



## Meeting Minutes

September 15, 2020

### OPENING

The regular meeting of DataSHARE Peterborough was called to order at 1pm on September 15, 2020 via virtual Microsoft Teams connection by Nancy Fischer.

### PRESENT

Nancy Fischer – Senior Program Analyst, City of Peterborough  
Caren Thayer – Data Analysis Coordinator, City of Peterborough  
Tammy Sikma – Manager of GIS, County of Peterborough  
Peter Williams – Community Development Coordinator, Peterborough Police Services  
Emily Jones – Community Development & Engagement Coordinator, Peterborough Police Services  
Jane Hoffmeyer – Manager, Foundational Standards, Peterborough Public Health (PPH)  
Anita Wong – Health Promoter, Peterborough Public Health (PPH)  
Sean Dooley – Labour Market Information Analyst, Workforce Development Board (WDB)  
Steven Tripp – Business Retention & Expansion Officer, Peterborough & the Kawarthas Economic Development (PED)  
Sarah Amirault – Research Analyst, Institutional Research Office, Fleming College  
Jason Dennison – Workforce and Labour Market Advisor, Fleming College  
Ellen Olsen-Lynch – Learning & Liaison Librarian, Trent University  
Kate Hodge – Data Visualization & Statistical Support Specialist, Trent University

### REGRETS

Mohamed Kharbouch – Epidemiologist, Peterborough Public Health (PPH)  
Jennifer Chenier – Supervisor – Quality Initiatives, Kawartha-Haliburton Children's Aid Society  
Jennifer McLauchlan – Director of Corporate Services, Kawartha-Haliburton Children's Aid Society  
Brittany Wakefield – Crime Analyst, Peterborough Police Services  
Cheryl Stager – Program Support Partner, Peterborough Regional Health Centre  
Amanda Hiemstra - Quality Improvement Decision Support Specialist, Peterborough Family Health Team (PFHT)  
Jennifer Lamantia – CEO, Workforce Development Board (WDB)  
Kevin Hickey – Manager of Purchasing, Planning & Facility Administration, Peterborough  
Victoria Northumberland and Clarington Catholic District School Board (PVNCCDSB)  
Sherry Gosselin – Director, Project Management Office, Fleming College

### GUESTS

Cynthia Damba – Manager, Health Analytics, Toronto Central Local Health Integration Network/Ontario Health, Toronto Region  
Angela Robertson – Executive Director, Parkdale Queen West Community Health Centre

## WELCOME AND INTRODUCTIONS

Nancy welcomed the group and invited everyone to introduce themselves and their organization. The meeting's discussion focus was "**Race-based data collection – the challenges and benefits**". Nancy reminded the group that the May meeting had been cancelled due to COVID-19 response and member availability. The plan for Peterborough Public Health to discuss Community Safety & Wellbeing Plans was deferred temporarily to allow for today's presentation.

A discussion on the selection of a platform for data sharing was also to have occurred but, has been temporarily deferred.

## REVIEW OF AGENDA & PREVIOUS MINUTES

No corrections were indicated. Nancy asked the assembled to provide any corrections to her or Tammy by end of day. Barring a response, the agenda & minutes were tentatively received as distributed. (*None were received.*)

## PETERBOROUGH DATA CONSORTIUM SUB-COMMITTEE UPDATE

Nancy provided an update on the Community Data Program and indicated that a lot of information is being gathered related to COVID-19 and COVID recovery through the Community Data Program.

## RACE-BASED DATA

### Presenters:

**Cynthia Damba** – Manager, Health Analytics, Toronto Central Local Health Integration Network/Ontario Health, Toronto Region &

**Angela Robertson** – Executive Director, Parkdale Queen West Community Health Centre

- Cynthia opened the presentation by providing background on why, where, and how equity data has been measured at Toronto Central LHIN, including progress made, use of data, and lessons learned.
- Toronto serves a large, diverse population, served by many health programs
- When ethically used, equity data collection should create pathways to better health for all
- Overview of standardized equity data collection programs provided from Community Health Centres, Hospitals, etc
- Toronto Central LHIN's 8 standardized equity questions, derived from 2009 "We Ask Because We Care" research report discussed
- Child & Youth Equity Questionnaire developed in 2014-2015 to better meet the community

- Sinai Hospital conducted many activities to support ethical demographic data collection including training, visits & consultations, workshops & symposia, website (<http://torontohealthequity.ca>), communication & development
- Once standardized, hospitals & Community Health Centres (CHCs) are looking at how best to use the data
  - Demographic patient dashboards have been developed to share with boards, senior management & data collectors
  - E.g., Able to determine who are their high Emergency Department users, review cancer screening data to determine where women & female-identity clients experience lower screening rates
  - Inform hospital/CHC Quality Improvement Plans (QIPs) & point of care (e.g., direct diet planning with pregnant patients, develop appropriate language interpretation programs to the presenting population, use “income” to consult on dietary needs and respond with appropriate transit “token” assistance)
- Analysis allows the exploration of intersectionality (e.g., where does one gender-identified community intersect with disability, income, immigration, etc?)
- Overview of analysis on ICES data provided with more comprehensive analysis to follow in a coming report
  - Discovered that many who were uncomfortable providing income data were experiencing higher rates of multi-morbidity; area for future study
  - Alternate Level of Care (ALC) may include hallway medicine, etc and was found to relate to lower income groups
  - Currently looking for causes of disparities and ways to address them
- Found it important to embed equity data collection at the root of data collection
- It was important to address staff discomfort with the questions that were to be asked in order to collect in a respectful & inclusive way
- Early Wins in CHCs:
  - Used data in CHCs to improve cancer screening rates for racialized communities of female-identified, immigrant women, women whose first language was not English
  - Able to target screening to improve rates for under-served communities
  - A community with a higher Cantonese population targeted a community mass-screening event to reach out to a community of Mandarin-Cantonese speaking women
- Early Wins in hospital setting / system perspective:
  - Having this data has allowed agencies to quantify specific populations that they are serving and who have higher rates of need
- Recommendations on how to manage organizational & cultural change?
  - Question:
    - re: plan to collect race-based data, but concerned local homogeneity might require suppression of the data due to privacy considerations
      - Just starting to integrate these questions into “regular business”
      - There are some concerns with trust and the population not wanting to provide responses
  - Response:

- Toronto Central LHIN experienced similar concerns that data might be more costly to respond to, would limit responses
    - Have found that the data has guided health provider education and the need to better meet patient needs
  - Some communities in 2012 assumed they didn't have a significant racialized population and therefore didn't need additional supports
    - Found that even when ethnically diverse populations were smaller, there is still value in addressing other metrics (LGBTQ, poverty, disability)
    - Even so, it may still be valuable to collect and review race-based data for internal evaluation to remove barriers & improve care
- Ethics & Data Governance Considerations:
  - Current COVID-19 data collection, Medical Officer of Health promoted there was no need for race-based data b/c all would be served the same, but measured experiences have differed
  - "Healthy dose of mistrust" is rooted in negative historic experiences (e.g., Racism & Research: The Case of the Tuskegee Syphilis Study, Brandt, 1978; Indigenous residential schools; 1960s/70s sterilization of thousands of Indigenous American women without consent)
  - Community may ask, "Why should we trust you?"
    - Data is collected to identify where inequalities exist & collection must be immediately twinned with a response plan to address disparity
    - Mistrust in the community needs to be addressed openly & honestly
      - Will the data be collected & used to improve the community's health? Or will it ghetto-ize & pathologize various communities?
  - Ethics & use of data
    - Need to be cautious about further marginalizing communities
- Historical misuse & ethical concerns about data collection require data governance & accountability framework to adequately address
  - Not everyone will agree with collecting race-based data, but that does not mean it does not hold value
  - When there is not agreement about collection, what work can be done with communities to hear & address concerns?
- Issues for Consideration:
  - 1) Engagement
    - Convening individuals from within communities that are highlighted in analysis prior to release of reports
  - 2) Governance
    - Address the potential for stigmatization by pathologizing marginalized communities
  - 3) Inadequate analysis & misinterpretation of data
  - 4) Access
    - Data becomes the "domain" of large institutions, but evidence of resulting health improvements is needed

- Important to consider how broad access to the collected data may be provided to researchers, community organizations, etc
- 5) Protection
  - Important to put in place appropriate safeguards to ensure collected data will not be used against racialized communities, repurposed, sold, or monetized
  - E.g., FitBit might collect & monetize health data, but government must build trust
  - There are concerns that stem in part from lack of transparency at provincial level to clarify how data will be used
- Q&A:
  - **Q:** Is there any spatial analysis / mapping of the data being gathered?
    - **A:** COVID being spatially reviewed (e.g., where larger populations of racialized / black populations impacted)
      - Response = COVID-positive hotel has been set up to allow individuals in a shared household to isolate away from others
    - Mapping at neighbourhood level completed by LHIN done in order to explore profiles to review socio-economic demographics
    - Partner with Community Health Profile Partnerships to provide mapping <http://www.ontariohealthprofiles.ca/>
  - **Q:** How is value derived from racialized communities to interpret data? How to gather qualitative data to inform professional practice change / system design?
    - **A:** Declined experience & how to measure client experience in programs helps to guide future developments
  - **Q:** Race-based questions tend to match Statistics Canada metrics, however a mixed-heritage option is used in Toronto rather than inviting patients to select multiple boxes
    - **A:** StatsCan selections chosen because they were the most widely used
    - Mixed-heritage was used in order to create a smaller number of responses
    - Sarah & Lise at Toronto Public Health are currently redesigning this question based on community-feedback, specifically related to Indigenous communities, in order to better represent ethnicity
    - Recommend the need to evaluate community needs, program use, and make the best decision you can
  - Toronto Central LHIN has engaged with the Indigenous community to collect more finite data which is used internally & available to related community organizations but, following the OCAP Principles, it is aggregated when shared publicly

## ROUND TABLE

**What are your past or current efforts to collect race-based data? How were/will findings be used? Challenges/concerns?**

- Some local agencies have had a lack of race-based data which has limited the understanding of determinants of health
  - Some retrospectively analyzing data

- Indigenous communities not commonly consulted, but exploring report interpretations with the affected communities will help to inform their analysis prior to release
- Toronto Public Health are publishing results by race, income, but not yet including Indigenous experience
- First Nations Principles of OCAP (ownership, control, access & possession) need focused consideration
- As agencies consider changes to proposed questions, data analysts & community diversity experts are trying to understand one another's needs
- Once agency is mirroring staff survey with client survey
  - o How do staff & clients independently perceive service delivery?
- Toronto's Indigenous data management & engagement recommendations:
  - o Training re: Point of Care – Indigenous Cultural Safety (SanYas online training supported by Toronto Central LHIN) – highly recommended
  - o Ontario Perception of Care (OPoC) training to gather clients' perception of care includes good socio-demographic questions / information by CAMH

### **NEW BUSINESS / FUTURE MEETING DISCUSSION**

- Data Sharing within group (Sync.com?)
- Labour Market (40 min) Teams & Power BI visualizations at Fleming
  - o How do you use these tools to access information for decision making?
  - o Perhaps combine topic with a presentation by WDB for an early 2021 meeting?
  - o Delivery of employment services is changing significantly to become more integrated & Peterborough will serve as a pilot region
- PPH Marginalization Index -- to present in November 2020
  - o Ability to provide this presentation will depend on potential impact of a local COVID second-wave in November
  - o Would be able to present information on the research and ways that attendees can use the data in their own use

### **ADJOURNMENT**

Meeting adjourned at 3:02pm. The next meeting will be held from **1-3pm on November 3, 2020** virtually via Microsoft Teams.

Minutes submitted by: Tammy Sikma