

## Edwin S.H. Leong Centre for Healthy Children

A Seat at the Table:

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

Friday October 20, 2023

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## **Workshop Learning Objectives**

- ✓ To learn about the Leong Centre, vision and programming
- ✓ To understand health equity as a critical consideration when conducting research on children and youth in Canada
- ✓ To understand the importance of community engagement in health equity research.
- ✓ To learn how to co-design a community engagement plan for your own research





### **Conflict of Interest**

No conflicts of interest to declare.





#### **Poll #1**

Which of the following best describes your current role or title?





#### **Poll #2**

What is your current level of experience with patient and/or community engagement?





## Introduction to the Leong Centre and Child Health Equity

## **Background & Vision**



Harnessing interdisciplinary research to promote the flourishing of every child and family





## **Pillars of Activity**



#### Research

Our research program brings together scholars from across the University of Toronto, the Hospital for Sick Children and beyond, to catalyze work addressing child health inequities in Canada.



#### **Education**

We develop and deliver a variety of events and resources for those interested in learning about child health equity and outcomes research.



#### **Training**

Research training opportunities are available for graduate students, post-doctoral research fellows, and clinical trainees.



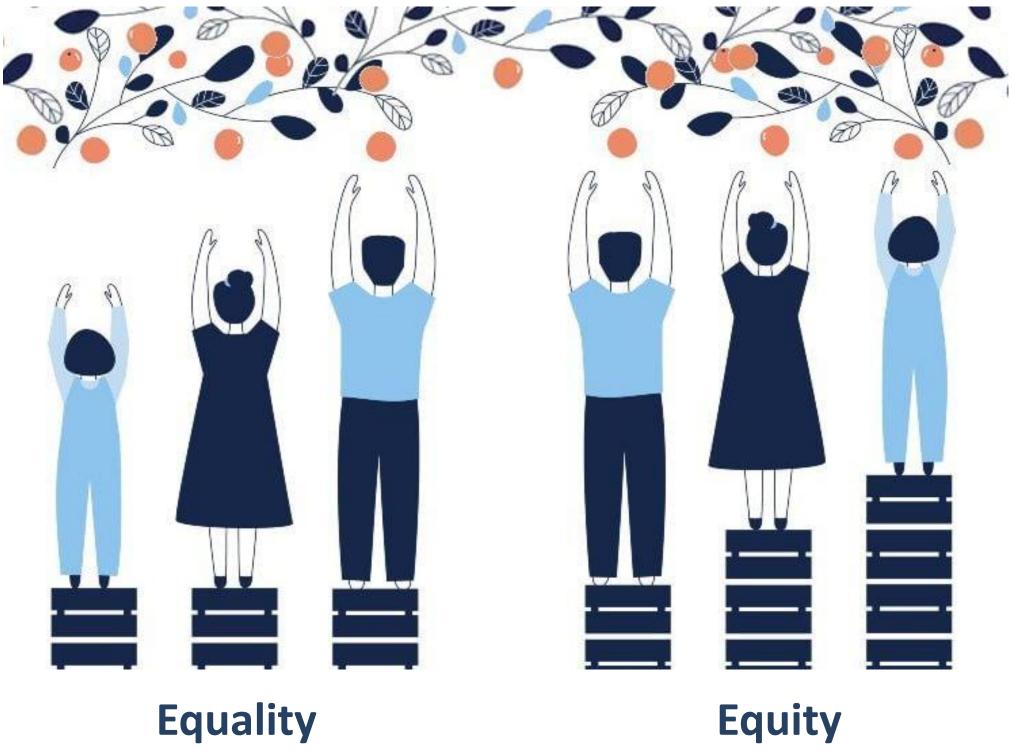
#### **Infrastructure & Services**

Expertise and resources offered to Centre members, resulting in the exchange of ideas, development of new knowledge, and practice in child health matters.





## **Health Equity and Children**







## Introduction to Community Engagement

## **Defining Community Engagement**

- A community is defined by shared interest, connection, occupation, place in society, health status and other common bonds, in addition to geography.
- Community engagement is 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.

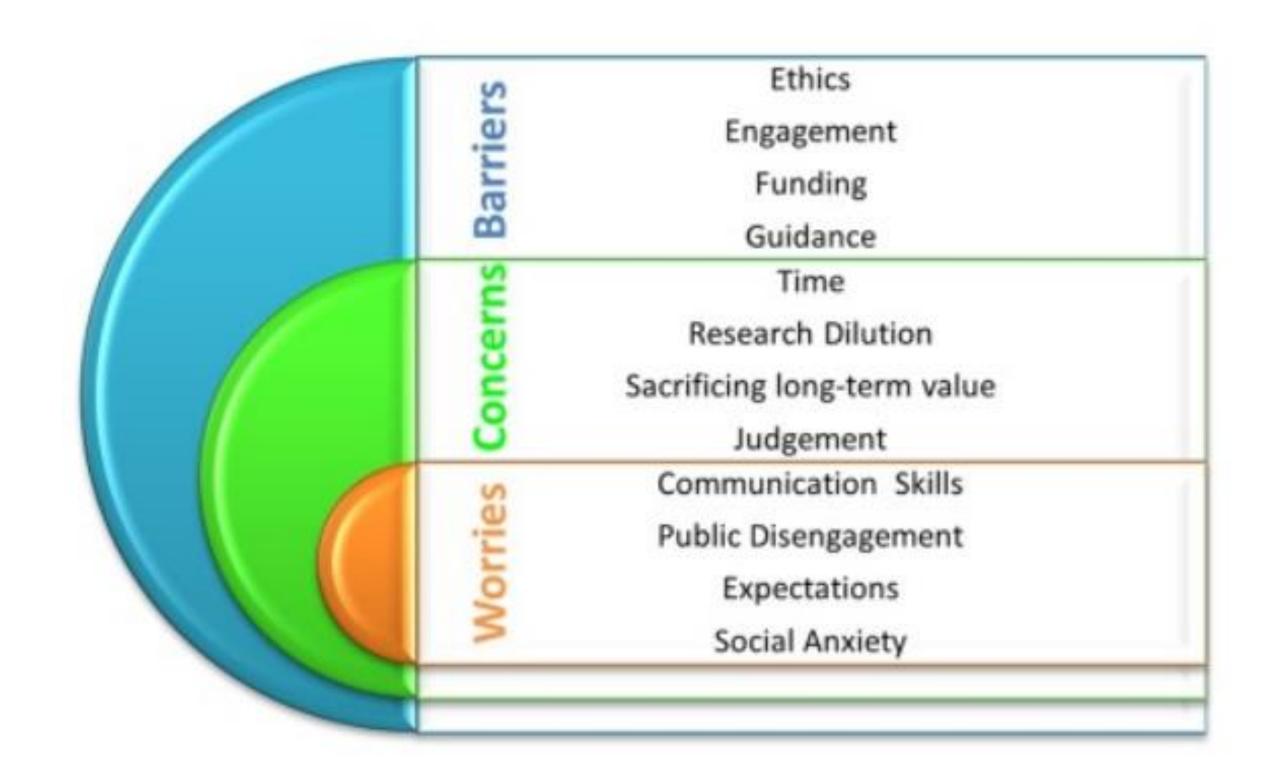
## **Principles of Community Engagement**

- 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.

## **Creating Meaningful Community 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.

## **Key Challenges for Engagement**



# NOTHING ABOUT US WITHOUT US



## Planning for Community Engagement

## Leong Centre Engagement Planning Worksheet



\*Open worksheet document pinned in the chat

This worksheet will assist you in thinking about your process for engaging patient and community partners in your work.





## **Engagement Planning Worksheet: Case Study Exercise**

**Topic**: Tutoring support for secondary school students

Characteristic	Description
Objective	To develop a free tutoring support program (in-class & after school) for youth in under-resourced schools, delivered in partnership with community organizations.
Co-Principal Investigators	U of T researcher & Toronto District School Board (TDSB) researcher
Study Design	Mixed methods, community-engaged research
Population	Teachers, parents, secondary school students, and community organizations
Funding	Yes
Outcome	To increase learning supports (i.e., homework assistance) for youth in under- resourced schools with the goal of improving academic outcomes.





### **Question 1**

1	What is your main goal for engaging patients or community members in your research project?	
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#### **Question 1: Potential Answers**

**Q1:** What is your main goal for engaging teachers, parents, youth, and community organizations in the research project?

- Their input on the design and planning of the project
- Schedule meetings at locations that works best for them
- Reach consensus on the best and most effective forms of communication
- Survey group and identify any requirements for providing training and support
- Survey group and reach consensus on the amount of time and commitment required by the members during the research project
- Survey group and identify the appropriate method of compensating them for their time and participation





#### **Question 2**

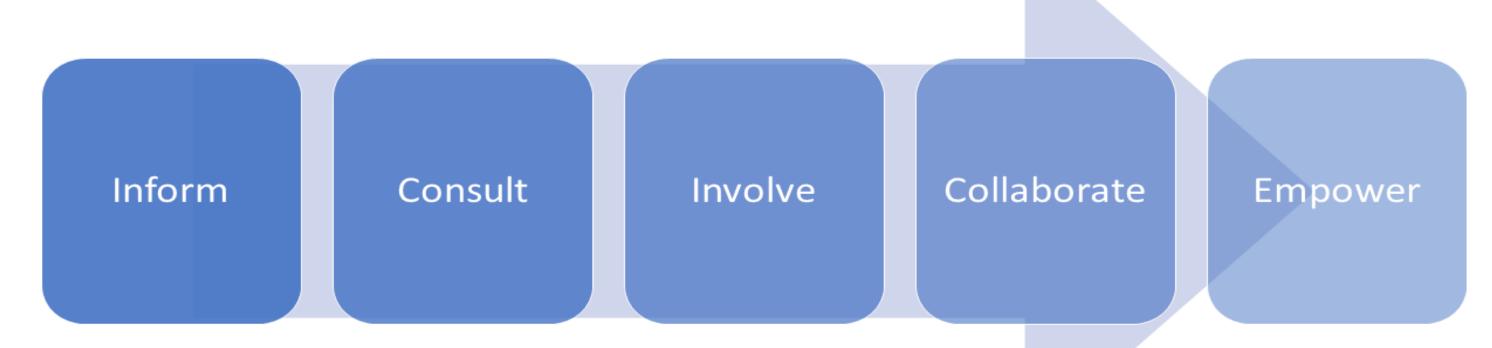
What level of engagement are you planning to use? \*see page 2 for more information

Inform Consult Involve Collaborate Empower





## **Question 2: Spectrum of Engagement**



#### 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

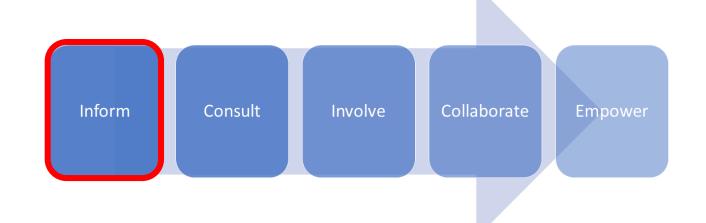
To partner in each aspect of decision-making

To place decision-making in the hands of community





### **Spectrum of Engagement: Inform**



**Definition:** To provide teachers, parents, youth, and/or community organizations with relevant information about the study.

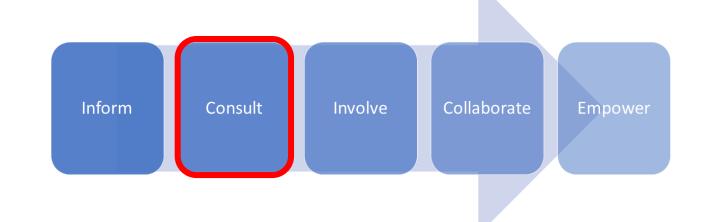
#### Ways to Inform:

- Teacher and community organization staff meetings
- TDSB email newsletters to teachers, parents, and youth
- Researcher emails to community organizations
- Printed information posters on school and community organization bulletin boards
- Social media (e.g., @TDSB, Instagram, Facebook, LinkedIn)





## **Spectrum of Engagement: Consult**



**Definition:** To gather input from teachers, parents, youth, and community organizations about the study.

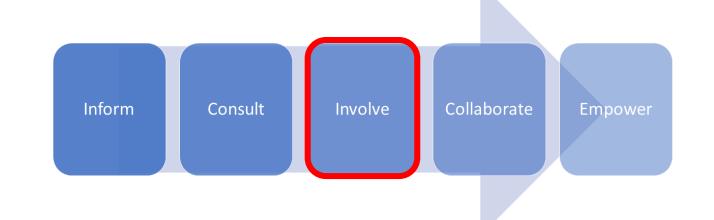
#### **Ways to Consult:**

- TDSB sends online survey to teachers, parents, and youth
- U of T researcher sends online survey to community organizations
- TDSB coordinates small group discussions with teachers, parents, and youth
- U of T researcher and community organizations coordinate public meetings for discussion and input
- Facilitate opportunities for input when participants require alternative methods of engagement (e.g., email/telephone)





### Spectrum of Engagement: Involve



**Definition:** To ensure the needs and concerns of teachers, parents, youth, and community organizations are understood and considered in the study. TDSB and the U of T researcher will engage the participants.

#### Ways to Involve:

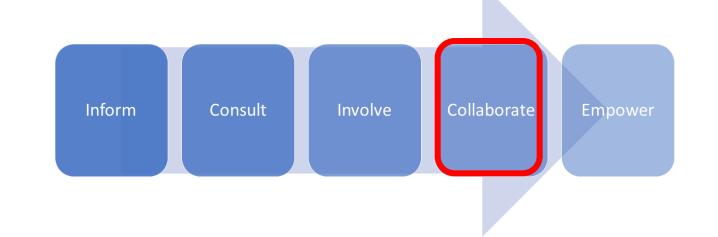
This can be accomplished using a variety of opportunities, such as:

- Regularly scheduled meetings using face-to-face or technology
- Establishing participant short-term advisory groups or planning committees
- Facilitate opportunities for input when participants require alternative methods of involvement (e.g., email/telephone)





### Spectrum of Engagement: Collaborate



**Definition:** To ensure teachers, parents, youth, and community organizations play a leadership role in decision-making processes about the study.

#### **Ways to Collaborate:**

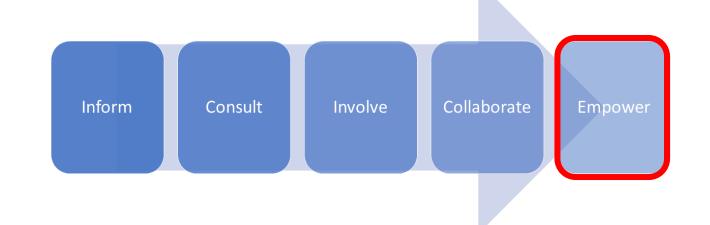
TDSB and the U of T researcher can:

- Host a meeting to establish a method of reaching consensus (e.g., 'round robin') that includes all participants
- Co-create an agreement on ways to work effectively together
- Establish participant advisory committees and small working groups
- Identify individual participants that are willing to assume leadership roles
- Identify point person on the research team dedicated to supporting the project





### Spectrum of Engagement: Empower



**Definition:** Ensure teachers, parents, youth, and community organizations make all final decisions about the study (across the research trajectory).

#### Ways to Empower:

TDSB and the U of T researcher can:

- Host a meeting to ensure the method of reaching consensus (e.g., 'round robin') includes all
  participants concerning final decisions
- Co-create an agreement on ways to work effectively together
- Establish and empower the participant advisory committees that will convey the final decisions to the researchers
- Identify the point person to the research team dedicated to supporting the project





### **Question 3**

What strategies inclusive?	will you use to ensu	re that your proje	ct is equitable and	





#### **Question 3: Potential Answers**

**Q3:** What strategy/ies should TDSB and the U of T researcher use to ensure that this project is equitable and inclusive?

#### TDSB and the U of T researcher can:

- Involve participants in as many aspects of the research as possible, from beginning to end
- Dedicate time for relationship building with participants
- Create a welcoming, safe place for participants to share and engage
- Set the realistic expectations about time commitments for participants
- Budget for involvement of participants in the study

#### **Results:**

- Share study results with partners and include them in knowledge mobilization
- Incorporate participants' suggestions and feedback
- Ensure recognition of contributions (e.g., authorship)





## **Question 4**

4	(A) What skill sets do you or your team currently have?
	(B) What training and/or preparation does your team need?
	(C) What resources do you need?





#### **Question 4: Potential Answers**

#### TDSB and the U of T researcher can:

- Involve participants in as many aspects of the research as possible, from beginning to end
- Dedicate time for relationship building with participants
- Create a welcoming, safe place for participants to share and engage
- Set the realistic expectations about time commitments for participants
- Budget for involvement of participants in the study

#### **Results:**

- Share study results with partners and include them in knowledge mobilization
- Incorporate participants' suggestions and feedback
- Ensure recognition of contributions (e.g., authorship)





### **Question 5**

	) How will you support patients and community members so they can contri
fu	lly to discussions and decisions?
<b>C</b> )	How will you check-in with your patient partners and community team





## A Seat At The Table: Best Practices in Community Engagement

## **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.





## Considerations for Planning a Community-Engaged Project













Staff

Money

Equipment & Tools

Partnership & Collaborations

Expertise

Risk





## **Understanding Impact**



#### Transactional Community Engagement

- Checking a box
- Narrow engagement
- Seeking input on near-final product
- Results in superficial or technical change

Challenges: may lead to community fatigue, lack of trust



## **Transformative Community Engagement**

- Sustainable relationships
- Transparency and "feedback"
- Results in cultural and structural change

Challenges: resource intensive, requires institutional commitment and readiness





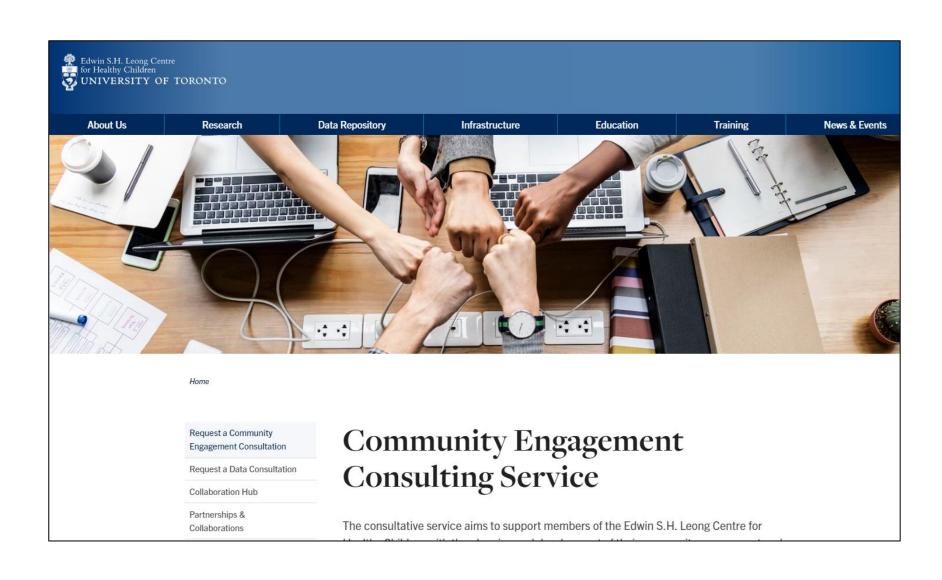
## Community Engagement at the Leong Centre

### **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







## **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 communityengaged experiences and ideas.



2023

	Expand All
Tuesday, September 19, 2023   "The Family and Child Health Initiative: Building Trusting Relationships and Working in Partnership with Diverse Communities in Peel Region"	+
Friday, May 19, 2023   "Lessons Learned: Cultivating Community Partnerships for Equity and Access in Children's Health"	+
Friday, April 21, 2023   "Equitably Engaging Patient and Community Partner in Our Research: Where Do I Begin?"	rs +
Tuesday, March 28, 2023   "Advancing Engagement Using Arts-Based Approaches"	+





#### **Trainee Hub**

- An initiative for graduate students, postdoctoral 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.

#### **Archived Sessions**

Tuesday, September 19, 2023   Trainee Hub Event: "Planning for Impactful	
Engagement: Developing an Engagement Plan for Partnerships in Child Health Research"	+
Wednesday, May 24, 2023   Trainee Hub Event: "Engaging the Community in Research: Insights from Youth Partners"	+
Wednesday, April 26, 2023   Trainee Hub Event: "Community-Based Research Axiology and Qualitative Health Research Methodology: An Introduction to Value-Adding Research"	+
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"	+





Expand All

#### **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, <a href="mailto:dianne.fierheller@thp.ca">dianne.fierheller@thp.ca</a>

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!





## Resources for Community-Engaged Research



#### 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).

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





## **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.





## Stay In Touch



www.leongcentre.utoronto.ca



leong.centre@sickkids.ca



@LeongCentre

If you have any questions about the Leong Centre or our Community Engagement work, please contact us at <a href="mailto:priscilla.medeiros@sickkids.ca">priscilla.medeiros@sickkids.ca</a> and <a href="mailto:ellie.adler@sickkids.ca">ellie.adler@sickkids.ca</a>.



