Community Agencies Promoting Social Equity through Collection of Ethno Racial and Sociodemographic Data: Lessons Learned from a 3-year Pilot Project in Ontario, Canada

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Project Oversight

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Project Partners

United Way of Peel Region
Legal Aid Ontario
Association of Legal Clinics of Ontario
Central West Local Health Integration Network: Caledon Community Services; Canadian Mental Health Association Peel; Heart House Hospice; Indus Community Services; Punjabi Community Health Services; Rexdale Community Health Centre; Supportive Housing in Peel; William Osler Health System; Wise Elephant Family Health Team.
Mississauga-Halton Local Health Integration Network
Ontario Council of Agencies Serving Immigrants
Quinte Local Immigration Partnership
West Neighbourhood House
Thorncliffe Neighbourhood Office
Secretariat of the Ontario Poverty Reduction Strategy
Windsor Women Working with Immigrant Women
John Howard Society of Ontario
Family Education Centre
CultureLink

Background

Data starts conversations; creating the space to ask why differences exist. *Are our services accessible? Are we meeting the needs of our local population equitably? What are the needs of our cultural communities?* The following recommendations reflect the learnings of an ongoing project lead by the Policy Advocacy and Research Committee of **Colour of Poverty - Colour of Change**. Since the fall of 2014, the project has been funded by the Ontario Trillium Foundation, intended to build capacity for ethno racial and sociodemographic data collection in the province of Ontario, Canada.

During the course of the project, a number of facilitators, barriers and recommended strategies were identified across a variety of sectors, housing, child & family services, mental health and addictions, legal aid, settlement and community health services. The project partners include sixteen human service agencies across a variety of social and health sectors that interact with diverse communities across the province. Other partners include funding agencies (The Ontario Poverty Reduction Strategy Secretariat, Ontario Council of Agencies Serving Immigrants, United Way of Peel Region and the Central West Local Health Integration Network). The project lead also collaborated with regional planning groups, (Quinte Local Immigration Partnership, Peel Data Collection Community Partners).

Coordination of Regional Data Strategy by Funding and Planning Agencies

While the following guide is intended to build capacity among community agencies for local planning and advocacy, initiatives can be supported by regional planning and funding bodies that are able to coordinate and institutionalize data collection in the region.

- Require ethno racial and sociodemographic data collection among funded agencies.
- Engage sectors to define their own equity indicators collaboratively in an effort to track outcomes in a coordinated but sector relevant approach.
- Build evaluation support for data analysis that can be shared among funded agencies.
- Create a data collection strategy to coordinate local data collection, tracking priority areas of disadvantage in the region.
- Build collaborative relationships with community evaluators.
- Coordinate and integrate sociodemographic data collection with other local agencies to ensure service providers are not being asked to ask the same survey questions in different formats.

Example: Punjabi Community Health Services - Coordinated Resources and Implementation

PCHS in Brampton, was required to collect sociodemographic data by multiple funders in Peel, two of which were partners on this project. This CHC also receives project management, and consultation support from a neighbouring health integration network and utilizes a sector specific tool (HEIA), to integrate data collection processes into equity planning for programs and policies. (See Figure 1). In the presence of support for implementation, consultation, staff training (collection and analysis), PCHS was able to create a comprehensive implementation plan, (Figure 2.), rolled out from September 2015 to March 2016.

Figure 1. PCHS Coordinated Resources and Supports for Implementation

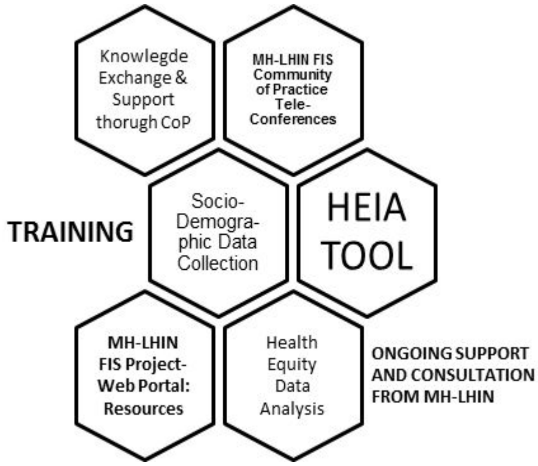
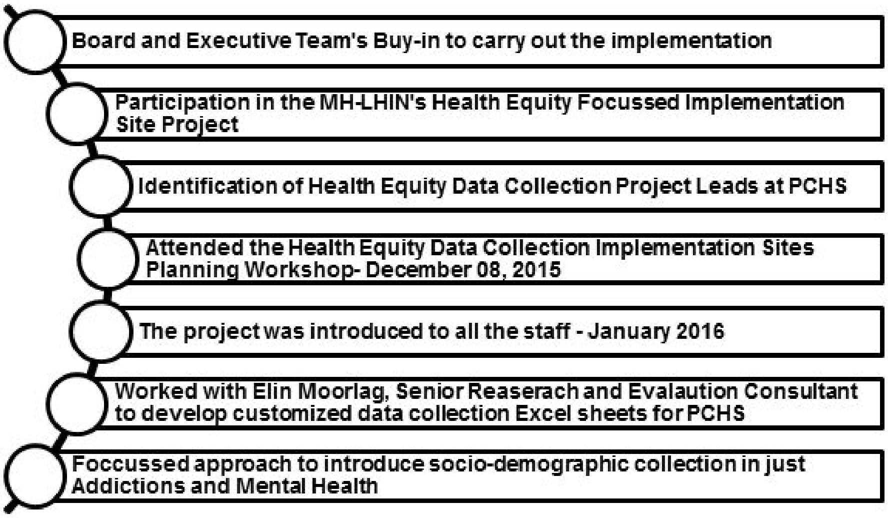


Figure 2. PCHS Comprehensive Implementation Plan.



- Board and Executive Team's Buy-in to carry out the implementation
- Participation in the MH-LHIN's Health Equity Focussed Implementation Site Project
- Identification of Health Equity Data Collection Project Leads at PCHS
- Attended the Health Equity Data Collection Implementation Sites Planning Workshop- December 08, 2015
- The project was introduced to all the staff - January 2016
- Worked with Elin Moorlag, Senior Reaserach and Evalaution Consultant to develop customized data collection Excel sheets for PCHS
- Foccussed approach to introduce socio-demographic collection in just Addictions and Mental Health

Elements of a Data Collection Process for Community Organizations Working with Diverse Communities

The first two stages of data collection, (assessment, and building the argument for data collection), can be completed concurrently. In larger more complex organizations this process may require additional supports obtaining organizational approval. Staff training is intended to build comfort and confidence among staff on data collection, as well as address resistance from organizational staff across all levels of front-line providers, supervisors/managers, data management personnel, and senior administrators.

Step 1. Assess Current Data Collection Activities

To determine your current data collection needs you will first need a snapshot of your data collection activities and be able to answer the following questions:

- What sociodemographic data do you currently collect? Is this organization wide or program specific? How is this data used? What are the current response rates to questions?
- What sociodemographic questions do you not currently ask, and why? What barriers or challenges prevent you from doing this? What supports are needed?
- What are the benefits and limitations of current data use? Is this integrated into organizational planning processes, case management and regional planning?
- Can your current data management software allow customizing of survey questions to accommodate sociodemographic questions?

Example: Adaptability of Sociodemographic Survey Tools across Settlement, Mental Health and Housing Services.

The adaptability of the collection tools among funders could facilitate or present a barrier to consistent data capture. Data collection across programs could be inconsistent and dependent and funders requirements for use of differing survey tools.

The Ontario Council of Agencies Serving Immigrants (OCASI) requires member agencies to collect sociodemographic data using OCMS (Client Management System) which allows for customizable field options. As a result, both Quinte Local Immigration Services, and Thorncliffe Neighbourhood Office were able to adapt their questions to accommodate questions they had about their local populations. While they data management software was adaptable, this these organizations reported need for support to generate buy-in from managers and front-line staff.

In the cases of immigration and settlement services, OCMS provided some consistency and comparability of data across the sector. In the case of mental health and housing sector, survey tools could be inconsistent. This process presented a potential burden to agency staff who preferred to integrate survey questions across programs and services. Ideally a consistent process across the entire range of clients, that is comparable with other sectors, having the most use for organizational planning.

> *There are multiple requests for the same information and the information is housed in multiple databases. The data analysis is limited and not streamlined across the various service providers. We have been using OPOC which collects similar socio demographic data that was launched in 2015. We will be launching the [funder's] registration form at intake starting the end of February. These questions may not be an accurate reflection of the individual's response as the referrer may assume certain responses and this is not a self report.*
>
> *Leslie Barnes, Director of Services for* Supportive Housing in Peel

Organizations that worked with people with mental health and addictions issues were required to collect data through a standard survey tool (Ontario Perception of Care Tool for mental health and addictions) to guide the client's case management. For the purposes of this pilot, organizations were permitted to use data from one survey instrument for the other, but considering that the data may not represent a self-report for identity data; organizations suggested funders coordinate consistent data capture questions in the future across a variety of health and social sectors.

Step 2. Implementing Data Collection - Staff Training and Organizational Buy-In

Previous data collection initiatives have highlighted the importance of training that addresses staff discomfort asking sociodemographic questions, building staff understanding of the value of data collection in their programs and services and confidence asking sociodemographic questions. Some of the best practices:

- Training should include the benefits of asking each sociodemographic question on the survey instrument so staff are able to explain to their clients the purpose of data collection.
- Training that includes at least an hour to practice questions with feedback from supervisors and other staff.
- Include front-line staff who collect data, and their managers, in a discussion of the benefits and limitations of anonymized data versus data linked to the client files. While anonymized data at intake is likely to have the highest response rates, linking data to client files can inform case management and tracking of outcomes over time.

Example:

Training sessions at each organization included a facilitated discussion among relevant organizational staff about how to make data collection work for their organization and clients.

Socio-demographic Data Collection training was important to facilitate understanding about socio-demographic data collection for everyone, staff and management alike. Another lesson learned was to be open to unexpected outcomes and timeframes. The conversation regarding data streamlining project was an unintended outcome.

- Mary Lou McDougall, Canadian Mental Health Association of Peel Region

Example: Collecting Data from Vulnerable Populations during point of crisis - Examples from agencies providing end of life care and legal aid services.

Among partner agencies, client's likelihood to respond to questions of sexual orientation, income, race and ethnicity, were higher when clients had a strong rapport with the service provider. For agencies that may interact for a short period of time, during crisis periods of client's lives, such as the partners on this project representing the legal aid, and end of life care sectors, they often face a particular challenge to ensuring high quality data collection. To ensure their data collection processes were effective, it was helpful for staff (front-line, management and board members) discuss how to both meet the service needs of their clients in a way that makes sense for their organization, while ensuring high quality data collection.

Heart House Hospice provides palliative care in Mississauga and Brampton areas, and is engaged in last 12-17 weeks of life care. While data implementation leads provided the training session, they facilitated a discussion among, data collection staff, senior managers, to decide how data collection processes can be sensitive to the needs of clients and their families at the end of their lives, by creating a protocol:

Questions will not be given to individual to check but will be discussed when counsellors understand it to be appropriate. For example in a situation where person is actively dying and contact is only with caregiver – data will not be collected where if a referral in received with prognosis of 6 months or less, and the environment is stable, counsellors will pose questions at the home assessment.

- For a sustainable data collection practice, the training should be integrated into HR or staff development processes.

- Engage with other local community organizations and groups that work with LGBT and cultural communities, to design effective training, that addresses staffs discomforts around questions of sexual orientation, gender identity and ethno-racial identity.

Example: Community Health Program for South Asian Elders in Brampton, Ontario.

At a health provider in Brampton that provides day programming for South Asian elders, staff expressed discomfort asking clients about their sexual orientation and gender identity. Through discussions with organizational staff it became clear that barriers to data collection included (1) Staffs perception of the cultural context of asking an elder within the community about their sexual identity. (2) Language within the community - Terms may become pejorative when translated into the the cultural context of the client.

Staffs practiced asking and explaining the purpose of questions with other staff and reported as they became more comfortable asking and explaining the rationale for the survey sections with their colleagues, their comfort level improved. After staffs began collecting data from their clients reports from this provider, and staff from a neighbouring community health center, suggest the survey process supported a safe space, where conversations could be opened about the needs of LGBT and queer people within the South Asian communities of Peel Region.

For larger organizations, buy-in from all levels of staff, managers and senior managers could be a gradual process. In responding to concerns around the additional time and staff resources required for data collection, it was important to outline the benefits of data collection for organizations and staff:

- Planning culturally appropriate programs that service the needs of local communities.
- Being able to identify, monitor and understand inequities.
- Being able to better evaluate services, identify gaps, influence policy and advocate for resources.
- Increased capacity for engagement with local communities.

It was also beneficial to outline concrete examples of similar local work that has been successful, refer to resources and outline potential support from local community evaluators. Staffs demonstrated the greatest appreciation for the work in their everyday data collection practices when they could connect that practice, to the potential benefits for their programs and clients.

Agencies and their staffs have commonly expressed a concern around the legal permissibility of collecting data from clients on their identity and socioeconomic status. Clients who submitted their sociodemographic information, did so voluntarily and were informed that receiving services was not conditional to their response to survey questions. Each question also included the option to respond, “prefer not to answer”, making available the option not to submit personal information. Despite data collection not being mandatory, client's response rates have a tendency to remain high at 75-98% across agencies.

For clarification on the local human rights code in relation to collection of identity data, the project partners were referred to resources by the Ontario Human Rights Commission, intended to encourage and support collection of diversity data.

(1) Count Me In: Collecting Human Rights Based Data.
(2) Pages 42-45 of the OHRC Policy and Guidelines on Racism and Discrimination, section referring to the collection and analysis of numerical data.

Step 3. Data Analysis and Interpreting Differences in Outcomes

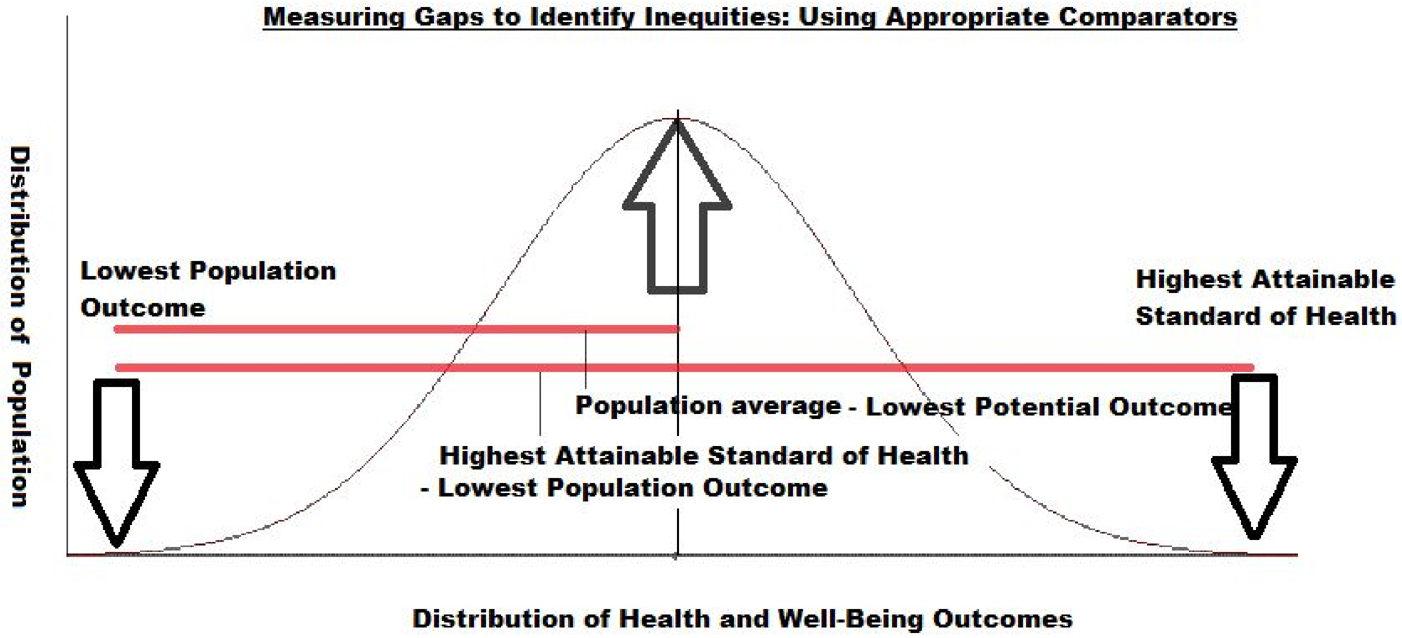
Community evaluators can work with organizations to build local capacity for data analysis. Data cleaning, verification, and preliminary analysis is well within the capacity of individual organizations to implement. For the process of interpreting the results of data analysis, organizations are encouraged to draw on the support of evaluators, communities and frontline staff.

- Seek feedback from experienced evaluators to interpret descriptive statistics and identify strengths as well as disparities.

- If disparities are identified, engage the affected communities and include frontline staff to interpret the issue. This may take the form of member checking, focus groups or public consultations as methods of engagement.

- To understand the issue further engage the affected communities while considering the power dynamics of service relationships with vulnerable groups. In doing so, beginning key informant interviews with people closest to the disparity is recommended. This should include service users in the community affected, service staff, then program administrators and decision makers.

- When possible, use appropriate comparison data comparing highest and lowest outcomes, rather than population averages, to measure unequal outcomes. The distribution of health and well-being outcomes in a population usually falls far below the highest attainable standard of health, giving a measure of population health rather than setting an ideal benchmark for planning, understanding the ideal conditions which facilitate health for the healthiest population.For a conceptual overview of the relevance of this, compare the lengths of the red lines in the figure below. For the theoretical basis of this practice, refer to the work of Whitehead (1992) on the concept of health equity, as well as, the implications for practice outlined by Braveman (2006).



Step 4. Data Mobilization: Integrate Knowledge into Planning and Decision Making

Collecting diversity data should be done with the intended purpose of generating improved conditions for disadvantaged or under resourced populations through more informed planning. Conversations are guided by a concern to meet the needs of all clients and groups equitably. and address systemic barriers to effective service outcomes, both within services or in the community context.

Agencies should strive to build stronger relationships with the groups not typically involved in decision making to contribute meaningfully to decisions. Since inequity is often not visible to decision makers, the process of engagement initiates a conversation that should be sensitive to power imbalances that may exist between service providers and service users.

For examples of how to translate data into organizational processes, the Canadian Institute for Health Research offers a casebook of past examples of this work across health organizations.

The National Collaborating Center for the Determinants of Health offer another resource providing a critical review of knowledge to action models for the purpose of promoting more equitable health outcomes, as well as a more recent resource for identifying opportunities to integrate intesectionality into practice. The following recommendations reflect a proposed model for data mobilization in the context of organizations that interact with diverse communities.This is planned with project partners in the next phase of the project, April 2017.

- After identifying disparities during data collection, and having engaged with communities and service staff to understand the nature of those issues, involve communities, staff and managers in working groups to address the issue both within the agency and in the community.

- In the health sector, HEIA (Health Equity Impact Assessment) has been increasingly utilized as a tool in recent years to integrate data collection, policy and action on health equity issues.

- Set equity targets for vulnerable groups and communities using the highest attainable standard of health or well-being, as determined by the population with the most ideal outcomes, rather than population averages as a measure of the disparity.

Example. Mobilizing Data without Client Outcomes

Although data attached to client records had greater potential for monitoring outcomes and potential disparities over time, agencies who did not initially link sociodemographic data to client files, using anonymized surveys at intake instead, were still able to take concrete actions to integrate data collection into their equity processes. The descriptive data was still beneficial for planning purposes and requesting funding.

Although we capture data to aid in reporting to the LHIN and the United Way, we are limited in our ability to link the data to specific outcomes. The data collected helps to inform our service delivery, annual report, administrative audit report and, in some instances, our business cases for additional funding.

The pilot project has highlighted the importance of having an organizational understanding of health equity and socio-demographic data collection. The Health Equity Committee sub-group, the Access team and the Health Equity Committee, have become organizational champions for socio-demographic data collection. The data streamlining project is currently analyzing the data mapping of all the data elements we collect across programs. Recommendations are expected to come April 2017.

Mary Lou McDougall, Canadian Mental Health Association of Peel Region

Even in the absence of outcome data the CMHA of Peel was able to take concrete actions towards institutionalizing sociodemographic data collection as an organizational priority by integrating this into the work of organizational committees and by assigning leadership on implementation.

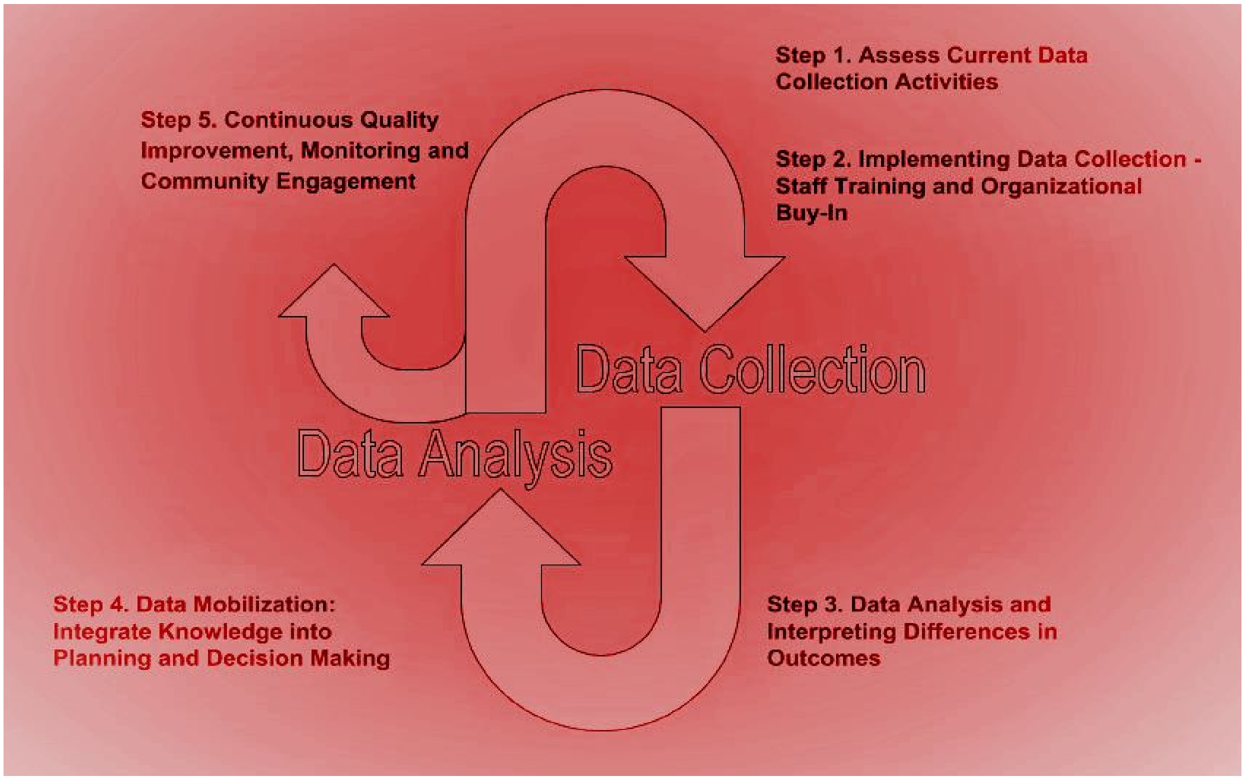
Step 5. Continuous Quality Improvement, Monitoring and Community Engagement

Sociodemographic data Is ideally a sustainable process of cyclical data collection, analysis and quality improvement followed by continued community engagement.

- Cyclical processes can be institutionalized by implementing regular reporting cycles. i.e. annual or relative to changes in programming, policies that could impact outcomes.

- Include perspectives people and groups disproportionately affected by policies and services in reviews and evaluations.

- Collaborate with local service providers, groups and associations to strategically address issues that commonly affect clients.



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