



ETHICAL COLLECTION AND USE OF EQUITY-PROMOTING DATA INITIATIVE

Implementor Meeting – September 21, 2022

Present (by invitation): Heather Lokko (Middlesex London Health Unit, CRHESI Community Director), Alison Locker (Middlesex-London Health Unit), Christian Daboud (Middlesex London Health Unit), Nadine Wathen (CREHSI Academic Director), Donna Baxter (City of London), Jill Tansley (City of London), Kinga Koltun (City of London), Zahra Khawaja (City of London), Lori Hassall (CMHA), Anne-Marie Sanchez (London InterCommunity Health Centre), Jennifer Martino (Crouch Neighbourhood Resource Centre), Luis Patricio (Pillar Non-profit Network), Sukhi Bains (LHSC/Schulich), Daniel Lizotte (Western University) and CRHESI co-Coordiators Christine Garinger and Arun Jentrick.

PURPOSE & APPROACH:

- In follow-up to the June 3, 2022, [event](#) on data for health equity, community partners who had expressed interest in implementing data collection strategies were invited to a further conversation.
- The online session began with a presentation from Alison Locker, MLHU Epidemiologist, on the work conducted by MLHU since June to identify potential data elements and indicators that could form part of a community-relevant and equity-promoting comprehensive data set.
- Small groups then discussed the prioritization and/or subcategorization of the variables regarding potential utility, red flags or concerns, etc.; opportunities for collaboration and mutual support and how this could work, in an equitable way (i.e., given different organizational capacities); and next steps.

SUMMARY OF DISCUSSION:

Regarding the MLHU comprehensive data set, the following domains are noted as potential gaps or with particular associated sensitivities:

- ⇒ Sense of belonging (or isolation)
- ⇒ Household composition
- ⇒ Impact of racism on mental health and wellbeing
- ⇒ Immigrant status—note that fear of increased risk of deportation will be a barrier for some
- ⇒ Food security offered as a domain gap
- ⇒ Clarification requested about “official language” versus childhood language. might be confusing for people to understand its meaning. A: this domain is from the Ministry of Health
- ⇒ Age could be an important domain, grouped as youth for example and adding youth specific services or changing messages about what services are available knowing who is seeking services.
- ⇒ Born in Canada – City of London has a policy (the free of fear policy), prohibits asking this question.
- ⇒ Education, Religion/Spiritually – be very cautious in asking for this information

The Table on the following pages summarizes key discussion points about collecting and using data at the within-organization/ client level, and inter-organizationally.

In terms of next steps, there was interest in CRHESI selecting this as a topic to re-initiate its Community Conversation series at Innovation Works. A plan will be developed for a potential date in December.

To assist in planning the agenda for this event, please consider and advise CRHESI staff regarding:

1. What is important to keep talking about? What have we missed?
2. What are the topics or areas we collectively need to continue to evolve and act on?
3. Referring to the Implementation Principles (see Table), what do you want to do next?
4. How can we collaboratively act for collective impact? Ideas included working groups, a community of practice for concurrent knowledge sharing activities

TABLE: KEY DISCUSSION POINTS

	Client/ Organizational/Programmatic Level	Collaborative/Inter-organizational Level
Why (Benefits)	<ul style="list-style-type: none"> To improve client access to services, we must better understand access barriers, e.g., related to transportation and mobility with data to support better system navigation (broadly defined); Organizations with system navigators can support staff e.g., government assisted refugees from a French speaking country can be connected to French services Approach the work like “We ask because we care” resource/campaign in Toronto 	<ul style="list-style-type: none"> Aggregate data could support organizations across sectors to understand who they are serving, help planning and service provision, and avoid duplication of services while identifying key service gaps Collective approach could support diligence efforts to minimize harm, for example in system or organizational level cline transfers
Who	<p>Re: Staff</p> <ul style="list-style-type: none"> Need coaching re: collection and use of data for continuous improvement as a change management effort within organizations (all levels) Capacity building and staff training should include how, when and where to collect data Staff are quite concerned with how to collect such data in non-harmful, non-offensive ways How to respond to data results that seem to indicate a problem or need (<i>how to avoid making assumptions about what is a problem or crisis</i>) Implement wellness approaches for staff collecting this data <p>Re: Clients</p> <ul style="list-style-type: none"> How will clients be informed about their rights, privacy, and processes, e.g., opting out without fear of loss of services or harmful repercussions such as deportation or police involvement? How to reach clients that are hard to reach (e.g., street involved) <p>Re: Boards/Leadership</p> <ul style="list-style-type: none"> Process must be approved by Boards etc. 	<ul style="list-style-type: none"> Continue to expand this collective to include more perspectives, especially among diverse organizations (service type, size, governance approach, etc.)

	<ul style="list-style-type: none"> • Board and/or operational policies might require development or adaptation 	
What	<ul style="list-style-type: none"> • Understand from clients and program staff what data are necessary and relevant (and don't burden people by collecting data that is not necessary; i.e., already exists or is not useful/usable) • When and how to use secondary data (data already collected) to reduce duplication and to identify gaps, such as who is being missed • If data are aggregated must consider that some data is sensitive (in the case of MLHU for example, the Board must approve data that would be shared even if aggregated) 	<ul style="list-style-type: none"> • Suggest: Implement a 'two-level' data collection process: 1. includes data that all agencies will collect, and 2. specific to agencies/clients' needs and tailored to specific programs/services • Could data be shared by organizations that serve the same populations (<i>or offer similar programs?</i>) to locate the gaps (who is not being served) for improved service provision?
How	<p><i>A project charter to which participating organizations will sign-on is recommended to guide an intentional process and ensure:</i></p> <ul style="list-style-type: none"> • Process is "client-centred" • Acknowledge there is continued deep distrust in collecting (and using) these types of data • Need to ensure transparency and communicate how data will be used and for what specific purposes and outcomes (who benefits?) • Need safe, trauma and violence informed processes for data collection and reporting, esp re privacy • Accountability and transparency are paramount • Data taken must be reported back to the communities e.g., <i>"this is how this service or program has changed since we learned XYZ"</i> • Operationally, how to ensure privacy at point of collection • Informed consent process is imperative • On-going community engagement approach integrated throughout ("keep meeting" ...) • Must do public engagement as well as this focused engagement, the community directs us to collect the data • Suggestion to collect postal code data (will help to assess where the population is living and highlight certain areas of the City's participation) (<i>Caution here-are there lessons learned from past similar approaches and would want to avoid inadvertent harms</i>) 	
When	<p>Circumstances change; important not to interpret data as a static representation and collect at meaningful intervals, without over-burdening. Consider what can become part of administrative data-sets vs periodic collection for specific purposes.</p>	