Tools of Togetherness: Designing and Planning a Community-Engaged Research Project

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Diversity & Inclusion in Your Research Design Workshop
May 2, 2023

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Art by Emily Kewageshig

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Defining Community Engagement

A collaborative approach to research that equitably involves all partners in the research process, builds on their strengths, and focuses on a research topic of importance to the community. The aim is to combine knowledge and action for social change to improve community health and eliminate health disparities. [1,2]

1. Community Health Scholars Program. The Community Health Scholars Program: Stories of Impact. Ann Arbor, MI; 2002.

2. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. Annu Rev Public Health. 1998;19:173–202

Principles of Engagement

1. **Collaboration**: meaningfully and mutually working toward shared vision
2. **Respect**: recognizing the validity of diverse perspectives, cultures, priorities, and needs
3. **Equity**: sharing power, resources, and decision-making
4. **Transparency**: having clear, frequent, honest, and open communications
5. **Impact**: findings are sharing with partners and stakeholders in ways they can use them.

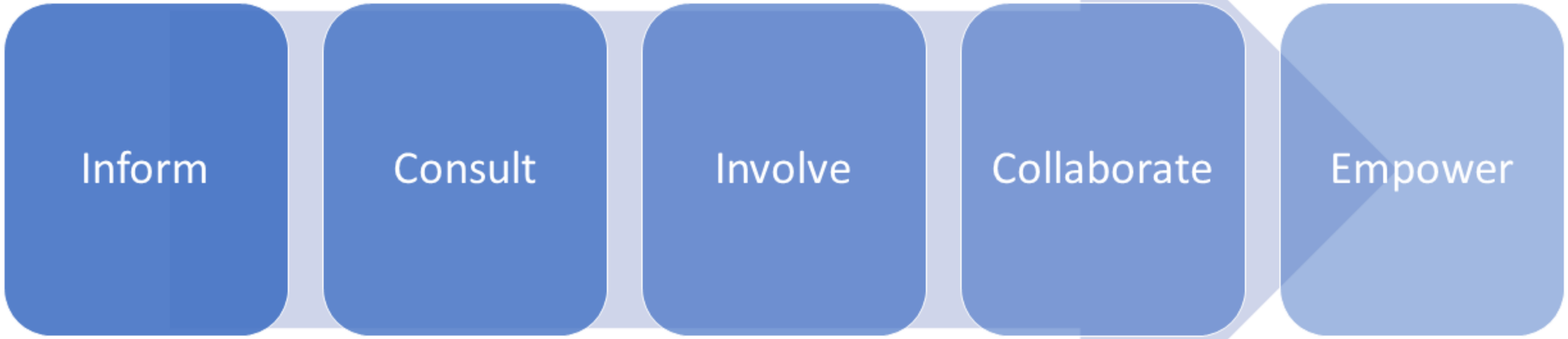
Characteristics of Engagement

1. **Trust**: build mutual respect and relationships.
2. **Common Interest**: determine the focus of interest for all parties.
3. **Perspective**: ensure both personal and professional points of view are included.
4. **History**: ensure patient and community partners are engaged in the process or formulation of research.
5. **Communication**: build trusting relationships and maintain them with or without active study involvement.

Kimminau K, Jernigan C, LeMaster J, et al. Patient vs. community engagement: Emerging issues. Medical Care, 2018; 56(10):S52-S57.

Spectrum of Engagement Framework

Increasing impact on decisions…



- To provide the community with relevant information
- To gather input from the community
- To work with community to ensure needs are integrated into the planning
- To partner in each aspect of decision-making
- To place decision-making in the hands of community

Adapted from the International Association of Public Participation Spectrum of Participation

Creating Meaningful Engagement

- Research participants are viewed as **experts** because of their lived experience.
- **Eliminating the power imbalances** between researchers and the community.
- **Equal value** is placed on experiential knowledge and academic knowledge.
- Commitment to producing **achievable data** to assist in building community capacity and improve the lives of research participants.
- **Remain invested** with the community beyond the life of the research project through engaging in knowledge mobilization activities.

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Engaging Patients & Communities as Equal Partners

Education and Support

- Recognition and compensation
- Shared decision-making

Environment

- Awareness of engagement opportunities and impact

Expectations

- Match between interest, skills and experience
- Clear role and responsibilities
- Time commitment

Value

- Co-learning experience
- Mutual beneficial

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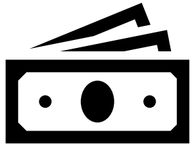
Practical Considerations for Planning a Community-Engaged Project

Staff



Money

Equipment & Tools

Partnership & Collaborations

Expertise

Risk

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Community Engagement Checklist

- [ ] **Engagement purpose**: Have you clearly defined the purpose of the engagement?

  This involves explaining the reason input or participation is necessary, i.e. what planning problem is the community helping to resolve or what decision does local government need to make? This process also involves defining the stakeholders affected and the decision-makers.

- [ ] **Engagement scope**: Have you clearly defined the scope of the engagement project?

  This involves explaining the decisions that need to be made, what the engagement process will focus on, and what you are seeking input on. This process also involves defining what is non-negotiable (i.e. what the community cannot influence) and what is negotiable (i.e. what the community can influence). At this point you could also reach out to internal engagement staff to confirm your approach, and determine if external engagement resources are required.

- [ ] **Engagement objectives**: Have you clearly defined the objectives that the engagement process will achieve?

  This involves explaining the objectives of your engagement process. Engagement objectives could relate to a range of potential outcomes, including:

  - [ ] building community capacity to understand planning and development issues
  - [ ] building stronger relationships with community and stakeholders
  - [ ] seeking innovative solutions for planning and development challenges
  - [ ] making better decisions about planning and development.

- [ ] **Context analysis**: Have you conducted analysis to understand the local, regional, state and national context that will affect the engagement process?

  This could involve exploring local demographic and economic characteristics, access to technology, level of understanding of planning issues, response to previous engagement processes.

- [ ] **Stakeholder and issues analysis**: Have you conducted analysis of the different stakeholders and community groups that could be interested in your process?

  This analysis could include identifying stakeholders and community groups, exploring what issues are of interest to them and how these individuals and groups might be affected, and what methods you will use to engage and build relationships with them.

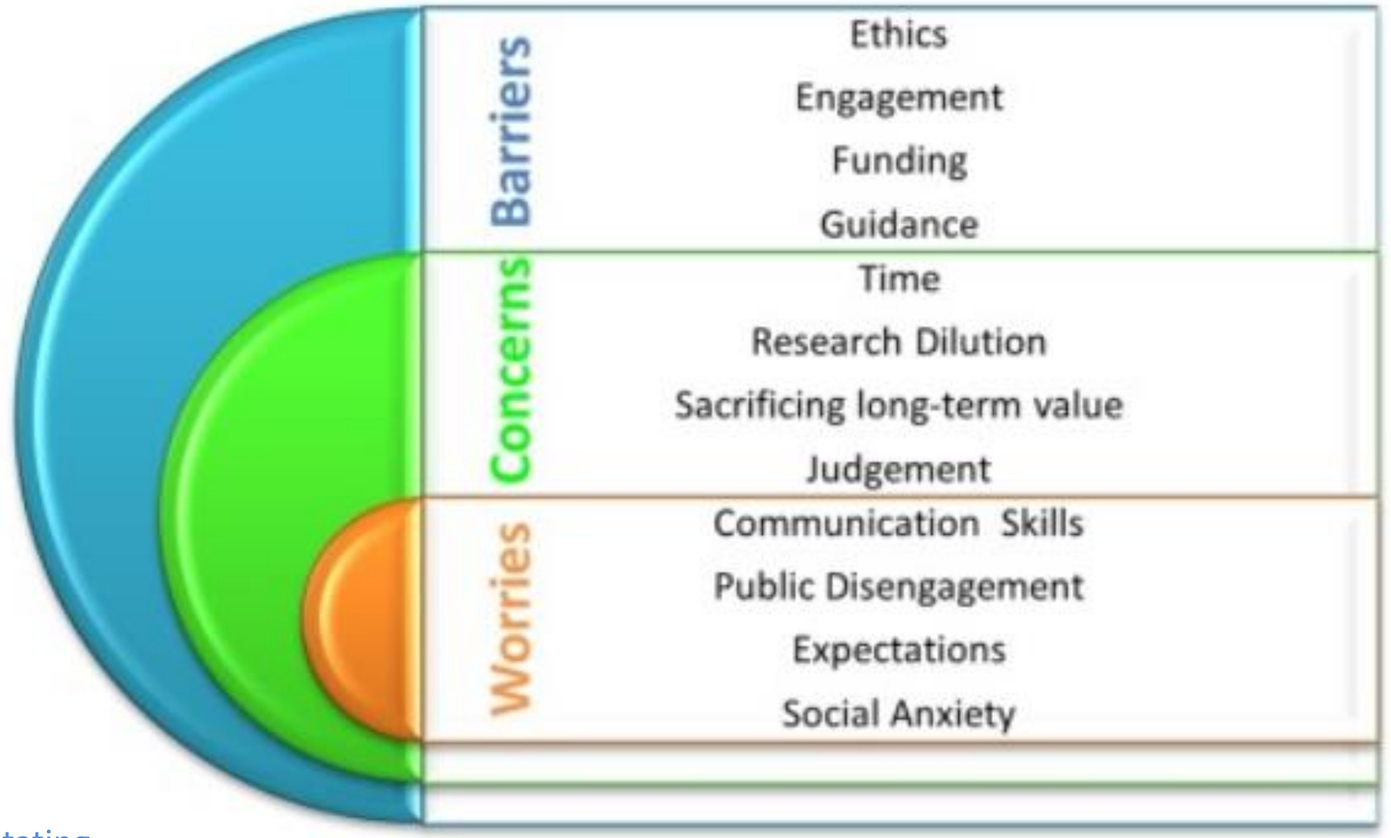
Queensland Government. 2017. Community engagement toolkit for planning

Best Practices for Community Engagement

1. Develop an ongoing relationship with community partners.
2. Examine and **remove barriers** based on abilities, age, gender, sexual orientation, and socioeconomic levels.
3. Examine the **impact of team language** and how words and terms like minority, underrepresented, vulnerable, marginalized, or similar terms may unintentionally reinforce notions of otherness, subsequently alienating partners.
4. Work collaboratively with community partners to set priorities.
5. Implement a trauma-informed approach to collecting data.

Unity Health Toronto. 2022. Resource Guide: Patient and Community Engagement in the Design and Implementation of Research Studies

Key Challenges for Engagement



Source: Macarthy et al. (2019). Facilitating public and patient involvement in basic and preclinical health research

Equity Engagement Framework

Step 2: Plan Collaboratively with Partners

Detailed Steps	Questions for Consideration
1. Map and prioritize potential partners	1. Who are the potential partners? How do they measure against the partnership prioritization criteria?
2. Convene partner(s) to discuss preliminary goals ▪ Relationships are important in this work and if this is the first time your organization is working with the partner, take time to meet and develop the relationship/understand their needs ▪ Present preliminary objectives and outcomes and solicit feedback on engagement purpose and identified population(s)	2. Do we have the right partnerships in place, or is there a need for new ones? Does the partnership opportunity help us to achieve the preliminary goals identified?
3. Refine goals based on feedback from potential partners ▪ Incorporate partner feedback to improve objectives and outcomes and demonstrate willingness to collaborate	3. How can we refine the preliminary goals to meet the needs of its partners and the community?
4. Reconvene with interested partners to define shared value ▪ Define shared goals ▪ Identify required resources, timelines and any potential early opportunities for direct engagement	4. What is our capacity to work with the interested partners? How do we want to work with them? What do they need from us? What is already going on within the partner organization that can be leveraged?

*At the end of this step your organization will have garnered **buy-in from partners** and a shared understanding of the engagement **purpose, objectives and outcomes.***

Cancer Care Ontario Equity in Engagement Framework

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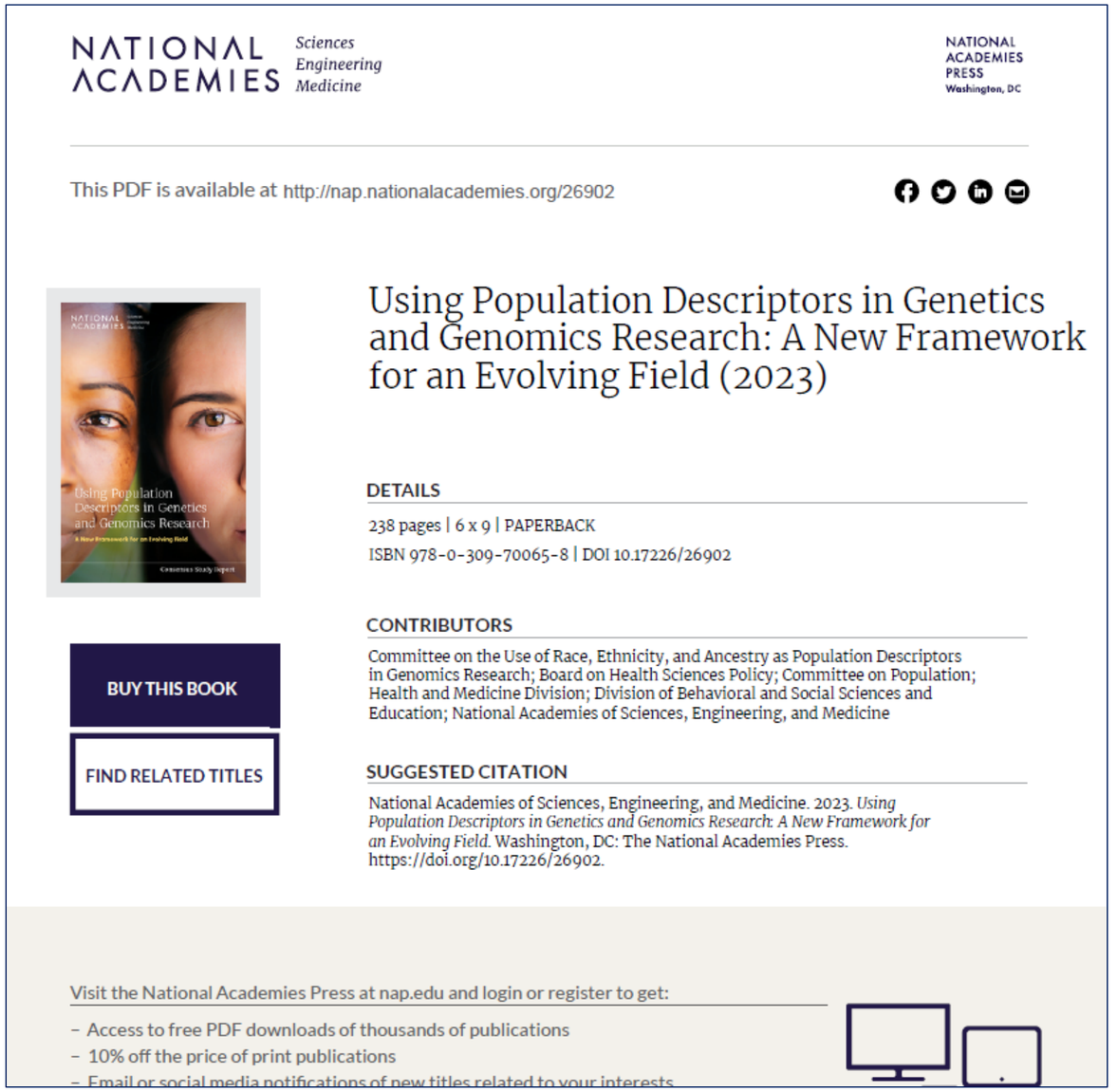
National Academies Report

"…the committee has prioritized addressing typological thinking, environmental factors, and **community engagement** in its proposed framework for transforming the use of population descriptors in genetics and genomics research. The committee trusts that this will accelerate the expansion of current efforts in these critical areas." (p.101)


NATIONAL ACADEMIES Sciences Engineering Medicine

NATIONAL ACADEMIES PRESS Washington, DC

This PDF is available at http://nap.nationalacademies.org/26902

Using Population Descriptors in Genetics and Genomics Research: A New Framework for an Evolving Field (2023)

DETAILS

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CONTRIBUTORS

Committee on the Use of Race, Ethnicity, and Ancestry as Population Descriptors in Genomics Research; Board on Health Sciences Policy; Committee on Population; Health and Medicine Division; Division of Behavioral and Social Sciences and Education; National Academies of Sciences, Engineering, and Medicine

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National Academies. (2023). [Using population descriptors and genomics research: A new framework for an evolving field]

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Community Engagement Conclusions & Recommendations in the Report

- Community engagement **recognizes the expertise of communities and relies on collaboration** between researchers and the communities they are trying to serve.
- Engaging participants in genomics research design **increases the likelihood that population labels will respectfully describe participants, reduce potential harms, and lead to more beneficial science** and translation to health and health care.
- Lack of transparency by researchers **threatens the trustworthiness of the entire research enterprise** and may undermine goals of equity and justice by disenfranchising minoritized groups from participating.
- Communities are dynamic and changing entities, therefore with each new study **it is important to consider how the community being asked to participate in research** could share in the selection of population descriptors.

- **Recommendation:** Researchers, especially those who collect new data or propose new courses of study for a data set, should work in ongoing partnerships with study participants and community experts to integrate the perspectives of the relevant communities and to inform the selection and use of population descriptors.

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Silent Genome Project

Aims of the project:

- To bridge the gap in healthcare access and improve diagnostic success for Indigenous children with genetic diseases.
- Create an Indigenous Background Variant Library from a diverse group of healthy 1,500 First Nations people as a start.
- Understand which genetic variations are common within a population critical to precision diagnosis
- Ruling out common variants that are less likely to cause disease
- Focus placed instead on rare variants
- Activities have included Indigenous community engagement, community education, and capacity-building, as well as developing standards for Indigenous oversight of the library and the biological samples from which it will be built.

For more information about the project: https://bcchr.ca/silent-genomes-project

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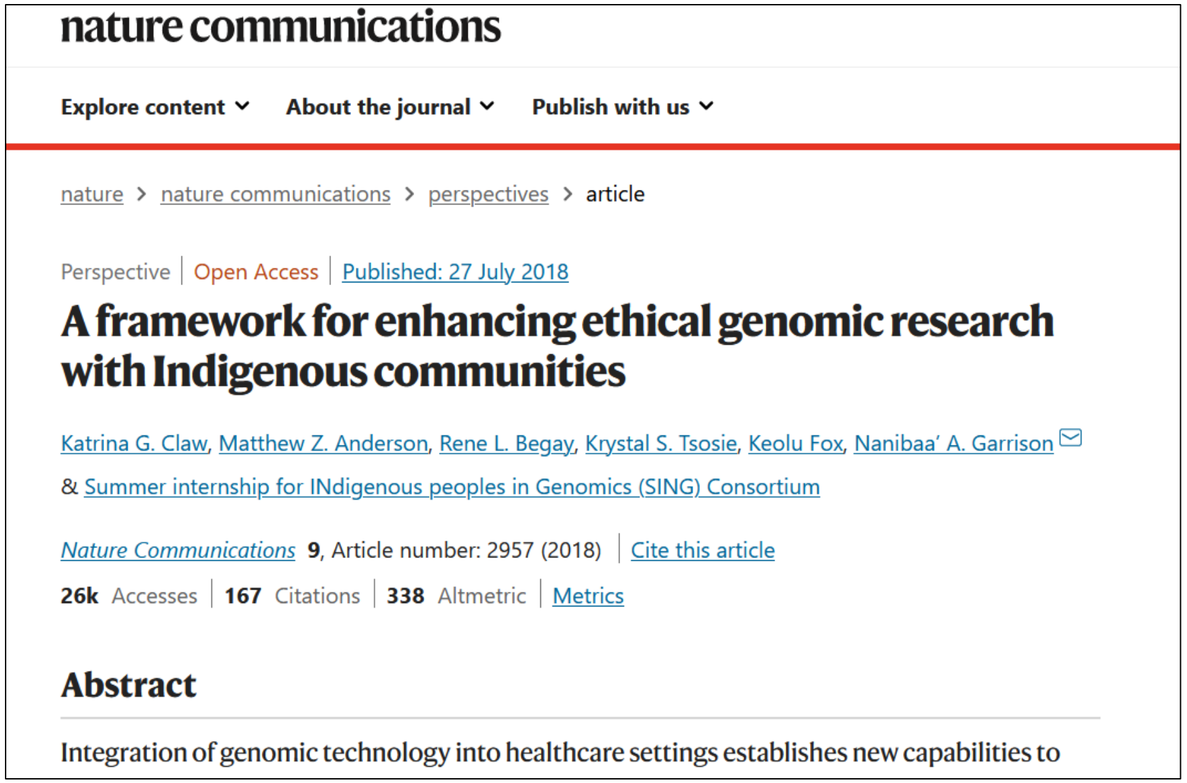
Silent Genome Project

"There is an unfortunate amount of **time pressure** that goes along with this project, but we knew we were trying to fit into something that is conventionally done differently than the way we do…We have to stick to our principles to the maximum degree because we have to ensure we're doing this in a way that's going to be sustainable. If we rush it and don't do it well, it's not going to work." [3]



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Perspective | Open Access | Published: 27 July 2018

A framework for enhancing ethical genomic research with Indigenous communities

Katrina G. Claw, Matthew Z. Anderson, Rene L. Begay, Krystal S. Tsosie, Keolu Fox, Nanibaa' A. Garrison ✉
& Summer internship for INdigenous peoples in Genomics (SING) Consortium

Nature Communications **9**, Article number: 2957 (2018) | Cite this article

26k Accesses | **167** Citations | **338** Altmetric | Metrics

Abstract

Integration of genomic technology into healthcare settings establishes new capabilities to

3. Paving the road to Indigenous genomic equity. Online.
Watch the film: Voicing the Silent Genome

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Evaluating Community Engagement

Evaluate the Process

The main evaluation questions for the process are:

- From both the perspective of the patients and the perspective of the planners:
  –What worked well about the process?
  –What didn't work well?
- What would you do differently next time?

Other questions that may be explored in a process evaluation include:

- Were recruitment strategies effective in recruiting participants from the population(s) of interest?
- Were patients satisfied with the process? Did they feel their voices were heard? Did they feel respected?
- Was the information provided by patients used in the planning process? Why or why not?
- What organizational characteristics supported or prevented the incorporation of patients' input into program planning?
- What characteristics of the program being (re)designed supported or prevented the incorporation of patients' input into the program?
- What characteristics of the patients (e.g., gender, age, language, socioeconomic status, etc.) were vital to address in the engagement process and how do the outputs reflect those characteristics?

Evaluate the Outcome

Evaluating the effects of patient engagement entails looking at the effect on the planning, and in turn, how that affected patient care and health outcomes. Standard evaluation methods (e.g., surveys, interviews, focus groups) can be used to address these questions. The main evaluation questions for the outcome are:

- In what ways is the program different than it would have been had patients not been engaged in the planning process?

Other questions that may be explored in an outcome evaluation include:

- What issues were raised by patients and how were they addressed in the program?
- Was the patient input used in any unanticipated ways?
- Does the new (or newly redesigned) service better meet the needs of marginalized patients?

Standard evaluation methods (e.g., surveys, interviews, focus groups) can be used to address these questions.

AWESOME Project. 2013. Patient Engagement Heard and Valued.

Community Engagement at the Edwin S.H. Leong Centre for Healthy Children

Initiatives include:

- Community Engagement Series, drop-in consultations, Trainee Hub, collaboration hub, and resources for community engaged research on the website.
- Fall 2023: funding to support the continuation and/or dissemination of community-engaged projects.
- Community advisory board in progress.

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Community Engagement Series

- Brings together researchers, trainees, and community members to discuss innovative community-engaged research projects and methods.

- Virtual 1-hour sessions focused on best practices for community engagement, and fosters opportunities for sharing community-engaged experiences and ideas.

2023

- Friday, April 21, 2023 | "Equitably Engaging Patient and Community Partners in Our Research: Where Do I Begin?" +
- Tuesday, March 28, 2023 | "Advancing Engagement Using Arts-Based Approaches" +

2022

- Thursday, October 20, 2022 | "Meaningful Community Engagement: An Introduction to Best Practices" +
- Friday, September 30, 2022 | "Let's Talk: Putting Community in Community-Engaged Research" +

See https://leongcentre.utoronto.ca/community-engagement-series

Community Engagement Consultative Service

Support for members in the planning and development of their community engagement and knowledge mobilization needs.

Support Available:

- Methodology support
- Consult on community engagement, health equity, and knowledge mobilization plans
- Advice on developing a knowledge mobilization plan
- Review of the community engagement and knowledge mobilization sections of grant proposals

See https://leongcentre.utoronto.ca/community-engagement-consulting-service

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Trainee Hub

- A **new** initiative for graduate students, post-doctoral research fellows, and clinical trainees who are interested in joining the Edwin S.H. Leong Centre for Healthy Children.
- Trainees will learn from community partners and researchers about the foundations, ethical dimensions, and planning for community-engaged research.

The Trainee Hub is moderated by Dr. Priscilla Medeiros, PhD
Knowledge Mobilization and Community Engagement Specialist, Edwin S.H. Leong Centre for Healthy Children, University of Toronto

Archived Sessions

Expand All

- Wednesday, March 29, 2023 | Trainee Hub Event: "Community-Based Research: Preparing Your Study for REB Submission" +
- Wednesday, February 15, 2023 | Trainee Hub Event: "Creating Equitable Spaces in Family Engagement in Research" +
- Wednesday, January 18, 2023 | Trainee Hub Event: "Community-Engaged Research and Learning" +

See https://leongcentre.utoronto.ca/trainee-hub

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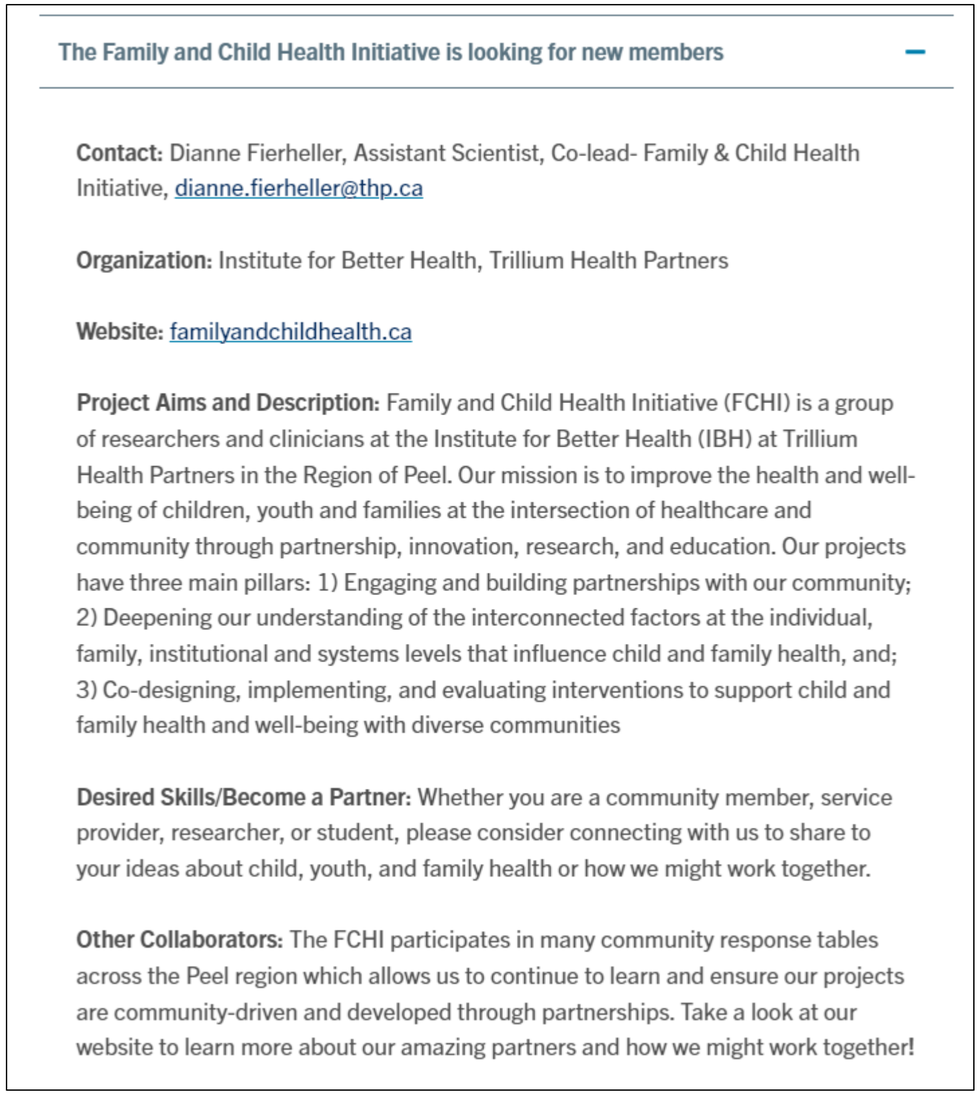
Collaboration Hub

- A service that connects researchers, trainees, and community members of the Edwin S.H. Leong Centre for Healthy Children.



The Family and Child Health Initiative is looking for new members −

Contact: Dianne Fierheller, Assistant Scientist, Co-lead- Family & Child Health Initiative, dianne.fierheller@thp.ca

Organization: Institute for Better Health, Trillium Health Partners

Website: familyandchildhealth.ca

Project Aims and Description: Family and Child Health Initiative (FCHI) is a group of researchers and clinicians at the Institute for Better Health (IBH) at Trillium Health Partners in the Region of Peel. Our mission is to improve the health and well-being of children, youth and families at the intersection of healthcare and community through partnership, innovation, research, and education. Our projects have three main pillars: 1) Engaging and building partnerships with our community; 2) Deepening our understanding of the interconnected factors at the individual, family, institutional and systems levels that influence child and family health, and; 3) Co-designing, implementing, and evaluating interventions to support child and family health and well-being with diverse communities

Desired Skills/Become a Partner: Whether you are a community member, service provider, researcher, or student, please consider connecting with us to share to your ideas about child, youth, and family health or how we might work together.

Other Collaborators: The FCHI participates in many community response tables across the Peel region which allows us to continue to learn and ensure our projects are community-driven and developed through partnerships. Take a look at our website to learn more about our amazing partners and how we might work together!

See https://leongcentre.utoronto.ca/collaboration-hub

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Resources for Community-Engaged Research

- Our online library is designed to be updated with current and new resources related to community engagement.

Resource Guide: Patient and Community Engagement in the Design and Implementation of Research Studies ›

This resource guide was developed by Unity Health Toronto's research community to support researchers in expanding their knowledge of patient and community engagement.

Youth-Led Research Toolkit ›

This toolkit includes guidance on best practices for implementing youth-led community-based research. It was created by Mercy Corps Haiti in collaboration with the Centre for Community Based Research and other partners.

Community Engagement Toolkits ›

This collection of 14 introductory toolkits provides guidance on the issues to consider when planning and designing community engagement. The Community Tool Box is a service of the Center for Community Health and Development at the University of Kansas.

Developing and Engaging in Community Partnership Research Resources ›

The Centre for Research & Innovation Support at the University of Toronto has developed a list of resources on its webpage for faculty, students, and community partners with respect to community engagement.

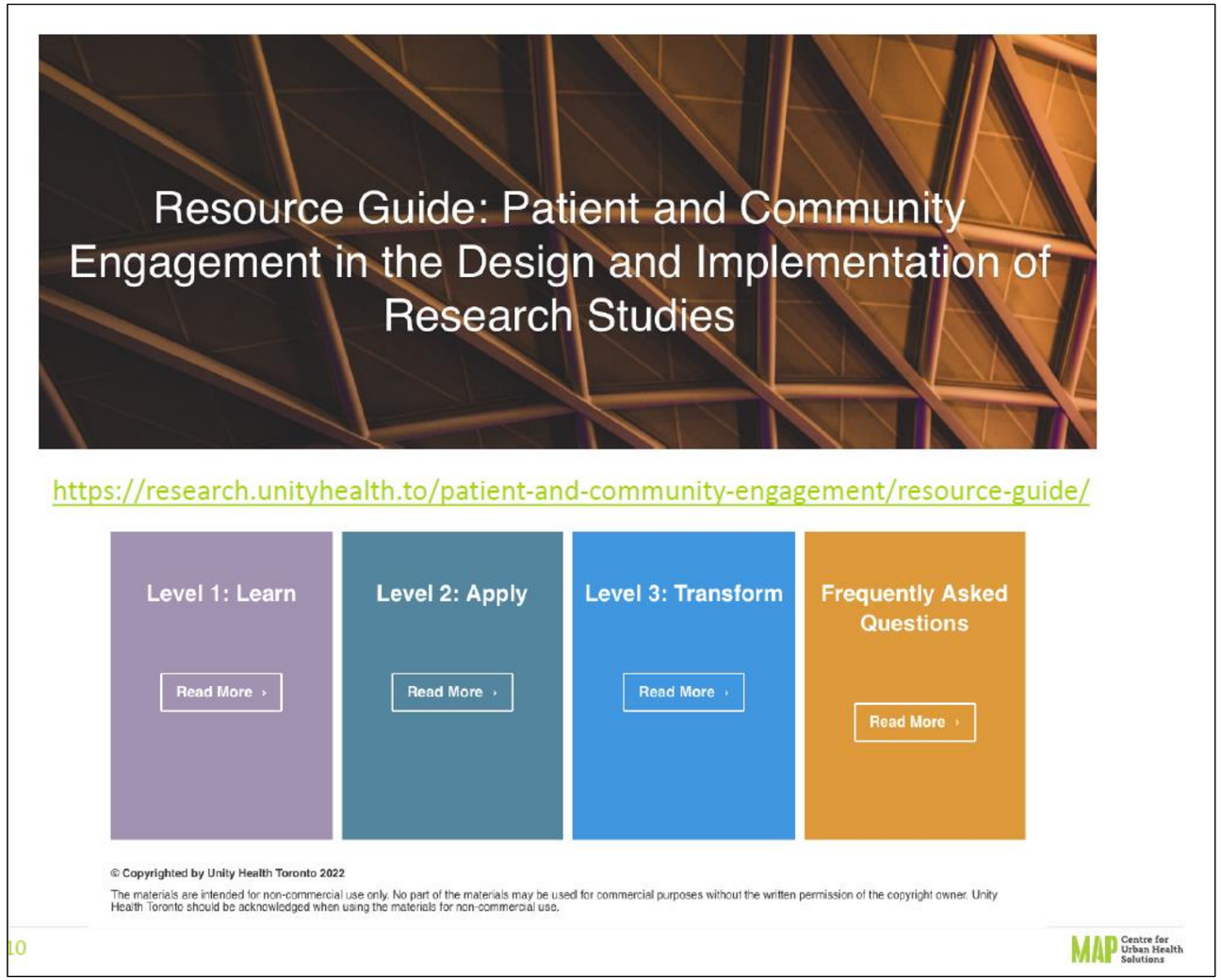
Allyship in Research Article ›

This document acts as a resource for non-Indigenous researchers seeking to collaborate with Indigenous communities. It speaks to the concepts of *allyship* and its potential for collaborative research projects. *Authors*: Smith, J., Puckett, C., Simon, W. (2015).

See https://leongcentre.utoronto.ca/resources-community-engaged-research

Unity Health Toronto Resource Guide

- A guide for learners interested in expanding their knowledge of equitable patient and community engagement in the design and implementation of research studies.



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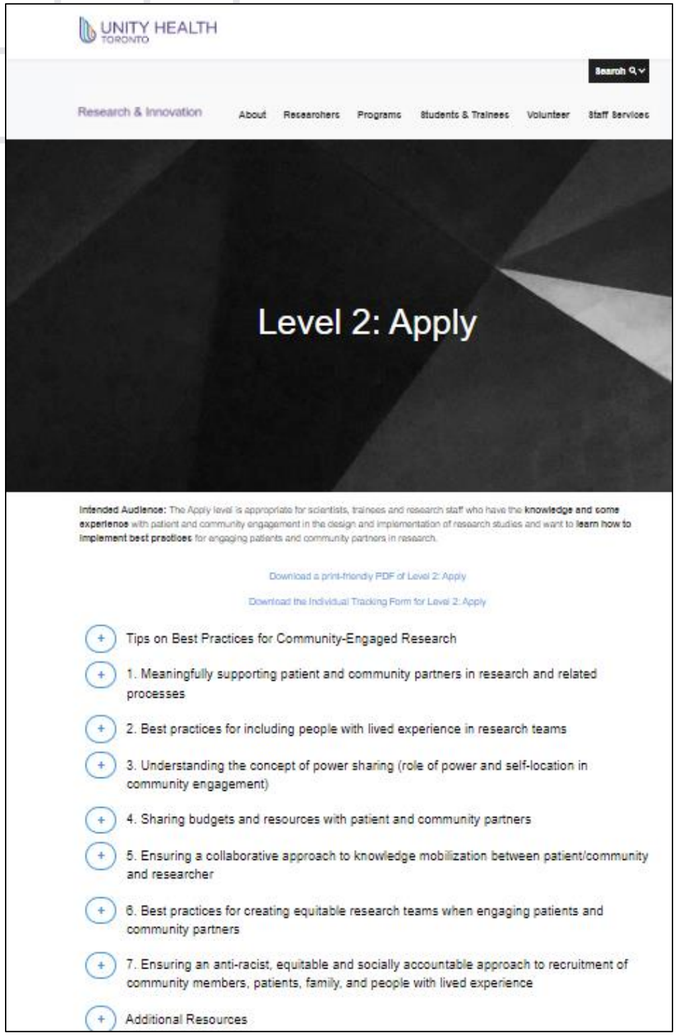

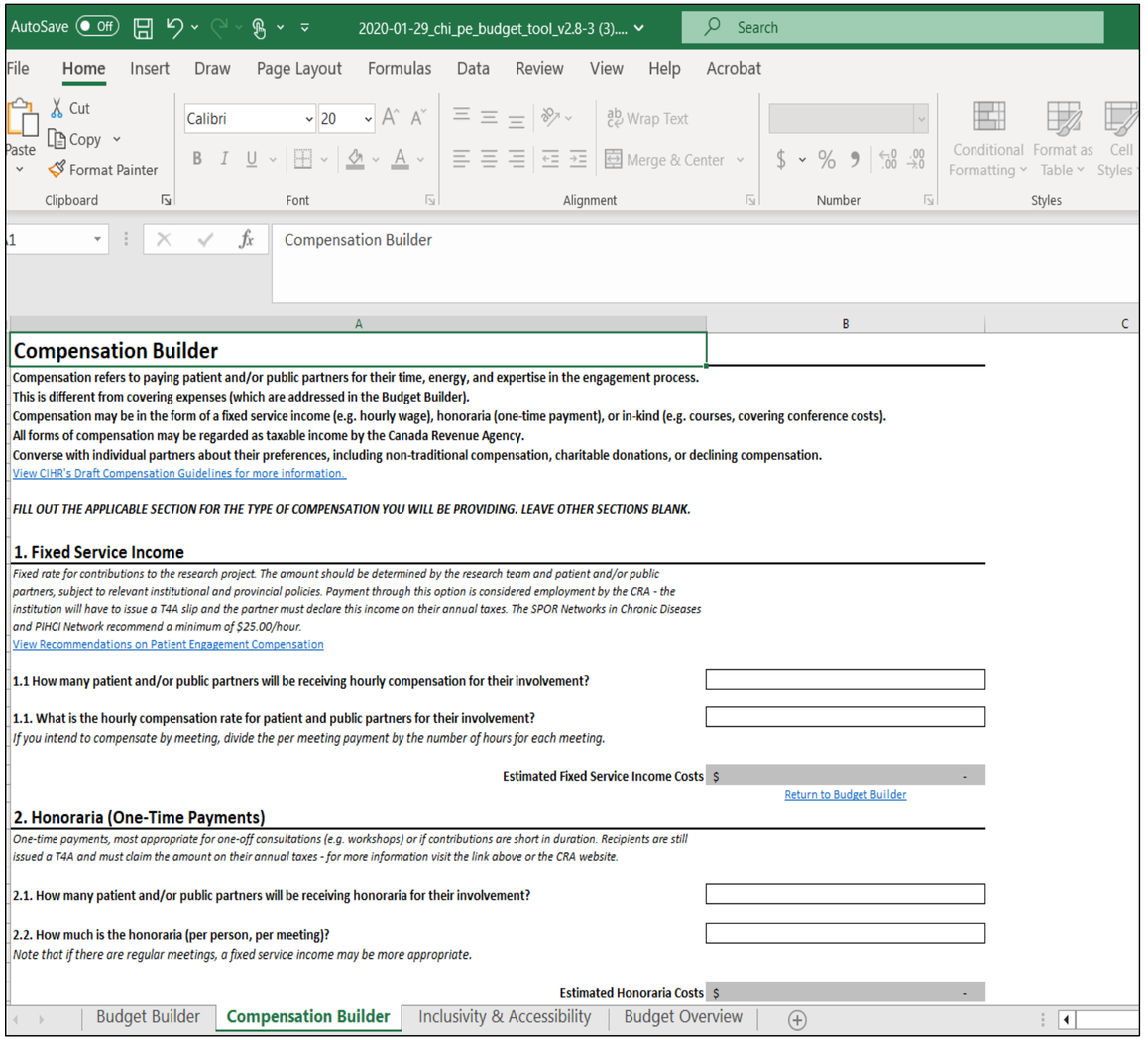

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Interdisciplinary Research to Promote the Flourishing of *Every* Child and Family

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Questions/Comments

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