research project.

Decisions should be made in **collaboration** with the researcher and community partners.

10. Foreseeable risks for community partners

Identify foreseeable risks for community members involved in the research, including any anticipated amid the health crisis. Outline how you will address perceived risks from community partners.

11. Mitigating risks to participation

Specify how identified risks will be mitigated by the research team.

12. Funding sources (if applicable)

Denote any sources of funding for this project. Attach a project budget including transparent information on how funds will be used by academic and community partners and who will be responsible for managing which portions of the budget.

13. Criteria imposed by funding agency/agencies (if applicable)

Provide an overview of the criteria set by any funding agencies (e.g., use of funds, end-of-project reports).

14. Project stakeholders

Identify stakeholders who may benefit from the results of this research, particularly those engaged in health crisis planning, preparedness, and/or response.

15. Communicating project updates/progress to community members, other CSOs, and media

Consider how relevant updates about the project will be shared with community members and other CSOs, thinking about dissemination methods and platforms relevant to these stakeholders.

If relevant, discuss who will respond to any external communication requests, such as media queries.

16. Mobilizing final outputs to community members and other CSOs

Note preliminary ideas for mobilizing final outputs to community members and other CSOs, considering dissemination methods and platforms relevant to these parties.

17. Researcher's commitment to the community partner

Outline the researcher's commitment to the community partner throughout the project (e.g., time, outputs and knowledge sharing).

18. Community partner's commitment to the project

Outline the community partner's commitment to the project (e.g., time, outputs and knowledge sharing).

19. Circumstances resulting in the interruption of the research project

Identify any circumstances that may interrupt the project, acknowledging disruptions caused by the health crisis.

Signature (on behalf of CSO): _____

Date: _____

Signature (Researcher): _____

Date: _____

+ Further learning

Further learning

Podcasts

- SFU Vancity Office of Community Engagement - Working in Community – with Jackie Wong: <https://www.sfu.ca/vancity-office-community-engagement/below-the-radar-podcast/episodes/56-jackie-wong.html>
- Community Planning Toolkit - Podcasts – Community Engagement: <https://www.communityplanningtoolkit.org/community-engagement/podcasts>
- National Institute for Health and Care Research - Spotlight on Community Engagement and Involvement (CEI): Managing CEI in a Pandemic: <https://pod.fo/e/16cc7d>
- Marquette University - Community-Engaged Research and Teaching in Times of COVID: <https://www.marquette.edu/innovation/covid-conversations.php> (Episode 19)

Peer-reviewed articles

- Michener, L., Aguilar-Gaxiola, S., Alberti, P. M., Castañeda, M. J., Castrucci, B. C., Harrison, L. M., ... & Wallerstein, N. (2020). Engaging with communities—lessons (re) learned from COVID-19. *Preventing Chronic Disease*, 17.
- Donnelly, E. K., Toof, R., & Silka, L. (2021). Community based participatory research during the COVID-19 crisis: Lessons for partnership resiliency. *Journal of Higher Education Outreach and Engagement*, 25(3).

- Edwards, H. A., Monroe, D. Y., & Mullins, C. D. (2020). Six ways to foster community-engaged research during times of societal crises. *Journal of Comparative Effectiveness Research*, 9(16), 1101-1104.
- Du Mont, J., Lebel, N., Coelho, M., Friedman Burley, J., Kosa, S. D., & Macdonald, S. (2022). Advancing community-engaged research during the COVID-19 pandemic: Insights from a social network analysis of the trans-LINK Network. *Plos one*, 17(11), e0271397.

Toolkits

- Beyond the Toolkit: <https://www.beyondthetoolkit.com/>
- Scripps Translational Science Institute & Scripps Whittier Diabetes Institute – Toolbox for Conducting Community-Engaged Research: https://www.scripps.edu/_files/pdfs/science-medicine/translational-institute/community-engagement/training-and-tools/Community_Engaged_Research_Toolbox.pdf
- Temple University – Toolkit for Remote Inclusive Research: <https://sites.temple.edu/reachlabtemple/toolkit-for-remote-inclusive-research/>
- Urban Institute – Community Engagement during the COVID-19 Pandemic and Beyond: <https://www.urban.org/sites/default/files/publication/102820/community-engagement-during-the-covid-19-pandemic-and-beyond.pdf>

References

Abara, W., Wilson, S., Vena, J., Sanders, L., Bevington, T., Culley, J. M., ... & Svendsen, E. (2014). Engaging a chemical disaster community: Lessons from Graniteville. *International Journal of Environmental Research and Public Health*, 11(6), 5684-5697.

Access Alliance. (2012). *Community-based research toolkit: Resources and tools for doing research with community for social change*. https://accessalliance.ca/wp-content/uploads/2020/07/CBR_Toolkit_1_-Jan2012.pdf

Adams, C., Albert, P., Benson, T., Cordingley, A., Daniels, B., Fynn, N., ... & Strobel, N. (2022). The realities and expectations of community involvement in COVID-19 research: A Consumer Reference Group perspective. *Research Involvement and Engagement*, 8(1), 1-10.

Alberta First Nations Information Governance Centre. (n.d.). *Framework for a data sharing agreement*. https://www.afnigc.ca/main/includes/media/pdf/community%20resources/Data_Sharing_Agreement.pdf

Alberta SPOR Support Unit Patient Engagement Team. (n.d.). *Terms of reference template*. Alberta SPOR Support Unit. https://absporu.ca/wp-content/uploads/2020/05/AbSPORU-PE-Terms-of-Reference-TOR-Template_February-2023.pdf

Bacon, C.M., DeVuono-Powell, S. Frampton, M.L. LoPresti, T. Pannu, C. (2013). Empowered partnerships: Community-based participatory action research for environmental justice. *Environmental Justice*, 6(1): 1-8.

Baggetta, M., Fulton, B. R., & Caplan, Z. (2022). Space and interaction in civil society organizations: An exploratory study in a US city. *Social Inclusion*, 10(3), 307-318.

Banks, S., Armstrong, A., Carter, K., Graham, H., Hayward, P., Henry, A., ... Strachan, A. (2013). Everyday ethics in community-based participatory research. *Contemporary Social Science: Knowledge Mobilisation and the Social Sciences: Research Impact and Engagement*, 8(3), 263-277. doi:10.1080/21582041.2013.769618

Barwise, A. K., Egginton, J., Pacheco-Spann, L., Clift, K., Albertie, M., Johnson, M., ... & Allyse, M. (2022). Community engaged research to measure the impact of COVID-19 on vulnerable community member's well-being and health: A mixed methods approach. *Wiener klinische Wochenschrift*, 1-7.

Belmont Report (1979) *The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research*. <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html>

Beyond the Toolkit. (n.d.). *Ethical considerations*. <https://www.beyondthetoolkit.com/ethical-considerations>

Boilevin, L., Chapman, J., Deane, L., Doerksen, C., Fresz, G., Joe, D. J., ... & Pham, S. (2019). *Research 101: A manifesto for ethical research in the Downtown Eastside*.

+ References

- Bordeaux, B. C., Wiley, C., Tandon, S. D., Horowitz, C. R., Brown, P. B., & Bass, E. B. (2007). Guidelines for writing manuscripts about community-based participatory research for peer-reviewed journals. *Progress in Community Health Partnerships: Research, Education, and Action*, 1(3), 281.
- Burgess, T., Rennie, S., & Moodley, K. (2023). Key ethical issues encountered during COVID-19 research: A thematic analysis of perspectives from South African research ethics committees. *BMC Medical Ethics*, 24(1), 1
- Canadian Science Publications. (n.d.). *Community-engaged research*. <https://cdnsiencepub.com/authors-and-reviewers/community-engaged-research>
- Canadian Science Publications. (2022). Authorship practices for community-engaged research. <http://blog.cdnsiencepub.com/authorship-practices-for-community-engaged-research/>
- Carleton University. (n.d.). *Approaching projects and setting goals*. Centre for Studies on Poverty and Social Citizenship. <https://carleton.ca/cspsc/approaching-projects-and-setting-goals/#PPCommunications>
- Carleton University. (n.d.). *Initial research steps: Target audience*. Centre for Studies on Poverty and Social Citizenship. <https://carleton.ca/cspsc/initial-research-steps/#RNeeds>
- CDC. (2018). Public Health Emergency Preparedness and Response Capabilities: National Standards for State, Local, Tribal, and Territorial Public Health. <https://www.cdc.gov/orr/readiness/capabilities/index.htm>
- Charitable. (2020). *8 non-profit challenges in a post-Covid world*. <https://www.wpcharitable.com/8-non-profit-challenges-in-a-post-covid-world/>
- Cheung, M., Leung, P., Leung, C. A., Chan, T. S., & Zhou, S. (2021). How to determine the order of authorship for social work research. *Research on Social Work Practice*, 31(3), 227-233.
- Chou, T., & Frazier, S. L. (2019). Supporting ethical practice in community-engaged research with 4R: Respond, Record, Reflect, and Revise. *Ethics & Behavior*, 1-15
- Chicago Beyond. (2019). *Why am I always being researched? A guidebook for community organizations, researchers, and funders to help us get from insufficient understanding to more authentic truth*. <https://chicagobeyond.org/researchequity/>
- Civicus. (2020). *Solidarity in the time of COVID-19: Civil society responses to the pandemic*. <https://reliefweb.int/report/world/solidarity-time-covid-19-civil-society-responses-pandemic>
- Colizza, V., & Vespignani, A. (2010). The flu fighters. *Physics World*, 23(02), 26.
- Community engagement alliance. (n.d.). *Tips for inclusive community-engaged research*. <https://covid19community.nih.gov/sites/default/files/2023-06/CEAL%20IPWG-ENGLISH.pdf>
- Corbin, J. H., Oyene, U. E., Manoncourt, E., Onya, H., Kwamboka, M., Amuyunzu-Nyamongo, M., ... & Van den Broucke, S. (2021). A health promotion approach to emergency management: effective community engagement strategies from five cases. *Health Promotion International*, 36(Supplement_1), i24-i38.
- Dawson, A., Emanuel, E. J., Parker, M., Smith, M. J., & Voo, T. C. (2020). Key ethical concepts and their application to COVID-19 research. *Public Health Ethics*, 13(2), 127-132.
- Dayal, S. (2020). *The impact of COVID-19 on civil society*. Candid. <https://blog.candid.org/post/the-impact-of-covid-19-on-civil-society/>
- Dillard, D., Billie, M., Bell-Rogers, N., FNP-C, Wang, S. X., & Harrington, M. A. (2022). The Benefits of Community Engaged Research in Creating Place-Based Responses to COVID-19. *Delaware Journal of Public Health*, 8(3), 60-64. <https://doi.org/10.32481/djph.2022.08.011>

Donnelly, E. K., Toof, R., & Silka, L. (2021). Community Based Participatory Research during the COVID-19 Crisis: Lessons for Partnership Resiliency. *Journal of Higher Education Outreach and Engagement*, 25(3).

Du Mont, J., Lebel, N., Coelho, M., Friedman Burley, J., Kosa, S. D., & Macdonald, S. (2022). Advancing community-engaged research during the COVID-19 pandemic: Insights from a social network analysis of the trans-LINK Network. *Plos One*, 17(11), e0271397.

Edwards, H. A., Monroe, D. Y., & Mullins, C. D. (2020). Six ways to foster community-engaged research during times of societal crises. *Journal of Comparative Effectiveness Research*, 9(16), 1101-1104.

Evidence Synthesis Network. (n.d.). *COVID-19 outcomes for priority populations and settings*. <https://esnetwork.ca/briefings/covid-19-outcomes-for-priority-populations-and-settings/>

First Nations Centre. (2007). *Template for a collaborative research agreement*.

First Nations Information Governance Centre (2011). Best practice tools for OCAP compliant research. <https://fnigc.ca/ocap-training/>

Gonah, L. (2020). Key considerations for successful risk communication and community engagement (RCCE) programmes during COVID-19 pandemic and other public health emergencies. *Annals of Global Health*, 86(1).

Goemans, M., Levkoe, C. Z., Andrée, P., Changfoot, N., & Christopherson-Cote, C. (2018). Learning to "Walk the Talk": Reflexive evaluation in community-first engaged research. *Engaged Scholar Journal: Community-Engaged Research, Teaching, and Learning*, 4(2), 61-84.

Government of Canada. (2022). *Canada's policy for civil society partnerships for international assistance – A feminist approach*. https://www.international.gc.ca/world-monde/issues_development-enjeux_developpement/priorities-priorites/civil_policy-politique_civile.aspx?lang=eng

Grain, K.M., Katumba, T., Kirumira, D., Nakasiita, R., Nakayanga, S., Nankya, E., Nteza, V., & Ssegawa, M. (2019). Co-constructing knowledge in Uganda: Host community conceptions of service-learning relationships. *Journal of Experiential Education*, 42(1), 22-36

Grain, K. (2020). *Community engaged research ethical principles*. Community Engaged Research Initiative, Simon Fraser University. <https://www.sfu.ca/ceri/ethics.html>

Grain, K. (2020). *Why money matters in CER*. Community Engaged Research Initiative, Simon Fraser University.

Greenwood, D. J., & Levin, M. (2006). Introduction to action research: Social research for social change. *SAGE Publications*.

Han, HR., Xu, A., Mendez, K.J.W. et al. Exploring community engaged research experiences and preferences: a multi-level qualitative investigation. *Journal of Research Involvement Engagement* 7, 19 (2021). <https://doi.org/10.1186/s40900-021-00261-6>

Isler, M. R., & Corbie-Smith, G. (2012). Practical steps to community engaged research: From inputs to outcomes. *The Journal of Law, Medicine & Ethics*, 40(4), 904-914.

Ismail, S. J., Tunis, M. C., Zhao, L., & Quach, C. (2021). Navigating inequities: A roadmap out of the pandemic. *BMJ Global Health*, 6(1), e004087.

Jackson, S. F., Morgan, G. T., Gloger, A., Luca, S., Cerda, E., & Poland, B. (2023). Relationships are everything: The underpinnings of grassroots community action in the COVID-19 pandemic in Toronto. *Cities*, 134, 104163.

Johns Hopkins University. (n.d.). *Baltimore community engagement: Guiding principles*. <https://publichealth.jhu.edu/about/key-commitments/baltimore-community-engagement/guiding-principles-for-community-engagement>

+ References

- Kantamneni, A., Winkler, R. L., & Calvert, K. (2019). Incorporating community: Opportunities and challenges in community engaged research. *A Research Agenda for Environmental Management*, 64-78.
- Kanthor, J., Seligman, B., Dereje, T., & Tarantino, L. (2014). Engaging Civil Society in Health Finance and Governance: A guide for practitioners. *Health Finance & Government Project*, Abt Associates Inc. Bethesda, MD: USAID
- Karim, F., Ali A., Rajsekar, T., Nicholson, E., & Gravely, E. (2021). *A guide to inclusive and meaningful research with Hamilton newcomers*. McMaster University. <https://macsphere.mcmaster.ca/bitstream/11375/26491/1/McMaster%20Research%20Shop%20Report%20-%20HIPC%20%28Newcomer%20Research%20Guide%29.pdf>
- Khodyakov, D., Mikesell, L., Schraiber, R., Booth, M., Bromley, E. (2016). On using ethical principles of community-engaged research in translational science. *Translational Research*, 171, 52-62. <https://www.sciencedirect.com/science/article/abs/pii/S1931524415004508>
- Korteweg, H. A., van Bokhoven, I., Yzermans, C. J., & Grievink, L. (2010). Rapid health and needs assessments after disasters: A systematic review. *BMC Public Health*, 10(1), 1-12.
- Labonté, R., Mohindra, K., & Schrecker, T. (2011). The growing impact of globalization on health and public health practice. *Annual Review of Public Health*, 32, 263-283.
- Laverack, G., & Manoncourt, E. (2016). Key experiences of community engagement and social mobilization in the Ebola response. *Global Health Promotion*, 23(1), 79-82.
- Lee K. (2010). Civil society organizations and the functions of global health governance: What role within intergovernmental organizations? *Global Health Governance: The Scholarly Journal for the New Health Security Paradigm*, 3(2), http://blogs.shu.edu/ghg/files/2011/11/Lee_Civil-Society-Organizations-and-the-Functions-of-Global-Health-Governance_Spring-2010.pdf
- Luger, T. M., Hamilton, A. B., & True, G. (2020). Measuring community-engaged research contexts, processes, and outcomes: A mapping review. *The Milbank Quarterly*, 98(2), 493-553.
- Mahoney, T., Grain, K., Fraser, P., & Wong, J. (2021). *Community resource handbook*. Community-Engaged Research Initiative, Simon Fraser University. <https://www.sfu.ca/cei/resources/publications/community-resource-handbook.html>
- McMaster University. (n.d.). *McMaster University research agreement*. McMaster University's Indigenous Research Engagement.
- Michener, L., Aguilar-Gaxiola, S., Alberti, P. M., Castañeda, M. J., Castrucci, B. C., Harrison, L. M., ... & Wallerstein, N. (2020). Peer reviewed: engaging with communities—lessons (re) learned from COVID-19. *Preventing Chronic Disease*, 17.
- Miles, S., Renedo, A., & Marston, C. (2022). Reimagining authorship guidelines to promote equity in co-produced academic collaborations. *Global public health*, 17(10), 2547-2559.
- Minnesota Department of Health. (2015). *Community health services administration handbook*. <https://www.health.state.mn.us/communities/practice/resources/chsadmin/docs/CHSAdminHB.pdf>
- MIT. (n.d.). *Brainstorming guidelines*. MIT Human Resources. <https://hr.mit.edu/learning-topics/meetings/articles/brainstorming>
- Mitchell, R. (2021). *How to overcome the challenges of doing research during Covid-19*. Institute of Development Studies. <https://www.ids.ac.uk/opinions/how-to-overcome-the-challenges-of-doing-research-during-covid19/>
- Mulligan, M., & Nadarajah, Y. (2008). Working on the sustainability of local communities with a “community-engaged” research methodology. *Local Environment*, 13(2), 81-94.

Nelson, C., Lurie, N., Wasserman, J., & Zakowski, S. (2007). Conceptualizing and defining public health emergency preparedness. *American Journal of Public Health*, 97(Supplement_1), S9-S11.

Newman, P. A., Guta, A., & Black, T. (2021). Ethical considerations for qualitative research methods during the COVID-19 pandemic and other emergency situations: Navigating the virtual field. *International Journal of Qualitative Methods*, 20, 16094069211047823.

Nixon, N. (2020). *COVID-19 raises new hurdles for CSOs*. The Asia Foundation. <https://asiafoundation.org/2020/10/14/covid-19-raises-new-hurdles-for-csos/>

Pasick R, Oliva G, Goldstein E, Nguyen T. (2010). Community-Engaged Research with Community-Based Organizations: A Resource Manual for UCSF Researchers. From the Series: UCSF Clinical and Translational Science Institute (CTSI) Resource Manuals and Guides to Community-Engaged Research. Clinical Translational Science Institute Community Engagement Program, University of California San Francisco. <https://ctsi.ucsf.edu/our-work/ucsf-researchers>

Payán, D. D., Zawadzki, M. J., & Song, A. V. (2022). Advancing community-engaged research to promote health equity: Considerations to improve the field. *Perspectives in Public Health*, 142(3), 139-141.

PCORI. (2021). *Equity and inclusion guiding engagement principles*. PCORI's Advisory Panel on Patient Engagement. <https://www.pcori.org/sites/default/files/Equity-and-Inclusion-Guiding-Engagement-Principles.pdf>

Plunk, A. D., Carver, A., Minggia, C., Prasanna, K., Sheehan, B. E., Herman, M., ... & McQueen-Gibson, E. (2022). Virtual engagement of under-resourced communities: Lessons learned during the COVID-19 pandemic for creating crisis-resistant research infrastructure. *Journal of Clinical and Translational Science*, 6(1), e44.

Public Health Canada. (2018). *Pan-Canadian health inequalities reporting initiative*. Key health inequalities: National portrait executive summary. https://www.canada.ca/content/dam/phac-aspc/documents/services/publications/science-research/key-health-inequalities-canada-national-portrait-executive-summary/key_health_inequalities_full_report-eng.pdf

Public Health Ontario. (2015). Priority populations project: Understanding and identifying priority populations for public health in Ontario. Toronto, ON. <https://www.publichealthontario.ca/-/media/documents/P/2015/priority-populations-technical.pdf>

Public Health Ontario. (2022). *Response and recovery from public health emergencies: Assessment activities*. https://www.publichealthontario.ca/-/media/Documents/nCoV/focus-on-response-recovery-from-public-health-emergencies.pdf?rev=c0b93f64e65c40819d590100fbad8b80&sc_lang=en

Razavi, S. D., Noorulhuda, M., Velez, C. M., Kapiriri, L., Dreyse, B. A., Danis, M., ... & Williams, I. (2022). Priority setting for pandemic preparedness and response: A comparative analysis of COVID-19 pandemic plans in 12 countries in the Eastern Mediterranean Region. *Health Policy Open*, 100084.

Ringel, J. S., Chandra, A., Williams, M., Ricci, K. A., Felton, A., Adamson, D. M., ... & Huang, M. (2011). Enhancing public health emergency preparedness for special needs populations: A toolkit for state and local planning and response. *Rand Health Quarterly*, 1(3).

Ritter, S. M., & Mostert, N. M. (2018). How to facilitate a brainstorming session: The effect of idea generation techniques and of group brainstorm after individual brainstorm. *Creative Industries Journal*, 11(3), 263-277.

+ References

- Ross, L. F., Loup, A., Nelson, R. M., Botkin, J. R., Kost, R., Smith Jr, G. R., & Gehlert, S. (2010). Nine key functions for a human subjects protection program for community-engaged research: Points to consider. *Journal of Empirical Research on Human Research Ethics*, 5(1), 33-47.
- Rothwell, E., Brassil, D., Barton-Baxter, M., Brownley, K. A., Dickert, N. W., Ford, D. E., Kraft, S. A., McCormick, J. B., & Wilfond, B. S. (2021). Informed consent: Old and new challenges in the context of the COVID-19 pandemic. *Journal of Clinical and Translational Science*, 5(1), e105. <https://doi.org/10.1017/cts.2021.401>
- Saleh, A., Saelens, B., Hayes, M., Coker, T. R., & Health Equity Community Advisory Committee. (2022). Community partnership guide for engaging with academic researchers. *Progress in Community Health Partnerships: Research, Education, and Action*, 16(1), 129.
- Salma, J., & Giri, D. (2021). Engaging immigrant and racialized communities in community-based participatory research during the COVID-19 pandemic: Challenges and opportunities. *International Journal of Qualitative Methods*, 20. <https://journals.sagepub.com/doi/10.1177/16094069211036293>
- Sayani, A., Maybee, A., Manthorne, J., Nicholson, E., Bloch, G., Parsons, J. A., ... & Lofters, A. (2021). Building equitable patient partnerships during the COVID-19 pandemic: Challenges and key considerations for research and policy. *Healthcare Policy*, 17(1), 17.
- Scripps. (n.d.). *Toolbox for conducting community-engaged research*. https://www.scripps.edu/_files/pdfs/science-medicine/translational-institute/community-engagement/training-and-tools/Community_Engaged_Research_Toolbox.pdf
- Schwartz, J., & Evans, R. G. (2007). Causes of effective policy implementation: China's public health response to SARS. *Journal of Contemporary China*, 16(51), 195-213.
- Smart, J. (2019). *Needs assessment: Families and children expert panel practice resource*. Australian Institute of Family Studies. https://aifs.gov.au/sites/default/files/publication-documents/1902_expp_needs_assessment_0_0.pdf
- Smythe, S., Wilbur, A., & Hunter, E. (2021). Inventive pedagogies and social solidarity: The work of community-based adult educators during COVID-19 in British Columbia, Canada. *International Review of Education*, 67(1), 9-29.
- Sudbury and District Health Unit. (2016). *Priority population primer*. https://www.phsd.ca/wp-content/uploads/2016/05/Priority_Populations_Primer_ENG.pdf
- Suva, C., Liu, J., Sigurdson, E., Torio, J. E., & Benson, O. G. (2022). A case study of community-based, cross-sectoral crisis response to the COVID-19 pandemic: Serving racialized immigrant communities. *Global Social Welfare*, 9(3), 193-202.
- Tindana, P. O., De Vries, J., & Kamuya, D. (2020). Ethical challenges in community engagement practices in research during the COVID-19 pandemic in Africa. *AAS Open Research*, 3, 23.
- Trailhead Institute. (2012). *Data Sharing: Creating Agreements In support of community-academic partnerships*. http://trailhead.institute/wp-content/uploads/2017/04/tips_for_creating_data_sharing_agreements_for_partnerships.pdf
- UC Riverside (n.d.). *What is community-engaged research?* <https://healthycommunities.ucr.edu/what-community-engaged-research>
- UNICEF China. (2020). *The role of civil society organizations in preventing COVID-19 in Sierra Leone and China*. <https://www.unicef.cn/en/stories/role-civil-society-organizations-preventing-covid-19-sierra-leone-and-china>
- United Nations. (n.d.). *Civil society*. <https://www.un.org/en/civil-society/page/about-us>

University of British Columbia. (2017). Community engaged research practice: A resource for CTN members. <https://www.hivnet.ubc.ca/wp-content/uploads/2020/06/Community.engaged.resource.practice-2.pdf>

University of Kansas. (n.d.). *The community tool box*. Center for Community Health and Development. <https://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources/identify-community-assets/main>

Urban Institute. (2020). *Community engagement during the COVID-19 pandemic and beyond*. <https://www.urban.org/sites/default/files/publication/102820/community-engagement-during-the-covid-19-pandemic-and-beyond.pdf>

Wanat, M., Borek, A. J., Pilbeam, C., Anthierens, S., & Tonkin-Crine, S. (2022). Conducting rapid qualitative interview research during the COVID-19 pandemic—Reflections on methodological choices. *Frontiers in Sociology*, 7.

Wieland, M. L., Asiedu, G. B., Lantz, K., Abbenyi, A., Njeru, J. W., Osman, A., ... & Sia, I. G. (2021). Leveraging community engaged research partnerships for crisis and emergency risk communication to vulnerable populations in the COVID-19 pandemic. *Journal of Clinical and Translational Science*, 5(1), e6.

Wilson, E., Kenny, A., & Dickson-Swift, V. (2018). Ethical challenges in community-based participatory research: A scoping review. *Qualitative Health Research*, 28(2), 189-199

Wingate, M. S., Perry, E. C., Campbell, P. H., David, P., & Weist, E. M. (2007). Identifying and protecting vulnerable populations in public health emergencies: Addressing gaps in education and training. *Public Health Reports*, 122(3), 422-426.

World Health Organization. (n.d.). Ethics and COVID-19. <https://www.who.int/teams/health-ethics-governance/diseases/covid-19>

World Health Organization. (2021). Ethical standards for research during public health emergencies: Distilling existing guidance to support COVID-19 R&D. <https://apps.who.int/iris/bitstream/handle/10665/331507/WHO-RFH-20.1-eng.pdf?sequence=1&isAllowed=y>

World Health Organization. (2013). Evolution of a pandemic: A(H1N1) 2009, April 2009 – August 2010, 2nd ed. <https://apps.who.int/iris/handle/10665/78414>

World Health Organization. (2018). *Health inequities and their causes*. <https://www.who.int/news-room/facts-in-pictures/detail/health-inequities-and-their-causes#:~:text=Health%20inequities%20are%20systematic%20differences%20in%20health%20outcomes,%2C%20live%2C%20work%20and%20age>

World Health Organization. (2020). *Addressing vulnerability upfront*. [Infographic]. https://www.euro.who.int/__data/assets/pdf_file/0007/466108/Factsheet-October-2020-vulnerable-populations-COVID-19.pdf

World Health Organization. (2022). *Risk communication and community engagement (RCCE) for monkeypox outbreaks: Interim guidance*, 24 June 2022 (No. WHO/MPX/RCCE/2022.1).

World Health Organization. (2022). *Risk communication and community engagement (RCCE) for monkeypox outbreaks: interim guidance*, 30 June 2022. <https://www.ecdc.europa.eu/sites/default/files/documents/ECDC-WHO-Risk-communication-community-engagement-monkeypox-outbreak-Europe.pdf>

Yale School of Medicine (n.d.). *Benefits of community-engaged research*. <https://medicine.yale.edu/intmed/genmed/eric/cbprguidebook/principles/>



sfu.ca/ceri.html



PIPPS

Pacific Institute on Pathogens,
Pandemics and Society

pipps.ca



SIMON FRASER
UNIVERSITY

sfu.ca