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# Dialogue Summary: Identifying Facilitators and Processes for Sharing Local Data with Community Partners to Enable Improvement in Health Equity

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## Putting the pieces together

Public health sharing information with community  
organizations to promote healthy living for all

## **Locally Driven Collaborative Project (LDCP)**

This Dialogue Summary is part of an LDCP funded by Public Health Ontario. The purpose of this LDCP is to bring multiple perspectives together in order to collect locally relevant contextual information in a process to discuss research evidence gathered through the survey findings and literature review.

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## **Conflict of Interest**

The authors declare that they have no professional or commercial interests relevant to the dialogue summary. The funders listed above did not participate in the development of this dialogue summary.

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## Table of Contents

<b>Introduction</b> .....	<b>1</b>
<b>Summary of the Dialogue</b> .....	<b>1</b>
<b>Summaries of the Four Deliberations</b> .....	<b>2</b>
<b>Deliberation about the Problem</b> .....	<b>2</b>
Capacity limitations among LPHAs, Health Service Providers, and Community Partners .....	2
Lack of a Universal and Consistent Data Sharing Strategy .....	3
Lack of a Supportive Structure and Culture for Data Sharing.....	4
Resistance to Sharing Personal Information with Community Partners .....	4
Lack of Familiarity with Legislative and Ethical Processes and Practices Regarding Data Sharing ....	4
<b>Deliberation about Potential Solutions</b> .....	<b>5</b>
Analyzed and Interpreted Data (e.g., Executive Summaries, Fact Sheets, and Detailed Reports) Shared Electronically .....	5
Forming/Enhancing Data Sharing Networks of a LPHA and Community Partners .....	5
Public Health Assistance with Capacity-Building for Community Partners in Terms of Health Data ...	5
Developing Universal and Comprehensive Methods for Data Collection and Sharing with Between LPHAs and Community Partners .....	6
<b>Implementation Considerations</b> .....	<b>6</b>
<b>Deliberation about Next Steps</b> .....	<b>7</b>
A Holistic and Widely-Implemented Strategy .....	8
<b>Conclusion</b> .....	<b>9</b>

## Introduction

As part of a Public Health Ontario funded Locally Driven Collaborative Project, Health Equity Data Mobilization, a deliberative dialogue was held on September 26<sup>th</sup>, 2017 in Toronto. Eighteen individuals participated: two represented local public health agencies and sixteen participants were representing different community partners. The basis of this discussion was an evidence brief summarizing the findings of a literature review, and survey of community partners.

## Summary of the Dialogue

Dialogue participants generally agreed with the first theme related to the problem as presented in the evidence brief; identified as a lack of capacity among Local Public Health Agencies (LPHAs), health service providers and community partners to share data. Other themes related to the problem presented in the dialogue include: a lack of a universal and comprehensive data sharing initiative, a lack of a supportive work structure and culture for data sharing, resistance among clients to sharing personal information with community partners, and a lack of familiarity with data privacy and ethics legislations among community partners. Participants focused particularly on issues related to capacity and inconsistencies in data collection and sharing across organizations.

There was consensus among dialogue participants that all three potential solutions to the problem discussed in the evidence brief are necessary for change to occur. These solutions include: sharing data electronically, in the format of analyzed data through summaries (e.g., executive summaries, fact sheets, and detailed reports); data sharing networks of a LPHA and community partners within its catchment should be formed/enhanced; and public health support to assist with capacity-building in order to efficiently analyze, interpret and integrate health data into community partners' work. Another major solution discussed was developing universal and comprehensive methods for data collection and sharing with community partners. This includes creating a general framework for data collection across organizations. Participants also generally agreed that there is a need for an online database or reservoir to be developed at the provincial level where community partners can access data related to the social determinants of health (SDOH).

The next steps outlined in discussion included creating an inventory of data community partners are able to collect and manage, as well as the data sources available. This includes identifying what level of data should be shared, whether identifiable data should be included, and the data privacy legislation that goes along with sharing such data. Steps for the long-term include developing a comprehensive data strategy,

including a communication strategy that will outline a universal way to collect data related to the SDOH from clients and developing an online database/reservoir to share data across organizations.

## Summaries of the Four Deliberations

### Deliberation about the Problem

#### **Capacity limitations among LPHAs, Health Service Providers, and Community Partners**

Participants identified capacity issues related to collecting, analyzing, interpreting, and integrating the use of demographic and health outcome data among LPHAs, health service providers, and community partners. These limitations were said to have far-reaching consequences, and was a consistent thread throughout discussion.

All participants agreed with the observation that LPHAs also face capacity limitations especially in terms of providing data to community partners. Participants noted that in the reports that LPHAs do provide the data is not always relevant for all community partners, as LPHAs are attempting to share a wide scope of information and are approximating what data may be relevant to community partners. A number of participants suggested that this is largely due to a lack of knowledge among LPHAs about what types of data would best serve the needs of community partners.

Participants also identified capacity limitations within other health organizations. One participant shared that Community Health Centres (CHCs) in Ontario have a standard data collection framework, but collect limited SDOH-related data. Additionally, many CHCs do not have sufficient staff to analyze all the data available to them. Another dialogue participant noted that the infrastructure does not exist for sharing data between hospitals, as many hospitals utilize different electronic health information systems that would be difficult to combine.

In terms of data collection, participants agreed that frontline staff are often uncomfortable asking clients personal questions related to the SDOH, such as inquiries pertaining to income. Also noted by participants was that frontline staff can experience difficulty with balancing demands to provide clients with the best possible services as well as collecting personal data from them. All participants agreed that providing services would always be given precedence over data collection. Compassion fatigue due to extensive work with clients was noted here as another barrier by dialogue participants. Sufferers of compassion fatigue (lessening of compassion based on

consistent, stressful work with populations in distress) may be less productive and may not collect the necessary data from clients. Participants shared that frontline staff within their organizations usually collect simple reach and/or exit measures, such as the number of clients served. These basic measures often do not address the SDOH and do not fully show whether community partners are addressing the needs of their clients through their programs.

The need for qualitative data was highlighted in this discussion, as dialogue participants noted that they find the quantitative data they have access to is limited in its ability to make inferences or determine causation. Additionally, the data currently available – which is mostly quantitative – does not provide insights about how and why certain conditions or outcomes are (or are not) influenced by a number of determinants, which is what qualitative data is better equipped to do. The example noted in discussion was a program aimed at addressing low high school graduation rates, and the information lacking was why rates were low in the first place.

Community partners identified capacity barriers including a lack of time, skills, and/or resources to mine, collect, analyze, and interpret health and epidemiological data. This was noted to be especially true when applying for grant funding, which is often constricted to a short time frame. Community partners may not know how to access certain types of data apart from directly asking their clients (i.e. whether their clients have seen various health service providers). Some community partners stated that they receive data from sources such as LPHAs, CIHI, or the Census but may not have the time and/or skills to analyze and therefore fully utilize this information. Financial limitations were identified as a significant capacity barrier, which affect community partners' ability to pay fees to access data from organizations that house data, such as Statistics Canada. Community partners may be understaffed and even with funding to recruit staff; community partners noted it could be difficult to recruit a data analyst to meet their needs.

### **Lack of a Universal and Consistent Data Sharing Strategy**

A barrier identified by participants was the lack of a strategy for sharing health outcome data, resulting in fragmented data sharing initiatives among community partners and other local health organizations. There is no universally applied method to collect data, even within communities. As a result, community partners often have their own unique datasets. This leads to problems such as duplication of data counts when data is shared across organizations (i.e. having the same client counted as different persons across various organizations), variances in definitions for similar indicators (i.e. using different age ranges for 'youth' across different organizations) which can lead to unreliable findings. Within their individual data collection systems, agencies often collect data with different geographic boundaries and scales (i.e. neighbourhood, ward or municipal, LPHA, LHIN level boundaries) which can be difficult and costly to combine into one data

set. In addition, if data collection from clients is not mandatory there may be certain demographics not captured in the process, which can skew data results.

### **Lack of a Supportive Structure and Culture for Data Sharing**

Participants agreed that a culture of competition exists between organizations in regards to data sharing. Community agencies often use data in support of bids for funding, which puts them in direct competition with other similar and/or nearby agencies. This is a barrier to data sharing and building on mutual goals.

There is also a lack of emphasis on collecting SDOH data within community agencies. Many dialogue participants shared that the purpose of their data collection is to address Ministry requirements with specific end goal measures but not for any further inquiry beyond these basic demands, as many do not have the proper structure to do so. There is also a culture of prioritizing client services first among community partners, which can make it difficult to integrate direct data collection from the client without disturbing the service experience of the client. However, participants noted the value of SDOH data, in that not having such data may make it more difficult for community partners to determine how services have affected clients.

### **Resistance to Sharing Personal Information with Community Partners**

Another barrier to data sharing identified in the discussion was resistance among clients to share personal information with community partners. Clients may experience study fatigue as they are asked to provide data repeatedly, often within each service they use. It can be difficult to build trust with clients in the context of data collection if the motives for data collection are not fully explained to them. Clients may also fear how the data they provide might be used against them; such as being disqualified from receiving a service with a specific mandate (e.g. services provided only individuals under a certain income level). Stigma can also be a barrier to clients sharing information with service providers, in terms of the shame that can be associated with identifying as a member of a marginalized group.

### **Lack of Familiarity with Legislative and Ethical Processes and Practices Regarding Data Sharing**

Many dialogue participants voiced their concerns surrounding data ethics and privacy. One participant specified that is difficult to use neighbourhood level data such as postal codes since it can lead to identification of participants. Participants agreed that there is a lack of understanding about the regulations and ethics of collecting, analyzing and sharing data and one participant referred to this as a culture of “hypervigilance” to protect individuals’ privacy. Dialogue participants were additionally unclear about who owns the data once it is collected and at what point does data become secondary (data used for a purpose other than the intended research project) within data sharing initiatives between community partners and LPHAs.

## **Deliberation about Potential Solutions**

There was a consensus among dialogue participants that all three solutions offered in the evidence brief are necessary. Detailed summaries for these and other options are provided below:

### **Analyzed and Interpreted Data (e.g., Executive Summaries, Fact Sheets, and Detailed Reports) Shared Electronically**

Positive attributes of this option outlined in the discussion, included that it could save community partners time from having to interpret raw data if they have snapshot summaries being provided to them. One community partner noted that getting summary results from an epidemiologist on their project greatly reduces the amount of time the community partner needs to complete their project, as they do not have to mine and analyze the data on their own.

Participants raised several potential challenges of this option, including that summaries are provide high-level information and may not assist with informing the specific needs of local programs. In addition, summaries only provide a snapshot in time, which provides limited information.

### **Forming/Enhancing Data Sharing Networks of a LPHA and Community Partners**

Data sharing networks were identified as being an option to increase communication between LPHAs and community partners in order to share information about what data exists, where it exists and how community partners can prioritize their data needs. Many community partners attending the dialogue already participate in small networks and find that there are many challenges with it. This includes the power dynamics present within networks containing organizations of vastly different sizes and that it can be difficult to coordinate networks since community partners may not have the capacity to dedicate time to them. Participants highlighted that having a common goal is essential for networks to be successful.

### **Public Health Assistance with Capacity-Building for Community Partners in Terms of Health Data**

Participants shared that Local Public Health Agencies assisting community partners with data collection, analysis, and interpretation would save time for community partners, as they would not have to search for the data they need. In terms of seminars and workshops provided by LPHAs, a dialogue participant noted that often knowledge is not retained over time, especially if knowledge gained is not used or built upon. Dialogue participants agreed that stronger relationships between LPHAs and community partners are needed, and awareness needs to be raised of the value of using a SDOH lens to address health equity concerns.

Dialogue participants noted that including academic professionals in this support system would be useful for community partners to gain access to data. One academic resource mentioned in the dialogue was [knowledge mobilization officers](#) from Brock University who consult with community partners regarding their data needs to create research that can be applied to local settings.

### **Developing Universal and Comprehensive Methods for Data Collection and Sharing with Between LPHAs and Community Partners**

A common theme in the discussion was the need to take steps towards a common way to collect and share data between LPHAs and community partners. A suggestion to unify data collection methods was to develop a universal way to collect data similar to the Census. One suggestion was to develop a data collection framework specific to the SDOH for frontline workers when they collect data from the clients they serve. An example of such a framework is [The Tri-Hospital + TPH Health Equity Data Collection Research Project Report](#) which includes a questionnaire that frontline workers can use to ask clients specific socio-demographic questions related to factors such as age, gender, income and language.

Suggestions to improve data sharing initiatives shared by participants included moving away from the current top-down approach for data sharing and moving towards a more collaborative and non-hierarchical data sharing approach between all organizations. A suggestion for sharing health data made by participants is a data sharing reservoir or online database at the provincial level where community partners can: access data, have the ability to ask the data authors or local LPHAs questions about the data, and have the ability to tailor the data to local needs. An example of a similar initiative is the [National Homelessness Count](#), which uses shared terminology to collect homelessness data across the country at a single point in time with additional diverse questions that were applied to address local contexts.

### **Implementation Considerations**

Participants highlighted four major barriers to moving forward, including; Uncertainty around leadership; scale and geographic scope; existing data culture; methods used for collection.

Despite the barriers, participants also noted that progress may be facilitated by the current political climate (to cover fifth paragraph).

Community engagement is a consistent theme found in the discussion related to implementation considerations. Data collection on a large scale at the community level is seen as integral to this project. However, the group expressed concern about who would drive this process. For a large-scale data reservoir or database to work, dialogue participants agreed that provincial Ministries would have to approve the database but it

would be best for an independent institute to develop the database. One participant noted that in Indigenous communities, data governance is structured differently, in terms of management and ownership, which would need to be considered in order to engage Indigenous agencies in data sharing initiatives.

The scale and geographic boundaries of the data to be used (i.e. neighbourhood, city, region, level data) was highlighted as a key area of concern. All bodies collecting data must be doing so on the same scale in order to make comparisons and/or combine data into one data set.

Participants agreed that changes to the current culture of expensive and restricted data would be beneficial to all. Open-data sharing initiatives and/or making current data more affordable were noted as solutions. One example noted by a dialogue participant of this approach already taking place is from the Canadian Council for Social Development, which has a [Community Data Consortium](#) for nonprofits that provides them with access to large quantities of data for a small fee.

During discussion, it was raised that the way data is collected can be a barrier to communities. This can include questionnaires with punitive language (i.e. questions that serve no purpose other than to increase feelings of stigma) and language barrier challenges in terms of translation. These factors can have a significant impact on data collected.

Some participants noted that there might be a policy window currently for initiatives focused on health equity. LPHAs are governed by the Ontario Public Health Standards, to which Health Equity has just been added as a Foundational Standard. Now could be a time to influence how the Ministry mandates assessing and reporting of SDOH. Additionally, changes to the public health systems, including sub-LHIN regional planning, are taking place and the Ministry of Community and Social Services is undergoing change in terms of service delivery at the local level. This time of change may be an opportunity to advocate for the inclusion of a health equity lens. Government attitudes were identified as having a significant impact on initiatives like this. This initiative must be able to withstand a change in political ideology. The group agreed that part of the work that must be done is to highlight the value of data sharing and social determinants of health in order for these ideas to resonate with politicians. Government itself was also identified as a barrier, as funding for data sharing is often limited and comes with strict restrictions.

### **Deliberation about Next Steps**

A two-step process was suggested for next steps: an inventory to determine what data LPHAs and community partners have and do not have and then assess privacy and sharing considerations. This should take place on a provincial and regional scale, as

well as within individual agencies. This initiative must consider data maturity (i.e. assets and capabilities relating to data collection, management and interpretation) within agencies; this would inform the types of resources that could be provided to community partners.

A two-step process was suggested for next steps: an inventory of data community partners and LPHAs have and do not have, and then assess privacy and sharing considerations. This should take place on a provincial and regional scale, as well as within individual agencies. This initiative must consider data maturity (i.e. assets and capabilities relating to data collection, management and interpretation) within agencies; this would inform the types of resources that could be provided to community partners.

A high-level inventory of data sources would outline the assets and gaps that exist in the system already, as well as raise awareness of the resources that already exist that may be underutilized currently. Once data resources have been established a Privacy Impact Assessment could be completed to determine the level of risk and what legislation and policies must be adhered to and how to minimize risk in data sharing. To facilitate this, it must be decided at what scale data is most helpful.

One suggestion for how data sharing might be accomplished was for there to be a Health Equity Data Coordinator, a position dedicated to accomplishing this work and supporting future data sharing. There were several specific areas of focus in the discussion: creating and strategy supported by a framework, identify a champion, and consider ethics.

### **A Holistic and Widely-Implemented Strategy**

Going forward, there is a need to define the purpose and specific goals of this initiative and how to go about raising awareness about SDOH. A strategy would also outline where the responsibility lies in terms of who collects, and manages the data, and what data is utilized.

### **Establish a robust communication strategy**

Participants identified the need for a communication strategy to explain the benefits of this initiative, one that is accessible to many sectors in terms of relevancy to their mandates and language. Participants agreed that collaboration between health service providers and public health to this extent is unprecedented, therefore how the concept is introduced to potential participants is extremely important to the success of the process. It is important to highlight that this initiative is not a fundamental change to practice, but instead, leveraging what already exists in terms of resources and process to improve service provision. This initiative's emphasis on improving health outcomes and saving money through greater efficiency could be used to market this specifically to Local Health Integrated Networks.

It was noted by participants that clarifying with all involved that the data is not identifiable is essential. This is different from the norm for community partners, who usually deal with data on an individual level.

### **Explicitly consider ethics**

Ethical considerations were a strong theme in the discussion. While there is concern about fulfilling legislative and moral privacy obligations, the preferred types of data are already analyzed and therefore requires no work on the part of community partners. One participant noted that when the details are finalized regarding this initiative it will become obvious what processes must be followed regarding ethics.

### **Identify and support the efforts of a champion**

Participants identified the need for an individual to champion this work. It was felt that this work could easily get lost in overburdened staff, and to get the attention it requires it would need to be one person's primary responsibility. It was suggested also that a high-level champion, ideally a Provincial government Minister (whether this be of Health or Community and Social Services) to indicate that this work is a priority.

### **Build on current frameworks**

Developing a framework similar to The Tri-Hospital + TPH Health Equity Data Collection Research Project Report to collect data is a potential avenue moving forward. This framework includes questions frontline staff can ask their clients and training on how to gain the trust of clients to share personal information related to the SDOH. The majority of community partners agreed upon creating a database similar to that of National Homelessness Count. Such a database would be best developed at the provincial level and would allow community partners to have access to province wide data.

## **Conclusion**

This dialogue summary will be shared with the project team to inform a discussion of how the project will move forward. A pilot will be developed based on the findings included here along with the evidence brief and the expert opinions of team members. The conclusion of this project will involve the implementation and evaluation of the pilot, as well as a handbook aimed at other LPHAs detailing how others might move forward with similar initiatives.