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Locally Driven Collaborative Project (LDCP)

This guide is part of an LDCP funded by Public Health Ontario. This guide is meant for Local Public Health Agencies (LPHAs) to facilitate and encourage sharing data related to health equity with community partners. This guide provides steps to efficiently share data with community partners and provides the tools necessary to evaluate how community partners are using the data to assist their work on health equity issues.

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Disclaimer

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Conflict of Interest

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



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Glossary of Terms

Community Partners: Encompass all the types of organizations selected to take part in this project, including government bodies, health service providers, community health centres, locally-based non-profit/community partners and local branches of (Provincial/National/International) non-profit organizations.

Local Public Health Agencies (LPHAs): Refers to the 36 agencies/units which provide public health programs and services to communities across Ontario. Each of which is governed by a Board of Health as defined by the Health Promotion and Protection Act (HPPA).

Health Equity: Defined as “all people can reach their full health potential and are not disadvantaged from attaining it because of their race, ethnicity, religion, gender, age, social class, socioeconomic status or other socially determined circumstances.”¹

Health Inequity: Defined as “a sub-set of health inequality and refers to differences in health associated with social disadvantages that are modifiable, and considered unfair.”²

Social Determinants of Health: The “interrelated social, political and economic factors that create the conditions in which people live, learn, work and play. The intersection of the social determinants of health causes these conditions to shift and change over time and across the life span, impacting the health of individuals, groups and communities in different ways.”² Social determinants of health include access to health services, income and income distribution, and housing among other factors.

Data Sharing: Making data available to others. For the purpose of this project data sharing does not include client-level data.

Demographic Data: A type of descriptive data including characteristics of a population such as age, gender, income, and geographic location.

Health Outcome Data: Health outcomes are “changes in health that result from measures or specific health care investments or interventions.”³ This type of data includes early childhood development, mental health, morbidity, and mortality.



Purpose of This Guide

The steps described in this guide are derived from the pilot that was developed based on recommendations acquired from the data collection phase of the Locally Driven Collaborative Project (LDCP). This guide aims to outline the processes of engaging in data sharing to improve health equity at the local level. This includes selecting and analyzing relevant health data with community partners in a method that aligns with evidence in the literature and primary research conducted with community partners.

Who is This Guide For?

The guide has been developed to assist Local Public Health Agency (LPHA) staff who are: familiar with the data available to their LPHA; able to collect, analyze, and interpret data for the needs of their community partners; and/or able to foster relations with local community organizations. This can include, but is not limited to, LPHA staff such as epidemiologists, data analysts, health promoters, public health nurses, research staff, and those with a focus on health equity related issues in their communities.

Every LPHA and community partner is unique with different organizational structures and capacities for data sharing. It is therefore essential that LPHAs consider their local context when reviewing this guide.

Why is This Important?

This guide compliments the updated requirements found in The Ontario Public Health Standards: Requirements for Programs, Services, and Accountability in which health equity is now a foundational standard. Requirements now include assessing and reporting on “the health of local populations...and identifying effective local strategies to decrease health inequities” through engagement and collaboration with local community organizations.⁴ This guide uses research conducted by the LDCP to identify new and/or improved ways to facilitate sharing health data between LPHAs and their local community partners. The underlying theory of this approach is that if LPHAs work with their local community partners to provide them with relevant population health data then community partners will be better equipped to address health equity in their work and make evidence informed decisions. As a result, there is an opportunity to support community partners to:

- Participate in local advocacy efforts in their communities
- Better understand priority populations in their communities
- Inform programs and services that address priority needs
- Support funding proposals



Summary of the Data Sharing Process

Below is a brief overview of the recommended steps to share data with local community organizations based on the findings from this LDCP. Refer to Appendix A for a more detailed breakdown of each step.

Identify Partners

Focus on recruiting community partners that focus on addressing health equity issues at the local level

Conduct Consultation

Meet with community partners to gain an understanding of their data needs and goals

Provide Data

Develop data packages for community partners as determined in the consultation in the agreed upon format

Conduct Evaluation

Gather feedback from community partners regarding the data sharing process



Data Sharing Process

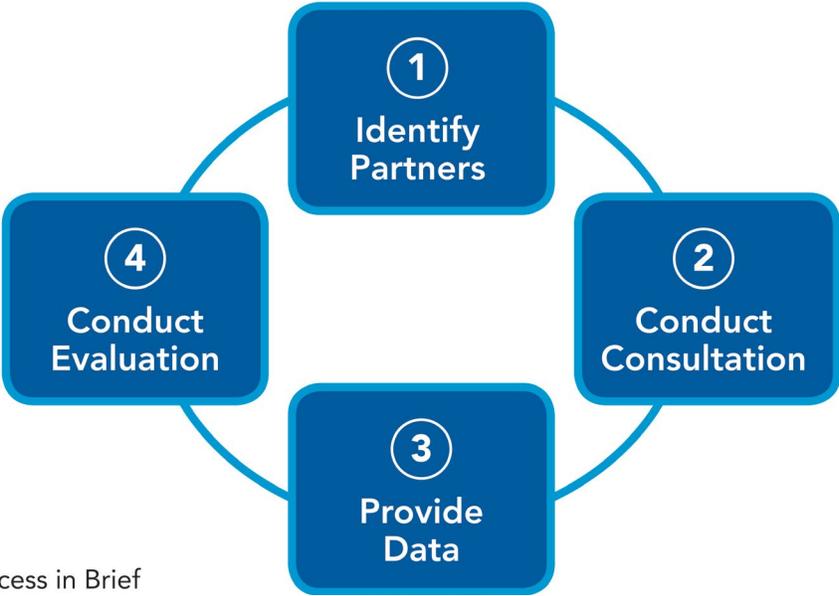


Figure 3:
Data Sharing Process in Brief

Four main steps are involved in sharing data with community partners as shown in Figure 3. These steps are meant to be a general guide for LPHAs to share their data with their local community partners and are not meant to be interpreted as an inventory of all possible actions for data sharing. Therefore, these steps can be adjusted as necessary to meet the LPHA’s and community partners’ capacity and needs.

STEP 1: Identify Community Partners

What does this step entail?

This step involves recruiting community partners whose focus is on addressing health equity issues at the local level. For the purposes of this LDCP, managers and frontline staff created a list of all community partners, consisting of government bodies, health service providers, community health centres, locally-based non-profit/community partners, and local branches of (Provincial/National/International) non-profit organizations. LPHAs can recruit community partners with whom to collaborate based on common areas of focus. For example, an LPHA with new data findings on local school-aged health can reach out to local community partners that service school-aged children and therefore may be more likely to use such data findings. For the LDCP, partners from the community partner list were selected to participate in the pilot based on their interest in child-related data. Community partners may also self-identify by requesting data from LPHAs; if that occurs the process can start from step two.



When recruiting potential community partners it is important to consider how many partners your LPHA has the capacity to support in data sharing. Also, consider whether the community partners have the capacity to use potential data that is provided to them from the LPHA. It is recommended to explain to community partners their roles in the data sharing initiative, the type of data that will be shared with them (e.g. aggregated population health data) and the potential uses for the data for them to determine their readiness to participate.

Who conducts this step?

Findings from the literature and dialogue for this LDCP project indicate the importance of trust between the LPHA and community partners for data sharing to be successful. It is therefore recommended to have LPHA staff who have established, or are able to establish, new relationships with local community partners to conduct this step.

When is this step conducted?

It is recommended to conduct this step once a logic model for the data sharing process has been developed by the LPHA to determine resources, staff, activities, outputs, and desired outcomes. Refer to Appendix B for the logic model developed for the LDCP pilot.

Why is this step important?

This step is essential for developing a greater understanding of potential community partners who may be interested in receiving data, have the capacity to use data provided to them, and benefit from a data sharing relationship with the LPHA.

STEP 2: Consultation

What does this step entail?

This step requires meeting with community partners to gain an understanding of their data needs and goals. It includes identifying the types of data they would like to receive as well as the most preferred format and method through which community partners would like to receive it. See Appendix C for an example Question Guide to assist in this process. The guide may be sent to community partners in advance of the consultation to allow time for them to consider some of the more involved questions.

At the start of the consultation, it is suggested to review the definitions listed in the Consultation Guide with the community partners, to add any additional relevant terms, and to ensure a common understanding of terminology among LPHAs and community



partners. This is especially important when considering data, as community partners often deal with individual level data and LPHAs are focused on population level data. It is recommended to gain an understanding of the capacity limitations of the community partner's ability to interpret and utilize the data that will be shared with them as well as the capacity and time the LPHA is able to provide in terms of data analysis.

Who conducts this step?

It is not recommended to have more than two staff present at the consultation: one to guide the conversation and the other take notes. This is done to help manage the potential power imbalance between LPHAs and community partners. Often the perception of public health is as an authority figure, therefore working to establish a sense of equality in the relationship will result in a better partnership. It is recommended that one of the staff members be familiar with the data available to the LPHA that can be shared with community partners, such as an epidemiologist or statistician.

When is this step conducted?

It is recommended to schedule the consultation shortly after the first step is completed; approximately two weeks. This period allows community partners sufficient time to review the consultation questions in advance and to consider their goals and objectives for the data they receive, all the while keeping the project current.

Why is this step important?

This step is essential to gain an understanding of the types of data community partners may expect their LPHA to be able to share versus what the LPHA is able to provide. This step allows common goals to be established between the LPHA and the community partner in regards to what data will be shared and how it may be used.

STEP 3: Data Provision

What does this step entail?

After consulting with community partners, the third step involves developing and providing the data packages as determined in the consultation to the community partners in the agreed upon format (e.g. a data report sent to the community partner electronically).

NOTE: It may be necessary to develop ethics documents with participating community partners such as data sharing agreements, depending on the sources and level of analysis of the data.



Who conducts this step?

For the pilot, the project team's epidemiologist collected and analyzed the requested data from available data sources identified in Appendix D. All of these data sources were available to the LPHAs participating in this LDCP. Depending on the complexity of the data being provided, various LPHA staff can conduct this step including a research assistant, epidemiologist, data analyst, or statistician.

When is this step conducted?

The length of time needed to analyze, interpret, and provide data to community organizations depends on various factors discussed throughout the consultation. See Appendix E for capacity considerations made by the LDCP's epidemiologist. These factors include how much data will be provided to the community partners, whether any data has to be compiled and cleaned by the LPHA and the format in which the data will be presented to the community partners (e.g. a one page summary or full report).

Why is this step important?

This step allows the community partner to gain a greater understanding of the data available to them from their LPHA. Providing them with a data package in an easily accessible format to address their needs can assist community partners with taking initiative on local health equity issues.

STEP 4: Evaluation

What does this step entail?

This step consists of gathering feedback from community partners regarding the data sharing process. Evaluation involves gathering information on the usefulness of the data sent to community partners to address health equity issues in their community. The pilot evaluations were conducted in-person but they can be conducted over the phone if time and resources are limited. See Appendix F for the evaluation question guide developed for the LDCP project. The questions asked in the evaluation include whether the data sharing process met the community partners' intended goals, if it influenced their work on health equity related issues, and whether there were any additional data they would have liked to receive. It is suggested to review the data package provided to the community partner at the onset of the evaluation to ensure a common understanding of the data and to address any questions community partners may have about the data.



Who conducts this step?

As during the initial consultation, it is recommended that no more than two LPHA staff attend the evaluation including at least one member who developed the data package. This will allow the LPHA staff to address any data related questions the community partners may have. Another staff member should attend to take notes of the evaluation in order to be able to analyze and interpret the evaluation results.

When is this step conducted?

It is recommended to conduct the evaluations at least one week after the data is sent to the community partners, allowing them time to review the data provided. It is recommended to conduct multiple evaluations with community partners over time (e.g. at six months and 1 year after data is provided). This will assist with determining if medium and long-term outcome objectives of the data sharing process are met.

Why is this step important?

Conducting an evaluation with each of the community partners allows the LPHA to determine if the shared goals outlined in the consultation were met and provides potential areas for improvement in the data sharing process for future collaboration. It also assists the community partner to clarify any data related questions they have.



Locally Driven Collaborative Project Overview

Rationale and Goals

The goal of this project was to identify best practices to select, analyze, interpret, and distribute pertinent health equity-related data to local community partners to enable them to better advance health equity for the populations they serve.

This project identified:

1. The needs of a cross section of community partners and what kinds of data would be most helpful for them to advance health equity
2. How community organizations are currently using health related data
3. Possible interventions/actions and approaches that public health data could influence and strengthen
4. Data indicators or other metrics that could be provided to community partners
5. The kinds of data presentation formats that would be most accessible and useful for partners (i.e., infographics, online charts, geographic mapping of data)

The overarching goal of this project was to enable community partners to better address health equity in their program and service planning, while recognizing that impacts in this area may develop over time and not necessarily be reflected in the results of this project. While the data used in this project included demographic data that was not specific to health equity, having more information about populations served and area demographics allows community partners to see and address any gaps in service, and be strategic in the development of programs, all of which allows them to address health equity.

Data Collection

The project consisted of two main phases conducted over a one-year period. Phase one focused on assessing the current uses of health equity-related data by community partners, exploring their needs, challenges, and enablers to accessing and interpreting data and identifying additional data they may require. This was accomplished through an online survey of community partners, a literature review of data sharing initiatives, and a deliberative dialogue with team members and community partners. The second phase of the project built on these findings to pilot the provision of data to a selection of community partners for assessing its usefulness and likelihood to effectively impact their work on health equity.



Phase One

Survey

A survey was developed and implemented online via Survey Gizmo for just over two weeks to explore community partners' data use and needs. Survey participants were identified by team leads at each of the participating LPHAs. The survey was distributed via personalized emails with a 25% response rate of 99 completed surveys. Key survey results are identified in Figures 1 and 2.

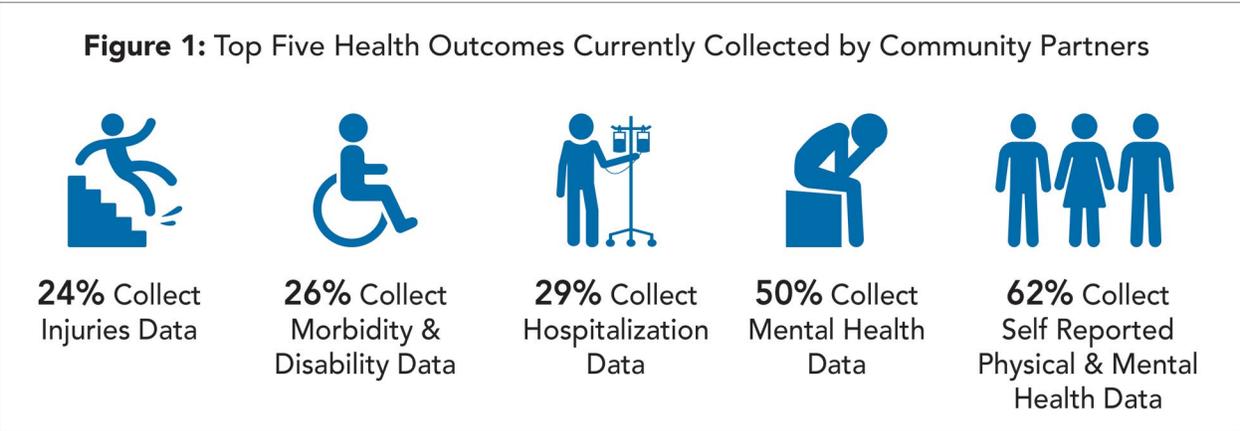


Figure 1 shows the top five health outcome data collected by community partners that completed the survey.

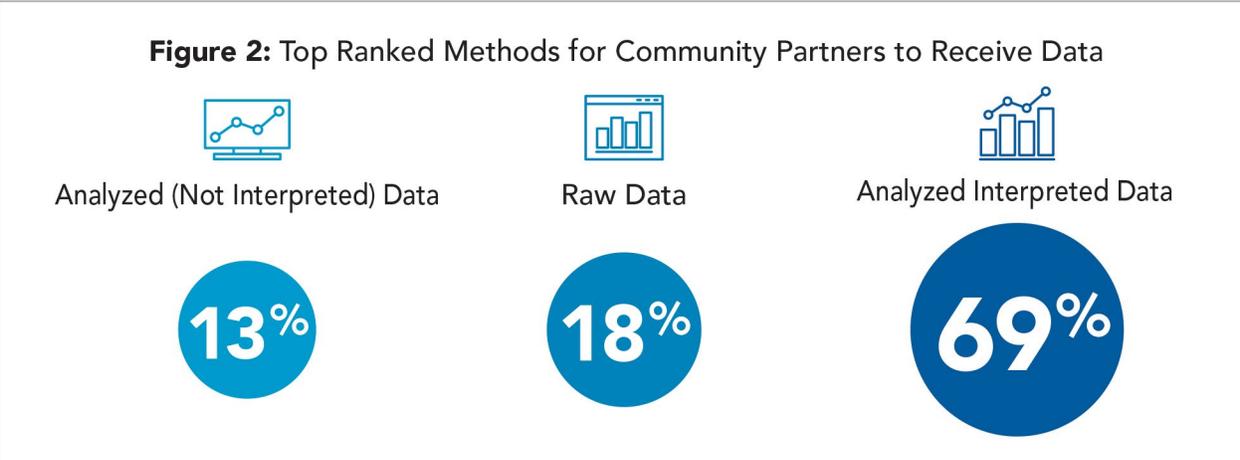


Figure 2 illustrates that community partners prefer analyzed data with interpretation (69%), in comparison to raw data (18%) and analyzed data without interpretation (13%). Survey comments suggest that community partners lack the skills or software to analyze raw data.



Literature Review

The project team conducted a literature review seeking to address the research question: how local health equity-related data be most effectively presented and shared with community agencies to support their needs. Project staff developed a search strategy that was reviewed by the project team and the librarian at the Middlesex-London Health Unit library. All databases via the Middlesex-London Health Unit library were searched, including Medline, Embase and CINAHL. Other sources searched included Google Scholar and grey literature sources (i.e. Canadian Best Practice Portal, National Collaborating Centre for Methods and Tools, and the National Academies Press). A total of 21 articles were critically appraised separately by two project team members for value and relevance. Any disagreements in appraisals were resolved by consensus for a final total of 12 included articles.

Deliberative Dialogue

The findings from the aforementioned survey and literature review were used to develop an evidence brief. This brief was used to inform a deliberative dialogue on data sharing. A deliberative dialogue is defined as “a face-to-face method of public interaction in which small groups of diverse individuals exchange and weigh ideas and opinions about a particular issue in which they share an interest.”⁵ This deliberative dialogue was conducted to include the perspectives of community partners to discuss three main themes: the problem (barriers in data sharing and use), options to solve the problem, and implementation considerations. The discussion took place among 16 community partners who indicated interest in participating in the dialogue in the aforementioned survey. Participants represented various organizations within the catchment areas of the participating LPHAs (i.e. homeless shelters, school boards, YMCA, etc.). Minutes were taken throughout the dialogue, which were used to develop a dialogue summary. This summary explored additional elements to the problem, solutions, implementation considerations, and next steps for data sharing.

Barriers and potential solutions to data sharing were identified by community partners at the deliberative dialogue. These barriers and solutions are identified in the following graphic with direct quotes from participants.



Barriers and Potential Solutions to Data Sharing

Barriers	Potential Solutions
<p>Capacity limitations across organizations.</p> <p>“There is data that does exist that we might not all have the capacity to use or have access to. There is a lot of data available that we need to learn how to use, there is also a lot we need to be collecting.”</p> <p>“We do not have the time to implement data, nor do we have the money to hire someone to be a data collector.”</p> <p>“Service needs to come first...how do we prioritize data collection without sacrificing providing our client services?”</p>	<p>LPHAs provide interpreted data to community partners.</p> <p>“We have a project arrangement that includes epidemiological support. Getting the summary results back about the program [from the epidemiologist] has been really helpful.”</p>
<p>Lack of a universal data sharing strategy.</p> <p>“[Our] food banks has moved to an electronic system- not everyone is trained to collect data the same way... there is no universal way to collect data.”</p> <p>“Many agencies count the same homeless youth which is not reliable. There is a duplication of data...it is frustrating.”</p> <p>“Everyone has their own internal data source/ information system, often leads to inconsistencies in defining terms.”</p>	<p>Enhance data sharing networks between LPHAs and partners.</p> <p>“I am interested with networking, making stronger linkages, and learning how to involve other social agencies. Working together to create a vision of what data sharing looks like.”</p>
<p>Lack of a supportive work structure for data sharing.</p> <p>“A barrier is technology; our [organization] is a paper environment; this hinders our ability to share data with people.”</p> <p>“We use data to fight against [other agencies] to apply for funding instead of working together.”</p>	<p>LPHAs provide assistance with capacity-building for community partners related to data.</p> <p>“[We] can really benefit from partners in public health to build that capacity internally and use them to access external data, to get a sense of other activities in the community.”</p>
<p>Lack of familiarity with ethical processes to share data.</p> <p>“A lack of understanding of what data we can actually share or not share...[there is a] culture of hypervigilance to protect privacy.”</p>	<p>Develop universal methods for data sharing across organizations.</p> <p>“If similar sectors within regions can use a single database to cover similar issues this would be a good baseline.”</p>



Phase Two

Pilot

A data sharing pilot was developed in light of the phase one research findings. For the purposes of this LDCP, the focus was on recruiting community partners who have an existing working relationship with Niagara Region Public Health and are involved in addressing social determinants of health in the local community. Three local community partners within the Niagara Region were invited to take part in the pilot, one that provided primary care services, one that provided a variety of services within a community, and one that is a local unit of a national agency. The pilot only included aggregated and fully analyzed data; no personal identifiers were used.

Noted limitations of the pilot include the following:

- 1. Time:** Due to the one-year timeframe of this LDCP project, the amount of data shared with community partners in the pilot was limited. Evaluations were also conducted only a few weeks after community partners received the data.
- 2. Number of participating organizations:** Due to capacity limitations, three local organizations within the Niagara Region boundaries were selected.



Results

Phase One Findings

Conclusions drawn from the literature review and survey, which were then confirmed by the deliberative dialogue include:

1. Community partners lack resources to analyze, interpret and integrate health outcome data into their work.
2. There is opportunity to strengthen relationships and communication channels between community partners and public health data analytics team.
3. Mutual goals for sharing health outcome data are not clearly defined.

These results highlight the need for a comprehensive data sharing strategy to be developed between LPHAs and community partners.

Phase Two Findings

Findings from conducting consultations with the three community partners that participated in our pilot included the following:

1. All three community partners identified that they would like to receive a community profile of Niagara Region municipalities with demographic information (e.g., age, sex and income).
2. Other types of data requested were related to at-risk vulnerable populations who these community partners serve and specific health outcome data (e.g., mental health, substance misuse, and hospitalization data).
3. All three community partners requested the data be compiled into an executive summary and a more detailed report of analyzed data.

Findings from conducting evaluations with the three community partners that participated in our pilot included the following:

Feedback on Data Received

1. All partners found the data they received useful for identifying gaps in services.
2. Partners appreciated having local data compared to regional and/or provincial data as a point of reference.
3. Partners identified the data packages to be “comprehensive” and found the data packages to be relevant to their needs.
4. Partners were satisfied with receiving the data via email. One recommended providing a phone call to ensure the data file has been received.



5. Partners appreciated reviewing the data at the onset of the evaluation; some requested to review the entire data package while others wanted a few questions addressed.

Data Use for Impact on Health Equity

1. Partners identified ways in which the data may have potential to influence their work on health equity including:
 - a. Using the data to identify clients they may not currently be reaching.
 - b. Being able to evaluate their current services to determine why these audiences are not being reached.
 - c. Using the data to demonstrate a need for additional funding/services to address these needs.

Feedback on Additional Data

1. Additional data requests included providing more specific data related to the findings received (e.g., providing more details such as the age groups of individuals classified as 'not in the labour force').
2. Some additional data requests were related to topics not currently available to Niagara Region Public Health (e.g., data related to adoption, at-risk older adults, Adverse Childhood Experiences (ACEs)) suggesting a potential lack of awareness of the types of data available to LPHAs and/or from what sources such data can be obtained.

Feedback on Data Sharing

1. None of the partners found disadvantages related to sharing data with LPHAs and/or other organizations.
2. Partners defined the data sharing initiative as one that gives them "potential" to define community needs and "leverage" to apply for funding for programs that meet local needs.
3. Partners indicated their desire to share aspects of the data package with other local organizations and/or committees.
4. Partners do not currently have the capacity to analyze and interpret their own client data; they indicated a lack of time, skills and technology. Participating partners were eager to start making a move towards an electronic database of their clients' information when asked how they see data playing a role in their organizations' future.



Recommendations

The following recommendations for data sharing are based on results from Phase One and Two of this LDCCP. This includes results from the literature review on data sharing, the dialogue with community partners, and piloting data with local community partners.

- **Trust:** Trust is key when engaging with data sharing. Many community partners have limited experience working with data and/or public health, and are concerned with privacy limitations. Establishing a transparent and straightforward process that can be shared with community partners will help build relationships.
- **Shared Goals:** Mutual goals for sharing data with community partners need to be discussed with community partners. Outlining high-level goals and processes together ensures all parties are aware of desired outcomes for the collaboration.
- **Shared Definitions:** Ensuring community partners know why the data sharing arrangement has been initiated. Throughout the course of this LDCCP, the team has come to understand that many community partners are not familiar with the role of public health, the social determinants of health, or health equity. Going over the role of public health and the meaning of related terms will assist with building a shared understanding on which to build the relationship.
- **Shared Understanding of Data:** It is recommended to identify what types of data community partners would like to receive and if this data can be accessed and provided by your LPHA. It was found in the pilot that primary care organizations requested clinical data that we were not able to provide. Non-profit community organizations showed a preference for population demographic and health outcome data.
- **Evaluate Over Time:** The evaluation portion of the pilot on which this guide is based was limited due to time constraints – future initiatives would benefit from a more extensive evaluation process to better determine how community partners' use of the data may have changed.



Conclusion

Engaging in data sharing with community partners has great potential to impact health equity in communities. This LDCP identified barriers, potential solutions, and implementation considerations related to sharing data with local community organizations. The pilot component of this LDCP was successful in providing data to a selection of community partners with positive feedback provided by the community partners in the evaluation of the pilot. The four steps for data sharing outlined in this document are a guide for LPHAs to use to share their data with their local community organizations and can be adjusted as necessary to meet the LPHA's capacity and needs.

Establishing a relationship with community partners can also create opportunities for future collaboration, including the potential for reciprocal data sharing, in which LPHAs receive data from community partners. This initiative is a move towards a culture in which data is more accessible and easily shared for all to work towards a shared goal of improving health outcomes in our communities.



Future Considerations

Engaging in data sharing with community partners is an ongoing process that continues beyond the scope of this project. Future steps to consider that have been raised throughout this project include:

- 1. Build on Current Frameworks:** Developing a framework similar to [The Tri-Hospital + Toronto Public Health, Health Equity Data Collection Research Project Report: We Ask because We Care](#)⁶ to collect socio-demographic 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. This is important to gain an understanding of the true picture of inequity through a consistent framework across the province.
- 2. Forming/Enhancing Data Sharing Networks of 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. Examples of such networks include online data portals such as the [Our Kids Network \(OKN\) Data Portal](#) developed by Halton agencies and organizations, [the Social Determinants of Health Map](#) application developed by Public Health Ontario, and the [CommunityView Collaboration](#) information system developed by agencies across Saskatoon.⁷⁻⁹
- 3. Public Health Assistance with Capacity-Building for Community Partners in Terms of Health Data:** Dialogue participants shared that LPHAs 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. 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. This can include having a contact person or team within LPHAs for community partners to alleviate communication barriers, assist with building trust, and provide support for data sharing initiatives. Such initiatives can include assisting community organizations with understanding the value of their own data, and how to use it.
- 4. LPHA Capacity for Continuous Data Sharing:** All community partners in the pilot stated that they would like to receive data from their LPHA in the future. This would involve addressing the capacity of the LPHA to continue to foster data sharing relationships beyond the scope of the pilot. This includes focusing on developing clear processes for handling data requests at LPHAs as well as having a point-person within LPHAs who can address such requests through a systematic process.



Appendices

Appendix A: Steps for Data Sharing

STEP 1: Identify Community Partners

This step focuses on recruiting community partners that focus on addressing health equity issues at the local level

Consider whether community partners have the capacity to use potential data that is provided to them

Explain to community partners their roles in the data sharing initiative and the type of data that will be shared with them to determine their readiness to participate

Have LPHA staff who have established or are able to establish new relationships with local community partners to conduct this step

See Appendix B for the logic model developed for the pilot

STEP 2: Consultation

This step involves meeting with community partners to gain an understanding of their data needs and goals

Review common definitions with the community partners to ensure a common understanding of terminology

Gain an understanding of the community partner's ability to interpret and utilize the data that will be shared with them as well as the capacity and time the LPHA is able to provide in terms of data analysis

It is not recommended to have more than two staff present at the consultation: one to guide the conversation and the other take notes

Recommended that one of the staff members be familiar with the data available to the LPHA, that can be shared with community partners, such as an epidemiologist or statistician

Schedule the consultation within a couple weeks after the first step is completed to allow the community partner to review the consultation questions in advance

See Appendix C for an example question guide to assist in this process



Appendix A: Steps for Data Sharing

STEP 3: Data Provision

The third step involves developing the data packages as determined in the consultation to the community partners in the agreed upon format (e.g. a data report sent to the community partner electronically)

Depending on the complexity of the data being provided, various LPHA staff can conduct this step including a research assistant, statistician, or epidemiologist

The length of time needed to analyze, interpret, and provide data to community partners depends on factors discussed throughout the consultation such as whether any data has to be compiled and cleaned by the LPHA

Providing community partners with a data package in an easily accessible format to address their needs can assist them with taking initiative on local health equity issues

See Appendix E for factors to consider when planning the data analysis process

STEP 4: Evaluation

This step consists of gathering feedback from community partners regarding the data sharing process

Review the data package provided to the community partner at the onset of the evaluation to ensure a common understanding of the data

Recommended that no more than two LPHA staff attend the evaluation to address any data related questions the community partners may have

Recommended to conduct the evaluations at least one week after the data is sent, so the community partner can review the data provided to them

Recommended to conduct multiple evaluations with community partners over time to determine if medium and long-term outcome objectives of the data sharing process are met

See Appendix F for the evaluation question guide developed for the LDCP project



Appendix B: Data Sharing Logic Model

Resources/Inputs	Activities	Outputs	Outcomes	Impact
Staff familiar with data accessible to LPHA, and familiar with community partners	Project staff consult with community partners regarding their data needs, goals and proposed activities in relation to this project	Consultation information from partners, regarding goals, preferred types of data and methods of distribution, etc.	Impact of community partners having data (potential impacts on program planning, funding applications, strategic planning)	Community partners are better able to address health equity within their work
Community partners within LPHA catchment area	Project staff acquire and analyze data	Data specific to community partners' needs, acquired and interpreted	Increased knowledge for community partners in terms of the role of public health for data sharing	Potential for increased data sharing initiatives between LPHA and partners, including two-way data sharing
Population health data	Project staff distribute results to community partners	Evaluation of process by partners in terms of the goals established in consultation	LPHA has a greater understanding of the data needs of their community partners	
	Community partners will utilize data as they see fit		Potential for increased data sharing initiatives between LPHA and partners	
	Community partners provide feedback on process		Evaluation information for better implementing future data sharing initiatives	



Appendix C: Data Sharing Consultation Questions

The purpose of this consultation is to gain a better understanding of your data needs. This consultation includes questions related to your goals, such as what data you would like to receive and how you intend to use the data. The consultation will be administered through an in-person one-on-one interview. Your answers will be kept confidential and anonymous outside of this interview. Your answers will not affect your access to agency services, relationship with the project team, or any other factor.

References to the term “data” in this consultation refer to the aggregated and fully analyzed data package you received from [Niagara Region Public Health] for the purpose of this pilot.

Definitions

1. Are our definitions consistent with your understanding of the terms before this meeting?

Role of Public Health

2. What data do you expect you would receive from Public Health?

Defining Shared Goals and Objectives

3. Do you currently have strategic goals/objectives, that having data for would assist in?

Inventory of Data Based on Survey Responses

4. Which groups of clients does your organization work with?
5. What types of quantitative data do you currently use?
6. What types of quantitative data would you like to receive?

7. Is there any type of information that you need to do your job that you are unable to access? What is the barrier that you are encountering?

8. In what format would you like to receive this data?

i.e. A full, detailed report (methods, data analysis, interpretation, and recommendations), an executive summary (one-page data analysis highlights), a fact sheet (categorized data in bullet format)

Data Use

9. Do you currently have the capacity and skills in your organization to use this data for other or future purposes?
10. For what purpose do you intend on using the data?
11. What is your expected timeline in using the data?
12. How will this data help your work related to health equity?



Appendix D: Data Sources Used

Below is a comprehensive list of all data sources used for the pilot. Approximately four data sources were used for each data package.

Better Outcomes Registry & Network

(BORN): “Ontario’s Better Outcomes Registry & Network (BORN) was established in 2009 to collect, interpret, share and rigorously protect critical data about pregnancy, birth and childhood in the province. BORN makes a positive and lasting contribution to the health of mothers, newborns, children and the citizens of Ontario.”¹⁰

Canadian Community Health Survey

(CCHS): “Cross sectional survey that collects information on attitudes and behaviours related to various aspects of physical and mental health (i.e. Perception of health issues, chronic conditions, use of health care services, exposure to second-hand smoke, physical activity, consumption of fruit and vegetables, and alcohol use).”¹¹

Discharge Abstract Database (DAD): “Data are collected from each patient’s chart at the time of discharge from hospital and are recorded on an abstract provided by Canadian Institute for Health Information (CIHI). The abstract collects information on the patient and the nature of their stay. One abstract is completed for each separation (stillbirth, death, discharge) from the hospital.”¹²

Emergency Medical Services (EMS) Edge:

“Real time surveillance data for emergency medical services transports.”¹³

Healthy Babies Healthy Children (HBHC):

“HBHC is a program funded by the Ministry of Children and Youth Services (MCYS) designed to help children in Ontario have a healthy start in life and provide them with opportunities to reach their potential. This voluntary program

is delivered through Ontario’s 36 public health units (PHUs) in partnership with hospitals and other community partners. The program consists of universal screening with targeted assessments and interventions for families and children from the prenatal period until their transition to school.”¹⁴

Integrated Public Health Information

System (iPHIS): “Contains case information on all reportable communicable diseases for provincial and national surveillance.”¹⁵

National Ambulatory Care Reporting

System (NACRS): “Emergency Room (ER) visit data are part of the Ambulatory Visit Database, obtained from NACRS developed by the Canadian Institute for Health Information (CIHI) and the Ministry of Health and Long-Term Care of Ontario (MOHLTC).”¹⁶

Statistics Canada Census: “These 2016 Census products provide statistical information about the population, age and sex, type of dwelling, families, households and marital status, language, income, immigration and ethnocultural diversity, housing, Aboriginal peoples, education, labour, journey to work, language of work and mobility and migration, as measured in the census program.”¹⁷

Parent Talk Line Data: The Parent Talk Line is a telephone information line that the public may phone to speak with a public health nurse about any parenting issue within the Niagara Region.

Vital Statistics: Mortality data from the Office of the Ontario Registrar General; managed by the Ontario Ministry of Health and Long-Term Care.¹⁸



Appendix E: Considerations for Data Analysis

Data Ownership

- Is the data easily accessible?
- Is special permission required to access/disseminate the data?
- If program-level data is to be used, are permissions required from specific programs?

Data Characteristics

- How recent is the data?
- How many years of data is available?
- Are there comparators available (e.g. municipal, health region, provincial, federal)?
- Is data generalizable (especially when using surveys with sample populations)?
- If providing defined indicators, or repeat statistics (e.g. annual reports), are the correct variable and indicator definitions used?

Privacy and Confidentiality

- Record-level data should be aggregated
- Does data need to be suppressed?
- Is aggregation by socio-demographic variables possible, particularly for smaller populations?

Data Cleaning

- When was the data last extracted?
- Does data need to be cleaned?
- Do different cycles of data (e.g. months, years) need to be merged?
- Are demographic variables obtained (e.g. municipalities; age range; year of record)?

Data Governance

- Are data sharing agreements required? (Generally not, if data is aggregated)
- Are recipient community partners allowed to share the report widely?
- Are there approvals required from within the organization before data products are shared?
- Are follow-up requests from community partners welcome?

Data Analysis

- Consider how long cleaning, aggregating and analysis will take based on the aforementioned considerations
- Will data interpretations and recommendations for the community organizations be included?



Appendix F: Data Sharing Evaluation Questions

Evaluation Question Guide

The purpose of this evaluation is to gain a better understanding of your experience of this data sharing project. This evaluation includes questions related to your goals as defined in the initial consultation, your satisfaction with the data provided, how you intend to use the data, and any feedback you may have. The evaluation will be administered through an interview. Your answers will be kept confidential and anonymous outside of this interview. Your answers will not affect your access to agency services, relationship with the project team, or any other factor.

References to the term “data” in this evaluation refer to the aggregated and fully analyzed data package you received from [Niagara Region Public Health] for the purpose of this.

Goal Setting

1. Let us review the goals we agreed upon at the beginning of the pilot during our consultation. On a scale of 1 (very unhelpful) to 5 (very helpful), how helpful has the pilot been with achieving these goals.

1	2	3	4	5
Very Unhelpful	Unhelpful	Neutral	Helpful	Very Helpful

What is the reasoning for your rating?

Data Received

2. On a scale of 1 (very dissatisfied) to 5 (very satisfied), how satisfied are you with the data you received?

1	2	3	4	5
Very Dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied

What is the reasoning for your rating?



3. On a scale of 1 (very dissatisfied) to 5 (very satisfied), how satisfied are you with the format (i.e. such as a full detailed report or a fact sheet) of the data you received?

1	2	3	4	5
Very Dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied

What is the reasoning for your rating?

4. On a scale of 1 (very dissatisfied) to 5 (very satisfied), how satisfied are you with the method in which you received the data (i.e. via email or in-person)?

1	2	3	4	5
Very Dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied

What is the reasoning for your rating?

5. For what purpose do you intend on using the data?
6. If you have not used the data and do not foresee using the data in the future, why is this?
7. What is your expected timeline in using the data?
8. A) Who in your organization currently has access to this data?
B) Who in your organization will have access to this data in the future?
9. Do you currently have the capacity and skills in your organization to use this data for other purposes?
10. Do you foresee any future challenges or barriers regarding the use of this data?
11. On a scale of 1 (very unhelpful) to 5 (very helpful), how helpful is the data provided for your work related to health equity?

1	2	3	4	5
Very Unhelpful	Unhelpful	Neutral	Helpful	Very Helpful

What is the reasoning for your rating?



12. Is there further assistance you would recommend public health provide for potential future data sharing initiatives with community partners?
13. How will this data help your work related to health equity?

Additional Data

14. Is there any additional quantitative and/or qualitative data that was not provided which you would have found helpful?

Data Sharing

15. What advantages and/or disadvantages do you see in sharing data between your organization, Local Public Health Agencies (LPHAs) and other community agencies?
16. Does your agency have any data relevant to public health available to be shared?

Feedback

17. Do you have any other feedback regarding this process that could be helpful for this and/or similar projects in the future?

Thank you!



Appendix G: Checklist of Activities for Data Sharing

A checklist of activities for each step of data sharing. The “approximate time to complete” column was based on the schedules of two part time staff dedicated exclusively to the LDCP project as well as a full-time epidemiologist within the health unit dedicated to the data analysis of the pilot in order to conduct the pilot with three community partners.

Steps	Activities	Approx. Time to Complete
1) Identify Community Partners	Develop list of potential community partners	4 weeks
	Schedule to meet with partner(s)	2 weeks
2) Conduct Consultation	Develop consultation questions (see Appendix B)	1 week
	Invite and schedule consultations with community partner(s)	4 weeks
	Identify data sources available to your LPHA	1 week
	Conduct consultations with community partner(s)	2 weeks
3) Provide Data	Obtain, clean, and analyze data agreed to be shared with community partners (see Appendix C for potential data sources)	2-3 weeks
	Compile analyze data into the desired format for community partners	2 weeks
4) Conduct Evaluation	Develop evaluation questions (see Appendix E)	2 weeks
	Schedule evaluation with community partner(s)	1 week
	Conduct consultations with community partner(s)	2 weeks



Appendix H: Additional Online Resources

Below is a list of relevant online resources that were provided to the community partners who participated in the pilot.

Measuring Health Equity: Demographic Data Collection in Health Care: “The Measuring Health Equity website was developed by the Human Rights & Health Equity Office at Mount Sinai Hospital with support from the Toronto Central Local Health Integration Network [Toronto Central LHIN] and is intended to serve as a comprehensive guide to demographic data collection in health-care settings. The goal of this website is to provide practical advice, tools, and resources on how to plan, implement, and use patient and client demographic data in health-care settings.”¹⁹ URL: Measuring health Equity: <http://torontohealthequity.ca/>

Let’s Talk: Populations and the Power of Language: “Explores how the language public health practitioners and organizations use to describe populations influences how we frame problems and solutions, make decisions, and implement activities that seek to reduce inequities between groups.”²⁰ URL: Let’s Talk: Populations and the Power of Language: <http://nccdh.ca/resources/entry/lets-talk-populations>

Socio-Demographic Data and Equity in Health Services in Ontario: “This paper reflects on the value of socio-demographic data in the context of health services, considers how we can build on existing strong foundations, and identifies some principles and considerations that can shape new initiatives on sociodemographic data collection and usage in health to ensure improved health and health equity.”²¹ URL: Socio-Demographic Data and Equity in Health Services in Ontario: <http://www.wellesleyinstitute.com/wp-content/uploads/2017/10/Collecting-Socio-demographic-Data.pdf>

Public Health Ontario (PHO): The Social Determinants of Health (SDOH) Map: “The Social Determinants of Health (SDOH) Map shows the distribution of SDOH indicators across the province, Local Health Integration Networks (LHIN) and public health units (PHU). The Map uses the Ontario Marginalization Index and Statistics Canada taxfiler data. It allows you to compare indicators and customize your Map based on most relevant statistics and geographic boundaries (LHIN, PHU). Raw data is also available for download.”⁷ URL: Public Health Ontario (PHO): The Social Determinants of Health (SDOH) Map: <http://www.publichealthontario.ca/en/DataAndAnalytics/Maps/Pages/Social-Determinants-of-Health.aspx>

Health Inequalities Data Tool: “The Health Inequalities Data Tool supports Canada’s pledges under the Rio Declaration. This resource is a collaborative effort of the Public Health Agency of Canada, the Pan-Canadian Public Health Network (PHN), Statistics Canada, and the Canadian Institute for Health Information, and builds on a set of indicators of health inequalities proposed by the PHN in 2010. The Health Inequalities Data Tool: contains data on indicators of health status and health determinants, stratified by a range of social and economic characteristics (i.e. social stratifiers) meaningful to health equity. Indicators are grouped into twelve framework components.”²² URL: Health Inequalities Data Tool: <https://infobase.phac-aspc.gc.ca/health-inequalities/>



Appendix I: References

1. Population and Public Health Division Ministry of Health and Long-Term Care. Health Equity Guideline, 2018.
2. Glossary of essential health equity terms - NCCDH | National Collaborating Centre for Determinants of Health. <http://nccdh.ca/resources/glossary/>. Accessed February 8, 2018.
3. Outcomes | CIHI. <https://www.cihi.ca/en/outcomes>. Accessed February 8, 2018.
4. Ministry of Health and Long-Term Care. Standards for Public Health Programs and Services. 2017;(11):15-16. <https://www.healthunit.com/uploads/2017-03-16-report-011-17-appendix-a.pdf>.
5. What is Deliberative Dialogue? - Insights on Educational Policy, Practice, and Research, Speak Up! Engaging Policymakers with Educators and Communities in Deliberative Dialogue, Number 9, October 1999. <http://www.sedl.org/policy/insights/n09/1.html>. Accessed March 27, 2018.
6. Wray, R., Agic, B., Bennett-AbuAyyash, C., Kanee, M., Tuck, A., Lam, R., Mohamed, A., & Hyman, I for the T-H+ TSC. We ask because we care: The Tri-Hospital + TPH Health Equity Data Collection Research Project Report. 2013. doi:10.1016/j.jvs.2016.08.085
7. Social Determinants of Health Map. <http://www.publichealthontario.ca/en/DataAndAnalytics/Maps/Pages/Social-Determinants-of-Health.aspx>. Accessed January 11, 2018.
8. OKN Data Portal - Changing the way we see data. <http://www.ourkidsnetwork.ca/Public/DataPortal.html>. Accessed March 29, 2018.
9. CommunityView Collaboration - Home. <http://www.communityview.ca/>. Accessed March 29, 2018.
10. About BORN : BORN Ontario. <https://www.bornontario.ca/en/about-born/>. Accessed May 11, 2018.
11. Surveys and statistical programs - Canadian Community Health Survey - Annual Component (CCHS). <https://www.statcan.gc.ca/eng/survey/household/3226>. Accessed February 23, 2018.
12. Discharge Abstract Database (DAD). <http://www.simcoemuskokahealthstats.org/resources/data-sources/dad>. Accessed February 23, 2018.
13. Opioid Usage - Statistics in Niagara - Niagara Region, Ontario. (2018). https://www.niagararegion.ca/living/health_wellness/alc-sub-abuse/drugs/opioids.aspx. Accessed May 11, 2018.
14. Healthy Babies Healthy Children (HBHC) Process Implementation Evaluation. <https://www.publichealthontario.ca/en/BrowseByTopic/HealthPromotion/Pages/HBHC.aspx>. Accessed February 8, 2018.
15. APHEO - 10 Integrated Public Health Information System (iPHIS). (2011). <http://core.apheo.ca/index.php?pid=187>. Accessed May 11, 2018.
16. National Ambulatory Care Reporting System (NACRS). <http://www.simcoemuskokahealthstats.org/resources/data-sources/nacrs>. Accessed February 23, 2018.
17. Statistics Canada. 2016 Census of Population - Data Products. <http://www12.statcan.gc.ca/census-recensement/2016/dp-pd/index-eng.cfm>.
18. IntelliHEALTH | MHLU - Health Status Resource. <http://communityhealthstats.healthunit.com/definition/intellihealth>. Accessed February 23, 2018.
19. Measuring Health Equity - Demographic Data Collection. <http://torontohealthequity.ca/>. Accessed January 11, 2018.
20. Let's Talk: Populations and the power of language | National Collaborating Centre for Determinants of Health. <http://nccdh.ca/resources/entry/lets-talk-populations>. Accessed January 11, 2018.
21. Bates L, Roche B, Cheff R, Hill M, Aery A. Socio-demographic data and equity in health services in Ontario: building on strong foundations Wellesley Institute works in research and policy to improve health and health equity in the GTA through action on the social determinants of health. Socio-demo. 2017;(September). <http://www.wellesleyinstitute.com/wp-content/uploads/2017/10/Collecting-Socio-demographic-Data.pdf>.
22. Health Inequalities | Public Health Infobase - Canada.ca. <https://infobase.phac-aspc.gc.ca/health-inequalities/>. Accessed January 11, 2018.

