

# A summary of findings:

A Locally Driven Collaborative Project on public health data sharing with community organizations to promote healthy equity



Locally Driven  
Collaborative Project



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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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# Introduction

Advancing health equity is a common goal shared between many community partners and local public health agencies (LPHAs) that requires communication and collaboration. One aspect of communication that this project focused on was sharing population level demographic and health outcome data between LPHAs and community partners. Prior to this project, research conducted at Niagara Region Public Health & Emergency Services identified that community partners had limited capacity to collect and analyze data and were interested in receiving more of the analyzed data that LPHAs could access. Research conducted by other organizations, such as the Robert Wood's Foundation<sup>1</sup> and the World Health Organization<sup>2</sup> supports the importance of public health sharing data with community organization as a means to positively affect community health. However, effective data sharing has not been widely practiced or studied among LPHAs.

This Locally Driven Collaborative Project (LDCP) began on the foundation of data sharing, funded as a one-year project by Public Health Ontario (PHO), with six LPHAs from across Ontario joining together 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. The LPHAs are listed previously as the Core Project Team and represented locations from across the province and a variety of urban, mixed urban-rural, and rural geographies.

After the initial LDCP project was completed, additional funding was applied for and received from PHO for one year to conduct an Impact Assessment on the project. The Impact Assessment was conducted by Niagara Region Public Health and Emergency Services and the North Bay Parry Sound District Health Unit. This report will describe both aspects of the project, beginning with the two phases of the LDCP and the creation of a guide summarizing the data sharing process, and then outlining the Impact Assessment methods, results and recommendations.



# Locally Driven Collaborative Project Overview

## Aim and Objectives

The aim 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.

**The objectives of this LDCP project were to:**

1. Reduce health inequities in the community;
2. Increase data sharing initiatives between LPHAs and local community partners;
3. Determine ways in which community partners could use population health data provided to them by LPHAs;
4. Understand community partners' preferred types of data, format, and methods of distribution;
5. Identify barriers, possible solutions and implementation considerations in data sharing and use among community partners;
6. Develop community partners' understanding of the role of public health for data sharing;
7. Increase understanding among LPHA staff of the data needs of their community partners)

The overarching goal of this project was to enable community partners to better address health equity in their program and service planning through providing relevant population level demographic and health outcome data. Providing demographic data is useful for community partners to better understand the context within which they work and the diverse populations they may or may not be reaching. Such support can identify gaps in services, facilitate strategic development of programs and collaboration with other community organizations, all of which supports better addressing health equity.

## Methods and Sample

The LDCP consisted of two 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. At the end of the first phase, a process of data sharing was developed. The second phase consisted of a pilot of the data sharing process with a selection of community partners. This pilot included following four steps of the process, assessing the process and the data provided for its usefulness and likelihood to effectively impact the organizations' work on health equity locally.

Phase one included an online survey, developed to explore community partners' data use and needs. A list of 401 community partners was developed by LDCP team members for each of their catchment areas. Individuals at these organizations received the survey through personalized emails in July 2017. A 25% response rate was achieved with 99 completed surveys received.

Concurrent to the online survey, the project team conducted a literature review seeking to address the research question: how can 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. 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.

The findings from the survey and literature review were used to develop an evidence brief<sup>3</sup>. 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."<sup>4</sup> 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 in September 2017 among 16 community partners and three LDCP team members who indicated interest in participating in the dialogue in the survey. Participants represented 16 community 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<sup>5</sup>. The summary explored additional elements of the problem, possible solutions, implementation considerations, and next steps for data sharing; it was shared with all participants shortly after the dialogue.

Based on the findings of Phase One, the LDCP team came together to discuss the data sharing process and came up with four key steps: Identify Partners, Consultation, Provide Data, and Evaluation. See Appendix A for a summary of the steps, or refer to



*Putting the pieces together: An updated guide for public health to share data with community organizations to promote healthy equity*<sup>6</sup>. Please note, due to the findings of the subsequent Impact Assessment, a fifth step of Collaboration was added to the data sharing process, and included in the updated guide.

For a more fulsome understanding of the literature review and survey results please see the publication resulting from this project: Utilizing public health core competencies to share data effectively with community organizations to promote health equity<sup>7</sup>.

A data sharing pilot was developed utilizing the phase one research findings. For the purposes of this LDCP, the focus was on recruiting community partners who had an existing working relationship with Niagara Region Public Health and were involved in addressing social determinants of health in the local community. Partners had participated in the online survey in phase one and indicated interest in participating in a pilot project. Three local community partners within the Niagara Region who expressed interest in receiving early years' data were invited to participate 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 population-level data; no personal identifiers were used.

Limitations encountered during this LDCP project included the allotted one-year timeframe which restricted the amount of data shared with community partners in the pilot. Due to capacity limitations, the pilot only included three local organizations within the Niagara region boundaries.

## Results

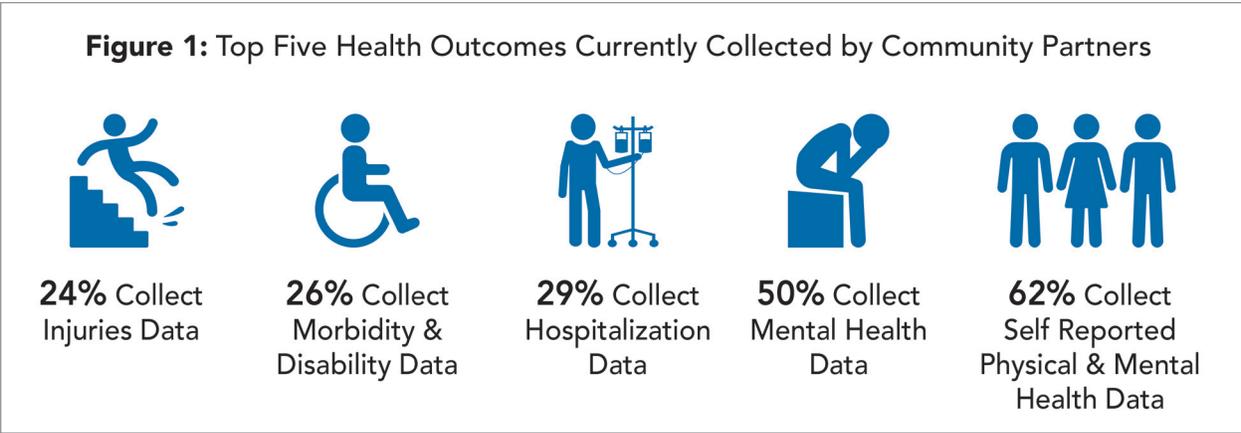
### Phase One Findings

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

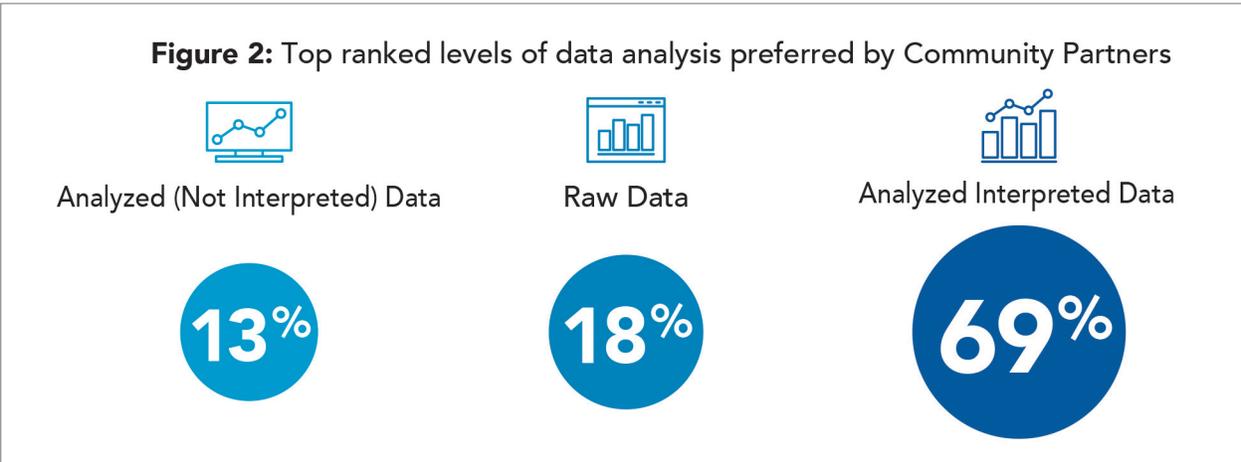
1. Community partners lack resources to analyze, interpret and integrate health outcome data into their work.
2. There is opportunity to strengthen relationships and communication channels between community partners and public health data analytics team.
3. Mutual goals for sharing health outcome data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

These results highlight the need for a comprehensive data sharing strategy to be developed between LPHAs and community partners. Additional results include the top five health outcomes that community partners currently collect (Figure 1) and the top three levels of analysis that community partners would prefer (Figure 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.

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 table with direct quotes from participants

Barriers	Potential Solutions
<p><b>Capacity limitations across organizations.</b></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><b>LPHAs provide interpreted data to community partners.</b></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><b>Lack of a universal data sharing strategy.</b></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><b>Enhance data sharing networks between LPHAs and partners.</b></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><b>Lack of a supportive work structure for data sharing.</b></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><b>LPHAs provide assistance with capacity-building for community partners related to data.</b></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><b>Lack of familiarity with ethical processes to share data.</b></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><b>Develop universal methods for data sharing across organizations.</b></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 Findings

Findings from conducting consultations with the three community partners that participated in the 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 served by community partners as well as specific health outcome data (i.e., 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.

All partners found the data they received useful for identifying gaps in services. Partners appreciated having local data compared to regional and/or provincial data as a point of reference. Partners identified the data packages as “comprehensive” and found the data packages to be relevant to their needs. Partners were satisfied with receiving the data via email. One recommended providing a phone call to ensure the data file has been received. Partners appreciated reviewing the data at the onset of the evaluation; some requested to review the entire data package while others wanted only a few questions addressed.

Partners identified ways in which the data may have the potential to influence their work on health equity including:

1. Using the data to identify clients they may not currently be reaching
2. Being able to evaluate their current services to determine why these populations are not being reached
3. Using the data to demonstrate a need for additional funding/services to address these needs

The evaluation included asking if additional data was desired. 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’). 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.

No disadvantages were articulated by participating community partners related to receiving data from LPHAs and/or other organizations. Partners described the data sharing initiative as one that offers “potential” to better identify community needs



and “leverage” in their applications for additional program funding. Partners outlined their desire to share aspects of the data package with other local organizations and/or committees. Partners do not currently have the capacity to analyze and interpret their own client data due to 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 LDCP and include findings from the literature review, the deliberative dialogue and the data sharing pilot. Recommendations are incorporated into the guide: Putting the pieces together: A guide for public health to share data with community organizations to promote healthy equity<sup>4</sup>.

- **Establish a Foundation of 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 about privacy limitations. Establishing a transparent and straightforward process that can be shared with community partners will help build relationships.
- **Discuss 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.
- **Review Key Terms and Definitions:** Throughout the course of the LDCP, the team came to understand that many community partners were not familiar with the role of public health, the social determinants of health or health equity. Discussing the role of public health and definitions of pertinent terms will assist with building a shared understanding on which to build the relationship. A glossary of key terms is included in the guide.
- **Discuss data needs, options and capacity:** It is recommended to identify the types of data community partners would like to receive and if this data can be accessed and provided by the LPHA. The pilot revealed that some primary care organizations requested clinical data which LPHAs are not able to provide. Non-profit community organizations demonstrated a preference for population level demographic and health outcome data. Capacity of the LPHA needs to be considered with respect to how much data they can analyze. The capacity of the community partner also needs to be considered.



- **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 and if the goals and objectives outlined at the beginning of the project were met.

## Impact Assessment

Following the conclusion of the LDCP, a one-year impact assessment was funded by PHO. The assessment consisted of an online survey and phone interviews with LPHA staff. The main objectives of the impact assessment were to evaluate how data provided to community partners during the pilot may affect work on health equity related issues and also to evaluate how the guide can assist LPHAs with sharing data with local community partners. These objectives helped determine if the project goal of enabling better health equity through data sharing processes with community partners was achieved. The survey and interview data were used to update the guide and make it more relevant for use by LPHAs.

### Methods and Sample

In June 2018, the LDCP team emailed the guide to 478 contacts to review and provide feedback on its content. These contacts were obtained from relevant public health groups including: the Association of Public Health Epidemiologists in Ontario (APHEO), the alPHA/OPHA Health Equity Work Group (HEWG), the Social Determinants of Health Public Health Nurse network, and the Ontario Public Health Evaluation Network (OPHEN). The guide was also emailed to individuals who signed up to receive it at The Ontario Public Health Convention (TOPHC) 2018 and the 2018 Public Health conference hosted by the Canadian Public Health Association (CPHA).

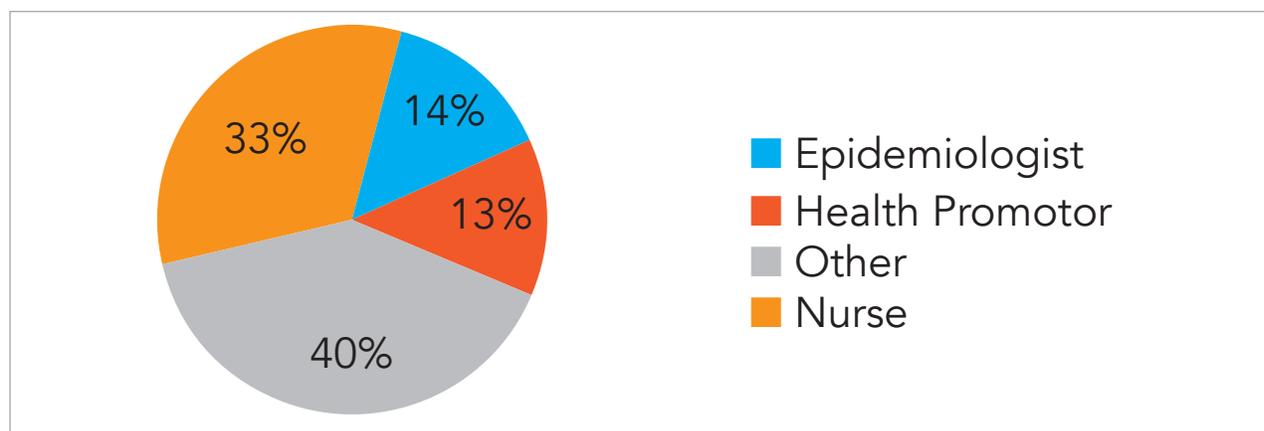
A survey link was sent to contacts approximately two weeks after the guide was sent. Contacts who resided outside of Ontario were excluded from the survey in order to maintain the applicability of recommendations to an Ontario context. As a result, the survey was sent to 470 contacts with approximately two weeks to complete it. The survey asked respondents to provide feedback regarding the usability and functionality of the guide. A 12% response rate was achieved with 55 surveys submitted.

Interview participants were recruited through the survey. Survey respondents who agreed to participate were asked for contact information and later contacted via email by project staff. Interviews were conducted with staff from nine different LPHAs. One or



two staff participated in each interview, for a total of 13 interview participants.

Approximately 33% (n=18) of survey respondents, who defined their role, classified themselves as Nurses, 15% (n=8) as Epidemiologists, 13% (n=7) as Health Promoters, and 40% (n=22) held a role outside of these categories (Figure 3).



**Figure 3:** Percent of survey respondents by their professional designation

The survey was completed by respondents working at 26 of the 35 LPHAs across Ontario (74%). LPHAs with the highest responses included: North Bay Parry Sound District Health Unit (n=4), Peterborough Public Health (n=4), Haliburton, Kawartha, Pine Ridge District Health Unit (n=3), and Kingston, Frontenac and Lennox & Addington Health Unit (n=3). Approximately 80% (n=44) of respondents stated that their LPHA has a dedicated data analysis team, department or staff. Of these 44 respondents, 9 stated that the data analysis role at their LPHA is comprised of an individual staff member.

## Results

### Barriers to data sharing

Barriers in terms of data were raised, specifically data access and the accuracy of data. One participant shared that some databases provide analyzed data on request without restrictions; however, others allow indirect sharing of their analyzed data (e.g., on a public facing website) but not direct sharing of their analyzed data (e.g. An LPHA gets data from a database purely for providing to community partners). In the case of direct data sharing, some databases prefer that each agency requiring data make a separate request.

Several participants in rural areas noted unique challenges, including data not aligned with LPHA regions, lack of data due to rural areas too sparsely populated to support aggregation of data, or that standard data analysis methodologies do not always work in rural areas. Regarding the latter, an example was given where it was discovered by a local advocacy group that data they gathered did not match the data from a large database. After comparing methodologies, limitations to the methodology of the



database were found in rural contexts specifically. Consequently, the LPHA presents both numbers and methodologies from the database and the local agency together.

Some participants identified that limited knowledge translation (KT) skills in LPHA staff is a barrier to sharing data. They emphasized the importance of simplifying data to be user-friendly and noted that KT is not a skill currently possessed by all LPHA staff.

Time constraints for both LPHA staff and community partners were noted as a substantial barrier. The time required for work associated with data sharing, identifying shared goals, specific projects, and other factors represent time that is often sparse at best.

Organizational culture was also identified as a barrier. Often the practice in LPHAs is to act responsively rather than strategically in terms of data sharing. In discussing organizational culture, participants identified that there are long-standing relationships with community partners that pre-date agreements or, in some cases, staff. Shared goals should be the foundation of data sharing relationships but these can be difficult to establish in pre-existing partnerships.

Several participants noted that simply remembering to use the guide can be a barrier. Participants describe being overwhelmed by reports and tools in constant circulation, and making the connection between context and resource is challenging, especially when the resource refers to processes that do not take place frequently.

## Data Sharing Initiatives

Approximately two-thirds (65%; n=37) of survey respondents stated that their LPHA takes part in a data sharing initiative with community partners. One-third (33%; n=18) of respondents described sharing data by posting reports on their LPHA website. Other respondents shared some details on their current data sharing initiatives. Additionally, 31% (n=17) of respondents stated that they share data through informal networks with local community partners. Fifteen percent (n=8) of respondents stated that their LPHA has or participates in an online data portal or data consortium. Although 67% (n=37) of respondents provided examples of data sharing initiatives that their LPHA participates in, approximately half (47%; n=26) stated that they were uncertain about the number of organizations their LPHA shares data with.

In terms of data sharing initiatives, interview participants were not confident that they could comprehensively list all data sharing activities occurring in their LPHAs. Several respondents sought additional input from colleagues or recruited a colleague to participate in their interview to assist with representing the data sharing activities occurring in their LPHA. Some participants requested further detail about the term, “data sharing” before responding. Participants felt they could not describe all instances of data sharing occurring at their health unit because there is a great deal of it occurring; largely without being tracked. This suggests that there is potentially a lack of centralized processes for data sharing.



## Strengths of the Guide

Several strengths of the guide were cited by participants; the layout and content of the guide, specific topics/sections (e.g., Appendix C, Evaluation information and consultation information) and the various uses to which the guide lends itself such as building internal capacity, standardizing language and being a reference for data sharing with community partners.

Three-quarters (75%; n=41) of survey respondents reported that they were satisfied or very satisfied with the guide overall. Respondents appreciated the data sharing steps, found the guide clear, concise, easy to read, and organized with useful headings. They found the guide easy to navigate and felt it included appropriate graphics, tables, and figures. Approximately 69% (n=38) agreed or strongly agreed that the length of the guide was appropriate. “It provides a quick snapshot in an easy-to-read fashion.”

Interview participants felt that the way in which the information was presented in the guide (e.g., order, language) was logical and informative. Several shared that they appreciated the linear process and believe the guide includes adequate explanation and relevant information in appendices. It was noted that having this assembly of information in one document was helpful for staff. Balance of visual aids and narrative explanation used in the guide was beneficial to understanding of the material.

The overall consensus among respondents was that the stepwise process for sharing data with community partners in the guide was useful. One survey respondent stated that the guide “lays out in a step by step fashion the process of engaging with our community/community partners so that we can share data that is relevant to our community.” One respondent thought this framework for sharing data was relevant to determine community partners’ needs and tracking how this data can be useful.

Survey respondents felt that all sections of the guide were helpful. They stated that the sections either provided background knowledge related to data or practical steps related to data sharing. However, the appendices were described as being especially useful to some (31%; n=17) because this section “provided resources and processes for taking action.” Some sections of the guide were noted specifically by participants based on their utility. Appendix C was cited as being a good outline for understanding community partners’ needs and developing a shared understanding of the data sharing process. The evaluation resources were considered useful in creating a standard process for evaluating and for facilitating evaluation even ‘off the side of the desk’. The consultation information in the guide was noted as helpful even for health units that do not have the resources to provide one-on-one consultations, as multiple partners could be consulted to get a general sense of the data needs that may exist for local community partners.



## Critiques

There were a few areas where participants thought the guide could be improved. Some found that including the description of the LDCP in the guide was helpful to their understanding of the material; it demonstrated that the authors of the guide represented a variety of expertise. However, 18% (n=10) of respondents found the guide to be too long with too much detail and 30 comments alluded to the fact that the description of the LDCP was not necessary to include in the guide. Many suggested splitting the guide into a technical document on data sharing and a separate report describing the LDCP.

When responding to open ended questions, 25% of respondents (n=14) suggested that the connection between data sharing and health equity could have been made stronger throughout the guide. Respondents commented that the guide focused on the data sharing processes but they were unsure how this advances health equity. One respondent suggested framing “the consultations around health equity to ensure the data shared is most useful in that regard”.

Nine survey participants (16%) stated that they wanted a definition of the term ‘data’ and more information about the types of data being shared with community partners. A few comments from respondents suggested that they wanted more details in the guide in the form of examples or data sharing case studies. One respondent stated, “It might be helpful in future updates of the guide to have brief real-life examples of how health units have engaged in each step”.

Eight survey respondents (15%) wanted more specific details related to data sharing. These respondents stated that they wanted more details on how to securely share data and details on “the logistics of performing a data transfer.” Suggestions included adding a template of data sharing agreements or Memorandums of Understanding.

Three survey respondents would have liked more details on the data sources available to share with community partners. More specifically, they would like to see added to the guide a list of different data sources/types, non-traditional data sources, limitations of these data sources, and how community partners would like to see data presented.

## Impact of the Guide

This guide has had minimal impact to-date on LPHAs’ data sharing practices. Most participants identified that they have not had enough time since the guide’s release to use it to realize organizational change. Also, some respondents felt that LPHAs were not ready to share data in a consultative way. One respondent stated, “If we do get to the point where we could actively assess and meet data needs more broadly in the community, I would consult this guide ... the report is clear and well-written, but it may not have a large impact on my practice.”



Seven of the LPHAs interviewed (13%) shared that they had not yet used the guide, but were hoping to do so in the future. One LPHA stated that they had used the guide with a number of community partners in a group led by their LHIN that is examining packaging of data in different agencies, and how a data sharing network can be developed. Another shared that they had begun using the guide internally as a tool to which current partnership building and data sharing practices could be compared. Some participants shared that recent changes to health unit structure, management and the inclusion of the Health Equity Foundational Standard in the Ontario Public Health Standards has influenced organizational policy and practice. It was not known to what extent each factor has or will impact practice.

The impact the guide has had so far on the knowledge of participants regarding sharing data for health equity purposes was described as minimal. However, this may be attributed to the self-selection bias in this study: individuals who work in health equity being more likely to volunteer to participate in the interview regarding the guidebook. Additionally, as the guide has been available for only a short period of time, it is still in the hands of early adopters who possess a high knowledge base in the area. Therefore it may not be appropriate to report that the guide does not have the ability to impact knowledge regarding health equity and data sharing, as the knowledge base of participants surveyed and interviewed is well established due to the factors outlined above.

Some participants spoke specifically to potential uses for the guide in their LPHA. Many participants shared that they found the definitions and explanations of different steps in the data sharing process to be helpful, even if it was not significantly different than their understanding or usual practice. The guide was referred to by one participant as a “foundational document” to which staff could refer and use to formalize their process of data sharing. It was noted by participants that the language and evaluation resources in the guide can provide the opportunity for data sharing and evaluation processes to be standardized across health units. It was also noted that the guide can be used in capacity building with LPHA staff, establishing organizational policies and procedures by allowing comparisons to be drawn between current practice and the procedure recommended in the guide.



## Recommendations

Based on the survey and interview responses the following set of recommendations were summarized to improve the guide while maintaining its areas of strength and clarity.

1. Divide the guide into two separate documents: an overview of the LDCP project, and a guide outlining the data sharing process.
2. Incorporate case-studies from the LDCP pilot to provide examples of the data sharing process, including identifying what data was shared and how the pilot results can lead to health equity improvements at the local level.
3. Incorporate more reference material: sample data sharing agreements; non-traditional data sources; privacy legislation relevant to data sharing; publicly available data sources; and an overview of the different health unit structures in Ontario and their data sharing implications.
4. Language and content changes: simplify academic language and note that this may not be a linear process. Include language throughout the document that makes the guidelines more flexible to be relevant for a range of LPHAs.
5. Add 'Collaboration' as a final step in the data sharing process. This can include two way data sharing, data consortiums, open data, and suggestions on collaborative action to improve health equity.

The majority of these recommendations were incorporated into the updated version of the guide. Due to the scope of this project, time restraints, and concerns about the length of the guide all the reference material requested in the third recommendation was not included. The questions were addressed in a newly added Frequently Asked Questions section, and also included below within Future Considerations.



# Future Considerations

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

- 1. Build on Current Frameworks:** Participants in this study discussed the lack of data related to the social determinants of health collected by frontline staff and the need for consistent data to be collected across multiple sources. Developing a framework similar to [The Tri-Hospital + Toronto Public Health, Health Equity Data Collection Research Project Report: We Ask because We Care](#)<sup>6</sup> 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 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.<sup>7-9</sup>
- 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 this project and includes developing



clear processes for handling data requests. Having an LPHA point-person who can address such requests through a systematic process would also be beneficial.

- 5. Central Source:** Many participants requested data beyond the scope of this project. For instance, requests were made for a list of all sources of data, including non-traditional sources. Such lists could become quickly outdated unless maintained centrally through a provincial network or organization with active links. Such a central source could serve as a reference especially for smaller LPHAs.

## Conclusion

Engaging in data sharing with community partners has tremendous potential to positively impact health equity in communities. This LDCP identified barriers, potential solutions and implementation considerations related to LPHA's sharing data with local community organizations. The pilot component of this LDCP was successful in providing data to a selection of community partners who offered recommendations and positive feedback. The steps for data sharing outlined in the guide for LPHAs was well received by participating LPHA staff. Useful recommendations resulted from survey and interview participants during the impact assessment, leading to revisions that will ideally have a positive impact on facilitating data sharing between community partners and LPHAs.

Establishing relationships with community partners can create opportunities for future collaboration, including the potential for reciprocal data sharing. 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 equity in our communities.



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# Appendices

## Appendix A: Steps for Data Sharing

### STEP 1: Identify Community Partners

Recruit community partners who focus on addressing local health equity issues

Identify the capacity of community partners to use data

Consider the capacity of the LPHA to share data

Determine the readiness of the community partner to participate

Build relationships between organizations based on trust

### STEP 2: Consultation

Send consultation questions in advance to allow community partner time to review

Review key terms and definitions to ensure a common understanding

Meet with community partners to discuss shared goals and objectives

Identify type and format of data to share, and desired method for data sharing

Identify community partner's capacity to interpret and utilize data & outline LPHA's data analysis capacity

Recommended one LPHA staff be very familiar with available data that can be shared



## Appendix A: Steps for Data Sharing

### STEP 3: Data Provision

Develop data package as determined during consultation in the agreed upon format

LPHA staff to conduct this step may vary dependent on complexity of analyses required

Identify time needed to analyze, interpret, clean, and provide data to community partners

Provide data package in preferred format identified by community partner

### STEP 4: Evaluation

Evaluate data sharing process shortly after data is provided

Review data with community partner to ensure common understanding and address questions

Review goals and objectives for data usage for next 6 to 12 months

Evaluate again between 6 to 12 months to determine if goals and objectives for data usage were achieved

Evaluation results can be used to improve and focus collaboration efforts



## Appendix A: Steps for Data Sharing

### STEP 5: Collaboration

Collaboration is a value underlying data sharing and should be present throughout all stages

Collaboration involves identifying and working towards common goals together

All involved in data sharing must contribute for true collaboration

The complexity of inequities is most effectively addressed through collaboration

