Community Report

Building a Learning Health Care Community (LHCC) Model for Women's and Children's Health in Peel

Chapter 1: Laying the Foundation

Trillium Health Partners | INSTITUTE FOR BETTER HEALTH
Family and Child Health INITIATIVE

Acknowledgements

Our community partners and networks in the Peel region

We would like to thank the Institute for Better Health and the Digital Health Committee for funding this work. We would also like to thank the Population Health-Related Data Collection advisory group for their ongoing support and guidance in developing a sociodemographic data collection model that is responsive to the needs and strengths of the Peel Region community. Most of all, we would like to acknowledge the community members who took the time to share their experiences and knowledge with us throughout the project.

Land Acknowledgement

We would like to begin by acknowledging the land in which this collective work takes place, and which the Region of Peel operates, is part of the Treaty Lands and Territory of the Mississaugas of the Credit. For thousands of years, Indigenous peoples inhabited and cared for this land, and continue to do so today. In particular we acknowledge the territory of the Anishinabek, Huron-Wendat, Haudenosaunee and Ojibway/Chippewa peoples; the land that is home to the Metis; and most recently, the territory of the Mississaugas of the Credit First Nation who are direct descendants of the Mississaugas of the Credit. We are grateful to have the opportunity to work on this land, and by doing so, give our respect to its first inhabitants.

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Correspondence:
Dianne Fierheller, dianne.fierheller@thp.ca, FCHI, The Institute for Better Health, Trillium Health Partners, Mississauga ON, Canada.

Background

The health of communities is influenced by the conditions in which they live, work, and play, and also known as social determinants of health. Health disparities occur when there is an unequal distribution of essential resources and power needed to achieve optimal health. This unequal distribution causes particular communities to suffer, contributing not only to poorer health but also to further marginalization.

The Peel Region faces unique health challenges that were further exacerbated during the COVID-19 pandemic. The region is amongst the most diverse in Canada, serving many racialized, marginalized, and low-income families. Systems of disadvantage negatively impact the health of communities. Barriers to optimal health can be dismantled by collecting data to better understand the systems and the people they affect.

By collecting this data meaningfully, holistically, and consistently, a better understanding of health barriers and needs within the Peel Region can be achieved. Community organization leaders in Peel and Trillium Health Partners (THP) identified data collection and integrated knowledge translation between health and community organizations as a priority to improve health outcomes for equity-deserving groups (1-3).

Definition:

A community-centred **Learning Health System (LHS)** formally referred to as a Learning Health Care Community (LHCC), is a framework that enhances healthcare through a partnership between the healthcare system and the community, emphasizing mutual accountability, continuous improvement, and shareholder engagement to improve care quality and outcomes (6,7).

Key Takeaways

1. Peel region faces unique health challenges and there is a lack of understanding of the current health data ecosystem that is pertinent to identifying and acting on health needs.

2. The Women's and Children's community-centred Learning Health System (W&C LHS) project team aims to partner with service providers and users to establish a set of recommendations for piloting the collection of women's and children's health-related sociodemographic data in Peel Region.

Within the specific area of maternal and child health, there is a need to understand the current health data ecosystem using the Learning Health System and community-centred Learning Health Care Community (LHCC) models to begin building an integrated health system that can influence healthcare decision-making and address health needs and care delivery challenges (4,5).

To better understand the community's health needs and promote health equity, the Digital Health Committee at THP convened a Population Health-Related Data Collection Advisory Group to create guiding principles and recommendations for collecting sociodemographic data at THP. With funding from the Institute for Better Health and the Digital Health Committee, the Family and Child Health Initiative (FCHI) worked alongside the Population Health-Related Data Collection Advisory Group to engage community partners and members and Women's and Children's (W&C) Program service providers and users to understand what data we want to collect, who we are collecting it from, how it will be collected, and what it will be used for. These recommendations will inform a future pilot to implement sociodemographic data in select clinical areas within the W&C Program at THP.

Methodology

Establish Initial Linkages

We established initial linkages and contextualized the project both within and outside of THP. We leveraged existing networks and committees, including the Population Health-Related Data Collection Advisory Group, the Anti-Black Racism and Systemic Discrimination Healthcare Collective, Peel Family Support Network, Peel's Community Safety and Well-being Plan Committees (mental health, family violence, and systemic discrimination), and THP's Health Equity Circle.

Problem Identification

We designed and disseminated an asynchronous survey for health providers across the Peel region (including within THP) to conduct an environmental scan of current sociodemographic data collection practices, challenges and needs.

Analyze

Using the survey findings, we co-designed and executed three workshops (two with health providers and one with service users) to begin understanding considerations for sociodemographic data collection and utilization.

Foundational Workshops Service Providers

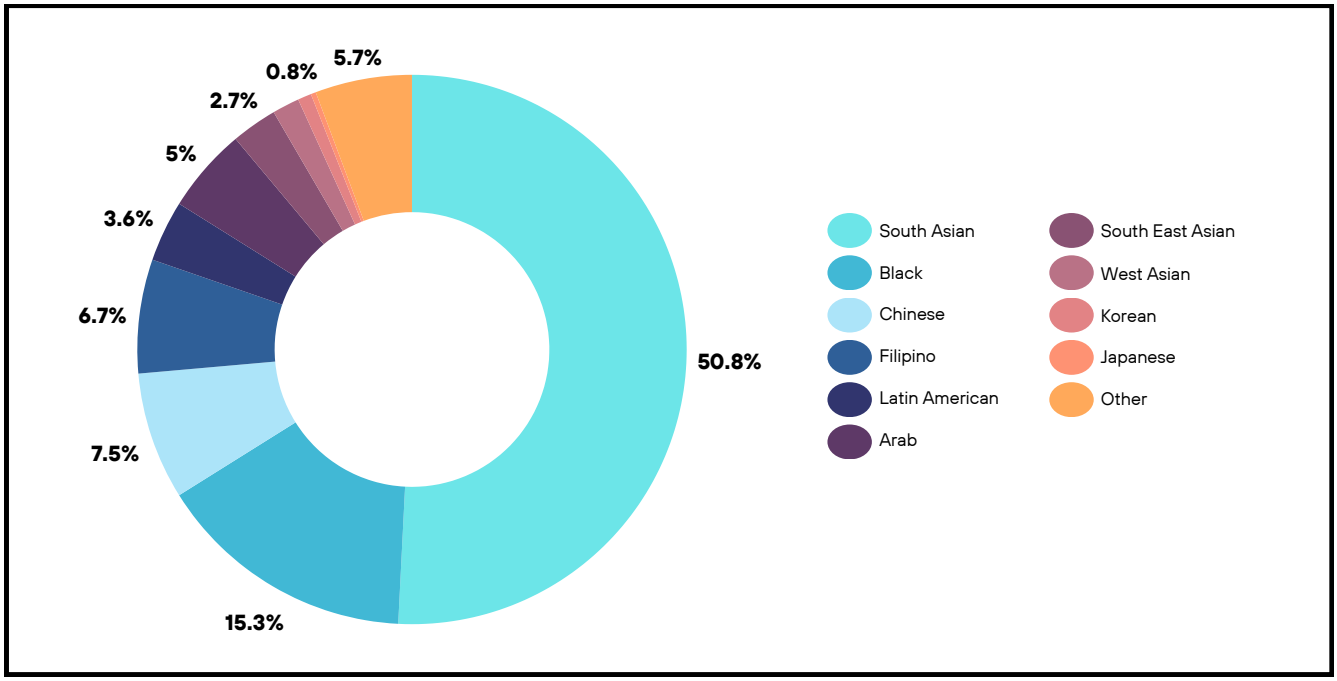
We held workshops to gather preliminary feedback on the purpose statement and guiding principles currently being developed to guide sociodemographic data collection at THP. We analyzed the qualitative data collected during the workshops using analytical memos and thematic analysis to identify foundational considerations for sociodemographic data collection within Peel Region.

Foundational Workshops Service Users

These findings will directly inform the expanded scope of the project by examining these considerations for implementation within the W&C Program at THP alongside service providers and users.

Setting The Stage

Figure 1. Percentage of Visible Minority Groups in Peel Region in 2016



Project Setting

The Region of Peel is one of the most diverse communities in Canada with more than 50% of residents having immigrated to Canada. (8,9) In 2016, more than half of Peel's residents identified from the South Asian community followed by Black (15.3%), Chinese (7.5%), Filipino (6.7%), and Arab (5.0%). (10) The recent immigrant and newcomer population comprises 13% of Peel's immigrant residents. (10)

Project Objectives

The project aims to develop a Women's and Children's (W&C) Learning Health Care Community that bridges THP with community and health systems in Peel to improve maternal and child health within diverse communities across the Peel Region. In the first phase of our project (detailed in this report), we focused on developing and validating foundational guiding principles for implementing sociodemographic data collection, aiming to close data gaps and strengthen community-clinical linkages. We achieved the above by:

1. Identifying key partners and networks in maternal and child health care at THP and across community services in Peel.
2. Exploring how community partners and healthcare providers can safely and efficiently collect and integrate individual-level sociodemographic data.
3. Creating a supportive environment for an LHCC by fostering partnerships and formalizing partner engagement.

Community Engagement

Engagement Summary

We used a community-based participatory research approach (CBPR). (11,12) THP service providers, patients/service users, community partners and members, and other shareholders played an active role throughout all stages of this project.

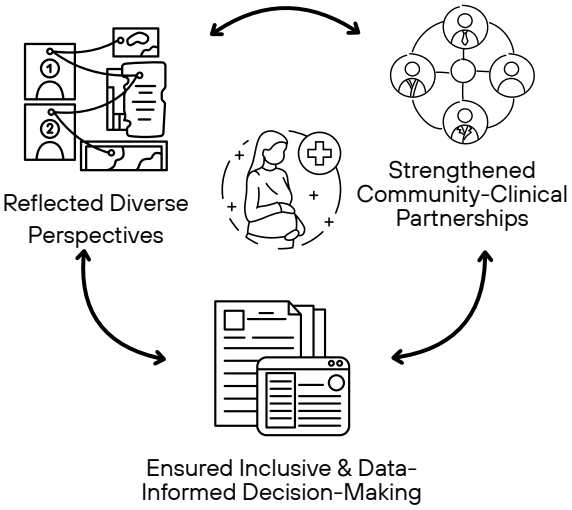
In a snapshot:

120+

Individuals engaged via an asynchronous survey, workshops, and engagement meetings

- **14** Service Users
- **50** Social Service Agencies
- **45** THP Clinicians and Administrators
- **8** Municipal & Regional Government Employees
- **6** Other Medical Providers and Administrators

Cross-disciplinary engagement ensured that the project:



All project findings were co-analyzed alongside a diverse project team consisting of:

- **IBH Staff**
- **Researchers**
- **Undergraduate Medical Students**
- **Masters of Public Health Students**
- **Biostatistician**

Throughout our project, we engaged in active knowledge translation across community and professional spaces:

- **Anti-Black Racism and Systemic Discrimination Collective of Peel**
- **Population Health-Related Data Collection Advisory Group at THP**
- **Women's & Children's Program Leadership**

Principles underlying our approach:

- **Long-Term Meaningful Relationships**
- **Large-Scale Reach**
- **Multimodal Engagement**
- **Interdisciplinary Collaboration**

Results

Survey Results

Our methods were phased and iterative, meaning the results learned in each stage continued to inform and refine the project activities that followed.

Survey completed by service users within and outside THP showed:

59% of responders were THP providers

26% of responders indicated that their organizations collect sociodemographic data

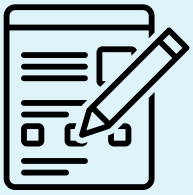
Most Common Indicators

- Age
- Biological Sex
- Address or Postal Code

73% utilized sociodemographic data, collected internally or externally, in their practice

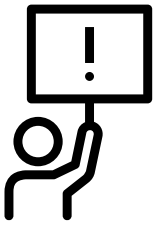
Most Common Mechanisms to Collect Sociodemographic Data

Electronic Health Records



Administrative Records including Intake Forms and Program Records

#1 Point of Care



#2 As Needed/Ad-Hoc Basis

Most Common Point of Data Collection

Results

Workshop Results

The survey findings were used to design the first set of workshops, which were conducted as part of this project. Workshops used clinical case scenarios to prompt attendees to consider the experiences and implications of collecting sociodemographic data from women and children. Individual workshops engaged 14 service users and 14 service providers. The workshops indicated the following as the key considerations to think about when exploring sociodemographic data collection:

1) Consider "When" Data Should be Collected

- The timing of data collection is an imperative consideration for planning. Attendees reported that data should not be collected at the initiation of care (registration), but perhaps at the end of the visit. Some mentioned the importance of collecting data during the visit that may be relevant to providing tailored care.

2) Explain "Why" Data Should be Collected

- Explaining the purpose and intended utilization of the collected data to service users was a key consideration from the workshops.
- Although explaining how the data will be used alongside the written questions was imperative, attendees believed there was also a need to have trained staff nearby to answer questions.

3) Staff Require Training for Data Collection

- Staff representation from the community the organization serves could help bridge the cultural gap.
- Staff collecting the data should be trained in ARAO/Equity, Diversity and Inclusion practices to create an environment of inclusion, trust, and belonging.

Data collection at appropriate times guided by patients' pressing priorities and care needs

Service Users emphasized the importance of understanding the WHY of data collection.

Data collected by staff who are trained in Anti-Racism and Anti-Oppression practices

Results

Workshop Results

Building Trust and Transparency During all Stages of Data Collection

Centering Diversity and Authenticity During the Data Collection Process

Providing Safe and Accessible Avenues for Data Collection

Adopting Best Practices for Data Collection & Continuous Evaluation

4) Build Trust and Transparency

- There is low institutional trust and concerns around data governance and stewardship as a result of systemic discrimination and chronic racial injustices.
- Asking sociodemographic-related questions using non-technical, simple terms, with consideration for language and cultural barriers, should be prioritized.
- Only necessary and relevant questions should be asked, and each question should have an explanation stating why it is being asked and how it will benefit the individual and their community.
- Service users should also be provided with information on the storage, governance, transfer, and privacy of their data.

5) Consider "How" Data Should be Collected

- Participants believed that a free-text option encourages inclusivity and allows patients to share their information using language or terminology with which they feel most comfortable.
- When providing options or categories, there needs to be a balance between categorizing people and allowing them to self-identify. There is a need to co-design key categories and indicators with communities to ensure they align with community values.

6) Institutional Factors for Effective Data Collection

- Face-to-face interactions, digital kiosk, or paper forms are among the modalities to consider when collecting data to increase accessibility. Questions should be available in multiple languages and supported by translation or interpretation services as needed.
- All data collection modalities should prioritize providing respondents with a safe and private space to answer these questions; staff should be available to answer any questions.

7) Prioritize Benchmarking and Continuous Improvement:

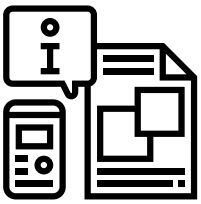
- Understanding the experiences of other healthcare institutions to inform the project design, implementation, and relevant feedback mechanisms was discussed in the workshops

Results

Feedback on THP's Purpose Statement and Guiding Principles for Sociodemographic Data Collection

Participants' feedback included:

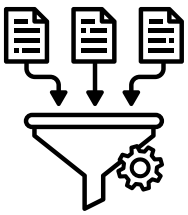
Include a principle that states "we will make an effort to explain why it is critical to have that information."



Language needs to shift from mandating data provision to volunteering information.

Include language about commitment to being an inclusive/equitable community

Include language about the voluntary nature of data provision.



Examine other data collection principles that exist in other healthcare institutions (e.g., Region of Peel).

Emphasize ongoing community engagement and that you are "not working in silos."

Feedback

Impact & Next Steps

Impact

1. We established critical connections to build an LHCC model for women and children in the Peel region.
2. We developed a foundational understanding of the current data collection practices within W&C programming in the Peel region.
3. We identified important considerations when developing data collection processes that meet the needs and values of service providers and users.

Next Steps

1. We will continue to engage patients/service users, community partners, and THP staff through focused workshops to develop recommendations for piloting sociodemographic data collection within the W&C Program at THP.
2. We will centre community knowledge and experiences from a grassroots level in the development of data collection processes, stewardship, ownership and governance at THP.

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