Collecting and Using Data for Collaborative and Equitable Change
Post-Event Summary Report

On June 3rd, 2022, CRHESI brought together community members, professionals, academic and community researchers and students to discuss key issues around collecting and using data for collaborative and equitable change in our community. A total of 51 people participated in the 3-hour event; 17 in-person at Innovation Works in London, and 34 virtually (on Zoom). The following synthesizes key points made during presentations and discussions to help us develop and action a collective understanding and next steps. Our objectives were to:

- set a common understanding about critical issues, such as trust, dignity and respect, in collecting and using equity-sensitive data, including race-based data
- articulate and frame why, how and for/with whom we might collect & use these data
- generate momentum for collective action by creating opportunities for parallel conversations, consultation and synergy
- identify lines of action and collective resources to move the work forward

Nadine Wathen, CRHESI's Academic Co-Director, & **Daniel Lizotte** from Western University facilitated discussions around four presentations.

1) **Sukhveer (Sukhi) Bains**, an emergency medicine physician at London Health Sciences Centre and a CRHESI Executive Committee member, centred her talk on the importance of raising awareness when collecting equity-oriented data. Since race is a social construct, not a biological trait, she discussed the that ways race-based data in particular have been weaponized by those in power to (re)marginalize communities. Sukhi emphasized the need to look structurally *and* historically and advised us to acknowledge that we cannot discuss socio-demographic data without an analysis of power.

2) **Mojdeh Cox**, CEO of Pillar Nonprofit Network, asked us to reflect on the intentions behind collecting data if we aim to build trust and strive for mutual benefit in such activities. In prioritizing the purpose of data collection, Mojdeh emphasized we must understand where we have been to know where we are going. *"How do we collect our audacity first?"*, she implored, particulary when historical injustices against Indigenous peoples have yet to be reconciled. Mojdeh appealed for "radical accountability" when embedding the components of sustainable justice, equity, diversity and inclusion in any data collection and analysis project. Also, asking people to reveal themselves is inherently intimate, Mojdeh stressed transparent, trauma-informed approaches as vital for trust-building.

Greta Bauer, Professor at Western University, presented a research exemplar on how to prioritize community knowledge when gathering data from structurally marginalized populations. The framework of Trans PULSE Canada, a research project focused on the health and well-being of trans and non-binary people, includes strategies that prioritize the interests and concerns of nine unique *intersectional* populations within trans and non-binary groups who also identify as, for example, differently abled, Indigenous, racialized, young, etc. Using a participatory approach balances power (where possible) and engages research participants in knowledge creation, including survey co-development and mobilizing research results in tailored-to-audience ways, while prioritizing their experiences as community knowledge.

Alison Locker, an epidemiologist with Middlesex-London Health Unit, showed us how surveillance data can be moved into action through a brief review of the HIV crisis in London from 2005-2015. Surveillance data helped public health experts to see and better understand evolving risk profiles. Local risk factor changes were found to be related to the increased proportion of people who inject drugs and this drove public health experts and community partners to tailor interventions (e.g. increased point of care testing, new and increased harm reduction initiatives) through sustained and collaborative efforts, with positive results on subsequent HIV infection rates.

Discussion points from presentations:
- How do we use data for advocacy alongside for policy and program decision making?
- We must recognize that data collection itself can be re-traumatizing and exhausting, and balance this potential harm with clear benefits to individuals and communities, not just researchers or organizations. In general, we need to think beyond just research ethics.
- When do we decide to stop collecting data on well-established phenomena? As one person said: "*Do we still need to collect race-based data when we already know about racism and its impacts?*" How do we know when to update data?
- To build trust we must ensure we are not perpetuating harmful beliefs/biases, and we must report back in a cycle of ongoing learning and communication for mutual benefit. Too often a deficit lens is used and don't want to perpetuate these kinds of stereotypes. We need humility and courage to understand narratives and histories, to use data to construct positive counternarratives, in a good way.
- Who should have access to collected data? Is there a place for open-source data collection and sharing?
- We need more voices developing research questions and more advisors from communities whose data is being collected.
- Data collected explicitly to make change will be disruptive and may lead to defensiveness and back-lash. We can anticipate and prepare for this, and how to "bring people along." How do we get people to separate personal guilt from structural violence?

The outcome of the small group consultation on data collection and use challenges and opportunities yielded the following key points:

Challenges
- How to make metrics/indicators comparable across contexts is a massive challenge.
- Control over datasets by researchers and/or organizations limits use, impact and transparency/trust.
- Everyone is eager to collect data, but they don't always have clear objectives for how the data will be used and how to translate the data and turn it into meaningful action that benefits communities. People are exhausted and over-engaged regarding data collection.
- We need to balance data quality/rigour with protecting people from data re-identification if we get too specific, especially for smaller identity/intersectional groups.
- We must develop a common understanding of concepts (e.g., equity) and language.
- How do we (re)establish trust in institutions that have and do create harm (universities, hospitals, etc.)?

Opportunities
- Data can make the case to increase or improve access to services.
- Capturing diverse data has the potential to transform the euro-centric roots of many of our professions.
- Creating ways to share data for personal (e.g., personal electronic health records) and community (e.g., dashboards, open source data) needs can reduce power differences.
- Being more intentional and genuine in engaging clients/the public around data collection-ask "what do you want or need?" *versus* "here's how you can be involved".
- More grants are available around EDI and data at the federal and provincial levels.

We then discussed what we can do next, as a community, to plan and implement data collection strategies to reduce inequities in London and beyond. We focused also on CRHESI's role in this process.

Potential Collective Next Steps
- Environmental scan of what has and is being done in London (e.g., follow-up with those involved in previous London data coordinating committee work). Who's collecting what, what's available, what's comparable, etc.?
- Series of workshops/data jams ("data-palooza"!) on collecting and using data for collaborative and equitable change.
- Series of discussions on the macro issues involved in data collection and use: trust, radical accountability, ethics, common language, open access, including lived/living experience experts, fair compensation for time; resourcing, etc.
- Explore existing and best practices in things like public/open source data dashboards (City of Toronto example) and data co-ops. How to make this an open and inclusive

process (including the right actors and voices) of how to talk about these things, how to decide who's collecting, what, how it's reported, how it's presented, media, etc.

CRHESI Next Steps
- Synthesize and summarize discussions (this document) and share with attendees
- Post presentation videos
- Plan next steps with our Executive Committee, including approval for immediate task of conducting a scan to see what's being done and where and how we can support efforts

In summary, this was a well attended event in a hybrid format with an approximate 75% attendance rate of those registered. There were some last-minute shifts from in-person to online attendance. Plenary discussions and presentations were effective in eliciting thoughtful and honest input from participants, and there was significant enthusiasm for CRHESI to take a lead role in ongoing discussions and activities.

We thank the event organizing committee: Heather Lokko, Sukhi Bains, Dan Lizotte, Arun Jentrick, Christine Garinger, James Shelley and the speakers & facilitators: Sukhi Bains, Greta Bauer, Mojdeh Cox, Alison Locker, Dan Lizotte, Christine Garinger, Jennifer Martino, Abe Oudshoorn, Nadine Wathen.