

Data Sharing Collaboration Toolkit

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Preamble: A Quick Start Guide

Preamble: A Quick Start Guide

i. About the project

The Toronto East Quadrant Local Immigration Partnership (TEQ LIP) initiated a Service Delivery Improvement (SDI) Project, the Scarborough Newcomer Needs and Trends Project, in July 2018, in partnership with the University of Toronto Scarborough (UTSC). The goal of the project was to support organizations in working together to maximize utilization of newcomer-focused service delivery data collected in Scarborough, Ontario. The SDI project was funded by Immigration, Refugees and Citizenship Canada (IRCC).

With the efforts of the TEQ LIP and UTSC, a data pooling platform, the Newcomer Insight Collaborative (NIC), was built to securely manage the settlement service delivery data and other public data collected from the participating agencies. The NIC platform is governed by an Advisory Committee with representatives from the TEQ LIP, the University, and a variety of organizations who serve the newcomer population.

Leveraging the partnership capacity of the TEQ LIP and the research expertise of UTSC allowed the project team to engage agencies in data pooling and analysis and provide the participating agencies with the Scarborough Newcomer Settlement Needs and Trends (S.N.N.T) Report, a bi-annual report consisting of numerous trends in service access based on analysis of the pooled data, and other operational insights that will inform planning of settlement and other services for newcomers to ultimately enhance newcomers' settlement experience in Scarborough.

The learnings of the SDI project informed the development of this data sharing collaboration toolkit. This toolkit is intended to provide organizations in the non-profit sector that are interested in establishing or participating in data sharing collaborations, with insights, tools, and learnings, on setting up successful data sharing collaborations.

ii. What is the purpose of this toolkit?

The Data Sharing Collaboration Toolkit for Non-profit Organizations intends to share learnings, tools, and resources, developed through the SDI project to show how collaboration on data sharing and analysis is feasible in the non-profit sector.

The goals of this toolkit are to:

- Provide a practical framework for non-profit organizations interested in the creation of a data sharing collaboration.
- Introduce ways to address competition in data sharing, along with privacy, in a data sharing collaboration.
- Make recommendations for cultivating a positive relationship among non-profit organizations and a post-secondary institution.
- Highlight the importance of capacity building on data in the non-profit sector.
- Showcase benefits of shared data pooling and analysis to provide operational insights that would enhance community services.

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iii. Who should use this toolkit?

The Data Sharing Collaboration Toolkit is designed to be used both by non-profit organizations and post-secondary institutions, for instance:

- Non-profit organizations, public institutions, and charities, interested in collaborating on data projects with other organizations, or with universities.
- Post-secondary institutions interested in finding new collaborative approaches to work with community-based agencies on service delivery data projects.
- Agencies involved in traditional data sharing, agencies with slow progress in activating data sharing collaborations on a larger scale, or dealing with complex initiatives.

iv. Why should we use this toolkit?

The Data Sharing Collaboration Toolkit provides useful approaches, guidance, and resources for agencies in the non-profit sector to understand, prepare for, and initiate, data sharing collaborations.

In this context, with data sharing, we focus more on agencies pooling together service delivery data they collect as part of their client services, for the purpose of shared analysis, to create learnings that in turn better inform service planning and service improvements.

The benefits of data sharing include:

- Organizations can share increasing volume and complexity of data between themselves using a secure, fair, and legal approach.
- Combination of data from different sources can increase the performance and the value of services, while enabling better research and development.
- Empowering unprecedented collaboration, data-driven decision-making, informing policy, and amplifying social impact.

v. How to navigate this toolkit?

While the Data Sharing Collaboration Toolkit presents the information in an ideal sequence, agencies may navigate this toolkit based on their needs and their current state in regard to data sharing, for example:

- If an agency is new to data sharing and would like to know more about the initiative, the agency is recommended to start from the **Preamble: A Quick Start Guide**.
- If an agency is considering proposing a data sharing partnership, the agency could make use of **Preparing to Begin a Data Sharing Project, iii. Assessing your organizational readiness** etc.
- If an agency already has a partnership, the agency could review the information of this toolkit and focus on **Sustainability Plan, i. Data Lifecycle**.





Preparing to Begin a Data Sharing Project

Although many data sources are available to identify trends and inform service planning, such as Census, Immigration, and Labor Market data, these sources are frequently outdated and often report on large geographical catchment areas. Many agencies also do not have the resources or expertise to make use of the data they collect and are reticent to share information with other organizations due to competition for funding.

This section provides guidelines for non-profit organizations to prepare for a data sharing initiative, in accordance with an organizational readiness assessment, environmental scan, and a data sharing decision matrix.

Preparing to Begin a Data Sharing Project

i. Assessing the landscape - environmental scan

Environmental scanning is the ongoing tracking of trends and events in an organization's internal and external environment that bear on its success. The results are extremely useful in moulding strategies.

Non-profit organizations should conduct an environmental scan before constructing a data sharing collaboration, to better understand the non-profit sector's current data use and collection procedures related to the intended project goals, along with what knowledge key stakeholders would like to gain from pooled data.

The environmental scan could be completed through a literature review, and individual stakeholder interviews and surveys, to gain and present knowledge on:

- Availability of desired data points
- Service provider in-house data management
- Data use in-house and with open, or public, data sets
- Knowledge and data analysis needed in the non-profit sector
- Willingness and perceived issues with participation in the proposed project

Participants could be asked a similar set of questions designed to encourage data sharing. The interviewers could ask additional questions for clarification or if participants' responses lead to topics not previously considered in the development of the questions during the in-person, or phone, interviews.

Alternatively, survey invitations could be sent to agencies providing a variety of services (e.g., health care, education, settlement, employment, housing, legal aid) to ensure a diverse group of service providers are represented. The surveys could be completed through an online survey tool, such as SurveyMonkey. See **Appendix i** for a list of the questions that were used in carrying out the SDI project environmental scan.

ii. Data sharing decision matrix

It is evident from an analysis of a range of models, that there are four essential components of a data sharing collaboration. These are framed in the decision matrix as the key decision points that non-profit organizations should consider when preparing for a data sharing initiative:

- **Why share data?**
 - Non-profit organizations should define their purposes of sharing data.
 - Potential goals/objectives include discovering new insights, unlocking innovation, accelerating decision-making, increasing prediction and forecasting capabilities, optimizing process efficiencies, and coordination.

Preparing to Begin a Data Sharing Project

- **What data to share?**
 - Non-profit organizations should identify their datasets for a data sharing collaboration. (e.g., individual data, open data, private data, and public data).
- **Who to involve?**
 - Non-profit organizations should decide which parties are to be involved in a data sharing collaboration. (e.g., other non-profit organizations, post-secondary institutions, public institutions, and charities).
- **How is data accessed?**
 - Non-profit organizations should choose which form of data access is best suited for their initiatives.
 - Potential forms include no access (available to the partnered agencies but not available to other stakeholders), open access at an international, national, or regional level, and restricted access (e.g., user registration, licenses depend on approval, value exchange such as money).

iii.

Assessing your organizational readiness

An organizational readiness assessment measures the preliminaries of an organization to initiate a significant new project. Conducting an organizational readiness assessment gives you the knowledge and the assurance about your agency's ability to engage in a data sharing collaboration.

In this context, the organizational readiness assessment should at least examine the following criteria:

- **Data sharing collaboration goals and objectives** (for example, better inform service planning and service improvements, support data-driven decision-making, create evidence to inform policy and/or amplify social impact).
- **Expectations and concerns for data sharing** (e.g., pooling together service delivery data for shared analysis, lack of resources and expertise, competition for funding).
- **Organizational capacity and leadership support** (e.g., staff time and resources required, commitment from senior management).
- **Project resources** (e.g., funding opportunities, appropriate allocation of resources).
- **Ways to reduce potential project failure regarding the important elements of a data sharing collaboration** (e.g., building trust, governance structure, privacy, data ownership, capacity building, and sustainability plan).

The above decision points are ordered in an ideal sequence. However, there is a degree of necessary circularity to the process. In that, certain decision points could be used multiple times, switching from one point to another, refining the level of detail and the participation of stakeholders, with each iteration.





Building Trust and Understanding for Data Sharing

Building trust and understanding is essential for successful data sharing. There are two aspects of trust building in the non-profit sector. First, the data sharing process needs to be transparent, meaning that the parties involved should be provided with an understanding of how the data are collected, analyzed, applied, and secured. Second, non-profit organizations should create an environment that is conducive to data sharing by ensuring privacy. For instance, data transfer agreements are an important tool to help build trust and set clear boundaries and expectations. The role of data transfer agreements is discussed in **Privacy and Confidentiality, iii. Data transfer agreements.**

This section makes recommendations for non-profit organizations to create trusted intermediaries, facilitate capacity building, partner engagement, individual consultations, and group decision-making. This section also addresses competition.

Building trust and understanding for data sharing

i. Neutral third-party participation: trusted intermediaries

In this context, we focus on agencies pooling together service delivery data for shared analysis and to create learnings that lead to better service planning and service improvements. However, agencies still seem to be reluctant to share their data due to reasons such as competition for funding. Therefore, the key question is how data sharing can be incentivized while avoiding potential conflicts of interest.

Data sharing platforms have emerged as trusted intermediaries to share data more efficiently and to a broader range of service providers while addressing the concerns and protecting the interests of data providers. For instance, the NIC platform built by the TEQ LIP and UTSC, was to securely manage the settlement service delivery data and other public data collected from the partnered agencies.

An agency's participation in the NIC project involved the following general stages:

- **Onboarding:** The NIC database was adjusted to accommodate the new participating agency. The agency, TEQ LIP, and UTSC, worked together to ensure that NIC was prepared to receive the agency's contributions to the project.
- **Data collection:** The participating agency uploaded their reports to the NIC database. This stage was facilitated by the Research Partnership Lead from TEQ LIP.
- **Research:** TEQ LIP and UTSC researchers combined the contributions of all participating organizations and performed detailed statistical analyses. The results of those analyses were presented to the participating organizations.

ii. Building capacity and understanding

Building capacity and understanding is a long-term, ongoing process by which non-profit organizations obtain, improve, and retain, the skills, knowledge, and other resources needed to engage in a data sharing collaboration. The organizational readiness assessment, environment scan, and the data sharing decision matrix, are all useful tools that allow agencies to perform at a greater capacity in a data sharing collaboration.

For example, the project plan for the S.N.N.T report included capacity building among service providers in years two and three of the project. The intent was to organize workshops to build and enhance their capacity to utilize their own data and other data sources for service planning.

However, the SDI project environmental scan participants demonstrated a knowledge gap regarding what service delivery data was collected regularly at their organizations and how they would have accessed that data in a manner appropriate for analysis. Participants also noted that they lacked an understanding of what information their data was capable of providing them ("Environmental Scan Report").

Consequently, capacity building is recommended to start early in a data sharing collaboration. **Integration of Capacity Building** through workshops and hands-on activities, guides participation in a data sharing collaboration. It provides opportunities to increase the ability of participating organizations to not only effectively participate in a data sharing collaborative but also to enhance their ability and capacity to utilize their service delivery data.

Building trust and understanding for data sharing

iii. Partner engagement in the development phase

During the development phase, an agency should arrange everything that will be needed to initiate a data sharing collaboration, including which parties to involve, such as non-profit organizations, post-secondary institutions, public institutions, and individual consultants. Active partner engagement and stakeholder involvement will create solid building blocks for future successes.

The SDI project was initiated by the TEQ LIP, in partnership with UTSC and funded by IRCC. Leveraging the partnership capacity of the TEQ LIP and the research expertise of UTSC allowed us to provide participating agencies with a means to pool data and conduct analysis on the shared data to produce the S.N.N.T Reports. It is evident from the S.N.N.T project evaluation carried out by Full Circle Consulting Inc., that the SDI project made a positive impact on its stakeholders, since many of the anticipated outcomes were met (“SNNT Evaluation Report”).

Similarly, non-profit organizations could search for funding opportunities from public institutions, and partner with post-secondary institutions and other non-profit organizations, to pool together service delivery data for shared analysis which will create learnings that would enhance community services.

iv. Importance of process and outcome evaluation

Evaluation helps to determine a data sharing collaboration’s effectiveness in achieving its stated outcomes. It is helpful to build evaluation into a data sharing collaborative to identify whether the process is conducive to meeting the project goals and what improvements can be made; to determine the extent to which the project has achieved its planned immediate, and intermediate, results; and to examine the degree to which the partner engagement is being established and maintained.

Key evaluation questions from the S.N.N.T report evaluation included:

- Has the project been helpful to TEQ LIP and how?
- Has the project been helpful to participating organizations, and how?
- Has participation in the project been worth the time and effort participating organizations have put into it?
- What capacity building has occurred outside of the capacity building workshops?
- If agencies are not contributing to the data sharing collaboration, why not?
- What unintended outcomes, if any, resulted from this project?

The evaluation report would highlight the successes, challenges, and recommendations for moving the project forward.

Building trust and understanding for data sharing

V. Group decision making

Group decision making is a type of participatory process in which individuals acting collectively, analyze problems, consider alternative courses of action, and make decisions. Such type of a participatory process is necessary for projects such as a data sharing collaboration, to ensure that each participating organization has a say in the type of data collected, the type of analysis conducted, and to inform the direction of the research questions.

Common group decision-making methods that non-profit organizations could apply in a data sharing collaboration are:

- **Brainstorming:** Group members verbally suggest ideas or alternative courses of action during a meeting.
- **Dialectical Inquiry:** Group members are divided into different sides and discuss the advantages and disadvantages of proposed solutions.
- **Nominal Group Technique:** Group members are required to write a comprehensive list of their ideas or alternative actions.
- **Delphi Technique:** Group members are selected due to the specific knowledge or expertise they possess (“Group Decision Making”).

The above group decision-making methods are useful in situations where decisions and changes need to be made in a data sharing collaborative. For example, participating agencies decided which data points to collect and which topics of inquiry were important to them – what they wanted to learn from the data. Also, the project plan for the S.N.N.T report included capacity building among service providers in years two and three of the project. However, capacity building was recommended to start immediately after identifying a knowledge gap from the SDI project’s environmental scan participants.

vi. Addressing competition in the sector

Data is an important resource that helps non-profit organizations compete for funding opportunities. This may explain the reluctance that agencies might have in sharing data with each other. However, sharing data for joint analysis enables non-profit organizations to be more knowledgeable about sociodemographic variables and service access trends which provides a clearer picture of what is happening beyond the data they collect. This thereby strengthens their ability to plan for effective services.

Non-profit organizations could address competition in the sector by:

- **Being well-prepared** (e.g., conducting an organizational readiness assessment, environmental scan, and using a data sharing decision matrix),
- **Building trust** (e.g., involving trusted intermediaries, using individual consultations, and leveraging group decision-making),
- **Having a well-established governance structure** (e.g., cultivating a positive relationship with a post-secondary institution, forming an advisory committee),

Building trust and understanding for data sharing

- **Ensuring privacy** (e.g., reviewing the relevant legislation, regulations, and agreements),
- **Taking ownership** (e.g., addressing the issue of power),
- **Integrating capacity building** (e.g., organizing workshops), and
- **Developing a sustainability plan** (e.g., data lifecycle management).

The above are all important elements of this toolkit. Non-profit organizations might take different actions to compete over a related cause, target audience, or funding opportunity. For instance, an agency might offer complimentary services for their beneficiaries, whereas the other agency might focus on generating awareness and public acceptance for their cause. Therefore, the key question is how to join forces together for the greater good.

The best collaboration occurs when partnered agencies have a common goal and a clear understanding of their roles to the relationship. In this context, we focus on agencies pooling together service delivery data for shared analysis and creating learnings that lead to better service planning and service improvements. Although many agencies are reticent to share information due to competition, the advantages of data sharing would compensate agencies for their concerns.



Governance Structure

With data sharing collaborations, a governance structure is a framework which supports project management and compliance. It directs how post-secondary institutions and participating organizations interact with the agency, and with stakeholders, to closely guide and monitor operations.

This section makes recommendations for collaborating with a post-secondary institution, governing a data sharing collaboration by an advisory committee, connecting with the non-profit sector community, and engaging and ensuring collaboration with participating organizations.

Governance Structure

i. Collaborating with a post-secondary institution

There are many advantages for collaborating with a post-secondary institution. The SDI S.N.N.T. project was done in partnership with the UTSC whose staff and students led the development of technology to pool the data and conduct data analytics.

The key deliverables of TEQ LIP's collaboration with UTSC included:

- Building the NIC platform that enabled diverse organizations to pool service delivery and other data for joint analysis.
- Motivating organizations to work together to pool their agency data through the NIC platform which was jointly analyzed to produce a bi-annual S.N.N.T report.
- Integrating capacity building to make better use of organizations' data for program planning and evaluation through workshops.

UTSC staff were enthusiastic about working with the agencies and they substantially valued the partnership with TEQ LIP. UTSC students were also pleased with having received remarkable learning opportunities with prototype development and implementation. Maintaining ongoing communication between the UTSC and the TEQ LIP team, coupled with the willingness of TEQ LIP to bring issues to the technical team's attention, helped the project move forward. It was highly important for the institution to learn more about the community by touring agencies.

Meanwhile, the collaboration with the University benefited the participating organizations by allowing them to become more familiar with university operations, providing them with access to research and technical expertise, and enabling them to build stronger connections. Ultimately, all parties were satisfied with the University's increased community involvement.

ii. Advisory committee

An advisory committee consists of a group of individuals who meet to advise the organization on operations, both internal and external. The responsibilities of an advisory committee governing a data sharing collaboration are to identify, investigate, and discuss issues, and to propose solutions and recommendations for them. The advisory committee should be made up of knowledgeable and qualified members who are intrinsically motivated.

The SDI S.N.N.T. project was guided by an advisory committee with representatives from the TEQ LIP, UTSC, and a variety of organizations who serve the newcomer population in Scarborough and could provide insight into data needs and capacities in the non-profit sector. Good project management and communication in and between meetings facilitates quality stakeholder involvement which is key to the success of collaborative projects.

It is important to ensure that the advisory committee is equipped with the necessary information, and that meetings are facilitated in a way that fosters balanced contributions from all members.

Governance Structure

iii. Engaging participating organizations

Engagement of organizations in a data sharing collaborative will be determined by the goals and objectives the collaborative aims to achieve. The TEQ LIP connected with a diversity of organizations in Scarborough, focused on engaging those non-profit organizations that provide social, settlement, employment, and similar services, to the community, with special focus on services for newcomers and immigrants.

Participating agencies were supported to pool their settlement service delivery data for joint analysis through the NIC platform, which allowed them to uncover trends and patterns related to newcomer service access in the Toronto East Quadrant geography. In addition to taking part in the data sharing aspect, the SDI S.N.N.T. project provided a number of ways for agencies to be engaged, such as participation in stakeholder interviews, surveys, advisory committee meetings, and capacity building workshops.

iv. Facilitating agency participation and accessibility

Non-profit organizations can facilitate and support agency participation by removing the need for participating agencies to change their current practices of data collection, collect additional data, or change their data management systems. In recognizing that agency staff are highly occupied with service delivery and may not have adequate time to devote to data collection, a key feature of the SDI project was making it as easy as possible for agencies to participate. Consequently, it was important that the data platform could accommodate data uploads from a variety of data management systems that agencies use. Customized templates were, therefore, built into the platform.

The data that was uploaded to the NIC database came from a number of agencies. These agencies used different information systems and methodologies to record their service delivery data. To achieve a thorough understanding of every contributing agency's reporting processes, the developers at UTSC used document templates specific to each agency's reporting process. This template system was designed to reduce the time and the resources required of an agency to participate in the project, and to ensure that no additional or duplication of data entry occurred.

Before any file from an agency was uploaded to the NIC database, the developers wrote code that extracted the relevant data fields from the files. To write the code, the developers first sought to understand how an agency stored its data. This was done by collecting information about each agency's unique data reporting process. They found an efficient way of collecting information about a given agency's data collection and reporting processes was to have the agency users generate "Document Templates" for the developers to study.

When an agency user uploaded a report to the NIC database, the platform organized the contents of that report so that every data field (e.g., client ID, gender, etc.) was stored in a standardized format, regardless of the system the report came from. To prepare the NIC database to receive an agency's reports, the developers at UTSC required a sample of each of those reports. By studying the agency's reports, the developers were then able to obtain a thorough understanding of the kind of data that is provided in each report and how it was formatted. These details guided the developers as they created templates that told the NIC database what to expect when an agency uploaded a particular kind of report. The developers then adjusted the NIC database to ensure that the reports were recognized,

Governance Structure

and that the data was formatted correctly upon entry to the database (“Participation and Template Guidebook”).

V. Facilitating the process of data upload and analysis

Collaboration among participating agencies and a lead agency, as well as clarity of the process of data transfer, upload, and analysis in data collaborations, is key to achieving a common goal. The S.N.N.T. project implemented three general stages to facilitate data collection, upload, and analysis.

First, agencies provided sample reports to TEQ LIP and UTSC for preparation of the NIC application. TEQ LIP worked with agencies to determine the steps required to generate their reports and to confirm the details for uploads. TEQ LIP reviewed the sample reports with UTSC to ensure that they had all the information needed for NIC to receive agencies’ reports during the data collection stage. Once NIC was ready, TEQ LIP advised agencies of any pre-checks that they should do after generating their reports. TEQ LIP also provided agencies with a login for the NIC website where agencies then uploaded their reports.

Second, agencies ran their reports and submitted them to NIC. TEQ LIP informed agencies of what data to upload, when data collection should begin, and the deadline for submission. When that time window arrived, agencies followed the steps to generate the data reports from their data management systems. Once generated, agencies performed the pre-checks and uploaded them to the NIC database.

Third, TEQ LIP and UTSC performed data cleaning and preparation, and then conducted statistical analyses on the contents of agencies’ uploaded reports combined with the uploaded reports from all the other participating agencies. The findings were assembled in research reports, which were presented to the participating agencies. These reports helped identify patterns and trends in service delivery based on the shared data which can be used as input for future service delivery improvement initiatives and funding applications.

Privacy and Confidentiality

Privacy and confidentiality are two important concepts when it comes to data sharing. In this context, privacy is known as the right for an organization to have moderate control over its service delivery data collected, used, or disclosed. Confidentiality, on the other hand, is the obligation of an organization to protect entrusted data that others shared with them.

This section introduces ways to address privacy and confidentiality in data sharing collaborations by reviewing legislation, the Privacy Commission of Canada regulations, and data transfer agreements. Maintaining privacy helps to secure participating organizations' information and to create an environment that is conducive to data sharing.

Privacy and Confidentiality

i. Reviewing legislation

Non-profit organizations should review several privacy legislations enforced within Canada and identify the legislation that applies to their particular data collaborative. Enforcement of these legislation is managed by various governmental organizations and agencies. For example, oversight of the **Personal Information Protection and Electronic Documents Act (PIPEDA)** is handled by the Office of the Privacy Commissioner. Regardless, certain factors determine what legislation apply and identifies the administrators of the legislation.

These factors include:

- The nature of the organization managing the personal information (e.g., federal government, provincial or territorial government, federal-regulated business, private sector, engaged in commercial activities, non-profit sector).
- Where is the organization based?
- What type of information is involved?
- Does the information cross provincial or national borders?

Non-profit organizations may collect personal information as part of their client services. Personal information includes race, religion, age, marital status, medical data, education attained, employment history, and financial status. Personal information does not include information that has been anonymized. Neither does it include an individual's business contact information that an organization collects, uses, or discloses, for the purpose of communication. It is important to ensure compliance with legislation when dealing with personal data to avoid risks associated with privacy breaches and violations, including the risk of court action, class action litigation, court-awarded damages and reputational injury ("Why Not-For-Profits Should Comply").

ii. Reviewing Privacy Commissioner of Canada regulations

There are two privacy regulations that are enforced by the Office of the Privacy Commissioner of Canada: The Privacy Act and the PIPEDA. The Privacy Act outlines how the federal government administrates personal information, whereas the PIPEDA outlines how businesses control personal information.

The Privacy Act applies to all federal governmental institutions listed in the Privacy Act Schedule of Institutions. The Act relates to an individual's right to access and correct their personal information, and the federal government's collection, use, or disclosure, of personal information to provide services, which includes personal information of federal employees ("Summary of Privacy Laws").

The PIPEDA applies to any organization that collects, uses, or discloses personal information in the course of commercial activities. Since PIPEDA governs commercial activity, non-profit organizations are often unclear as to if or how the Act affects them. It is important to understand that the nature of the organization does not determine whether PIPEDA applies. Rather, it is the nature of the activity undertaken by the organization that may elicit the requirements of PIPEDA. The term "commercial activities" is defined as: "...any particular transaction, act or conduct or any regular course of conduct that is of a commercial character,

Privacy and Confidentiality

including the selling, bartering or leasing of donor, membership or other fundraising lists (“Why Not-For-Profits Should Comply”). Consequently, the Act applies to non-profit organizations if they are engaging in commercial activities that are not central to their mandate and which involve personal information.

Furthermore, each province and territory in Canada has its own regulations governing privacy. For instance, Ontario is governed by **the Freedom of Information and Protection of Privacy Act and the Municipal Freedom of Information and Protection of Privacy Act** (“Freedom of Information and Protection of Privacy Manual”) Non-profit organizations are encouraged to review these regulations, maintain strict confidentiality and seek legal advice based on their specific circumstances.

iii. Data transfer agreements

Data transfer agreements are internal or external agreements to share data according to specific terms and conditions. These agreements identify the parameters which govern the collection, distribution, storage, security, analysis, and destruction of data. Data transfer agreements are an integral tool in data sharing collaborations since they govern the agreement and relationship between parties in the collaborative, set out legal and ethical obligations, and in consideration to the risks related to inappropriate data usage.

The terms and conditions of a data transfer agreement should correspond with the nature of the data collected, the probability of a privacy breach, and the potential magnitude of harm posed to agencies if their privacy rights were violated (“Data Sharing (or Transfer) Agreements”).

The agreement generally contains the following elements:

- **Project Description:** data sharing project brief.
- **Data Description:** the data to be collected, the nature and scale of the data to be used.
- **Format:** the data formats and standards, usability, longevity, and suitability justification.
- **Data Organization:** data management and quality assurance during the project.
- **Storage:** back up methods for the data and future implications.
- **Security:** technical and procedural protections for the information.
- **Responsibilities:** the owners and stakeholders of the data and their roles.
- **Legal Requirements:** relevant federal and provincial laws.
- **Privacy:** procedural protections for participant confidentiality.
- **Term and Termination:** the duration of the agreement.

See **Appendix ii** for a sample data transfer agreement created by TEQ LIP.



Data Ownership

Data ownership is the act of possessing legal rights and complete control over data. In relation to a data sharing collaboration, data ownership should be agreed upon as part of the data transfer agreements. Data ownership provides and specifies information about the rightful owner of data assets, and the collection, use, and distribution policy implemented by a non-profit organization or data collaborative.

This section introduces ways to govern ownership of data in a collaborative and addresses the issue of power. Data owners are critical in the data sharing process, since they are responsible for ensuring that the data is secured, the quality of data is measured, and that the right controls are in place for data access.

Data Ownership

i. Ensuring organizational ownership of data

There are three distinct roles in data governance: data owner, data steward, and data custodian. The data owner is concerned with risks and access to data (“Data Governance Roles”). For instance, in the SDI project, the agency retains ownership of the data they contribute to the data sharing collaboration and has the right to withdraw the data. Any additional use of the data that is not set out in the data transfer agreement must be approved by the contributing agency.

The data steward is involved with the meaning and correct usage of data (“Data Governance Roles”). In comparing data steward and data owner, often the data steward does not restrict users on the access of data as long as they use it correctly. The data custodian is responsible for managing servers, backups, and networks. The data custodian has mastery of a data schema and lineage and may provision access according to the data owner’s rules (“Data Governance Roles”). In comparison with steward and owner, the data custodian is often not involved in the decision-making process.

In relation to data ownership, transfer of data ownership to the research institution or the host of the collaborative should be agreed upon as part of the data transfer agreements. Non-profit organizations are encouraged to recognize data ownership as a formalized role to take responsibility for the management of service delivery data across its life cycle, i.e., from collection to analysis.

ii. Addressing the issues of power

In data collaboratives, where agencies work together on data sharing and pooling, power struggles may arise. Non-profit organizations should consider some of the issues of power below:

- **Ownership Claim:** a number of possible parties may desire to claim data ownership (e.g., non-profit organizations, partnered agencies, post-secondary institutions).
- **Data Hoarding:** factors influencing the decision to withhold data access (e.g., collecting data can be costly and time consuming, technical obstacles, concerns about qualifications of partnered agencies).
- **Balance of Obligations:** negotiation on the balance between an agency’s willingness to share data and its obligation to other collaborators (“Data Ownership”).

Non-profit organizations are able to address the issue of power by implementing the corresponding recommendations:

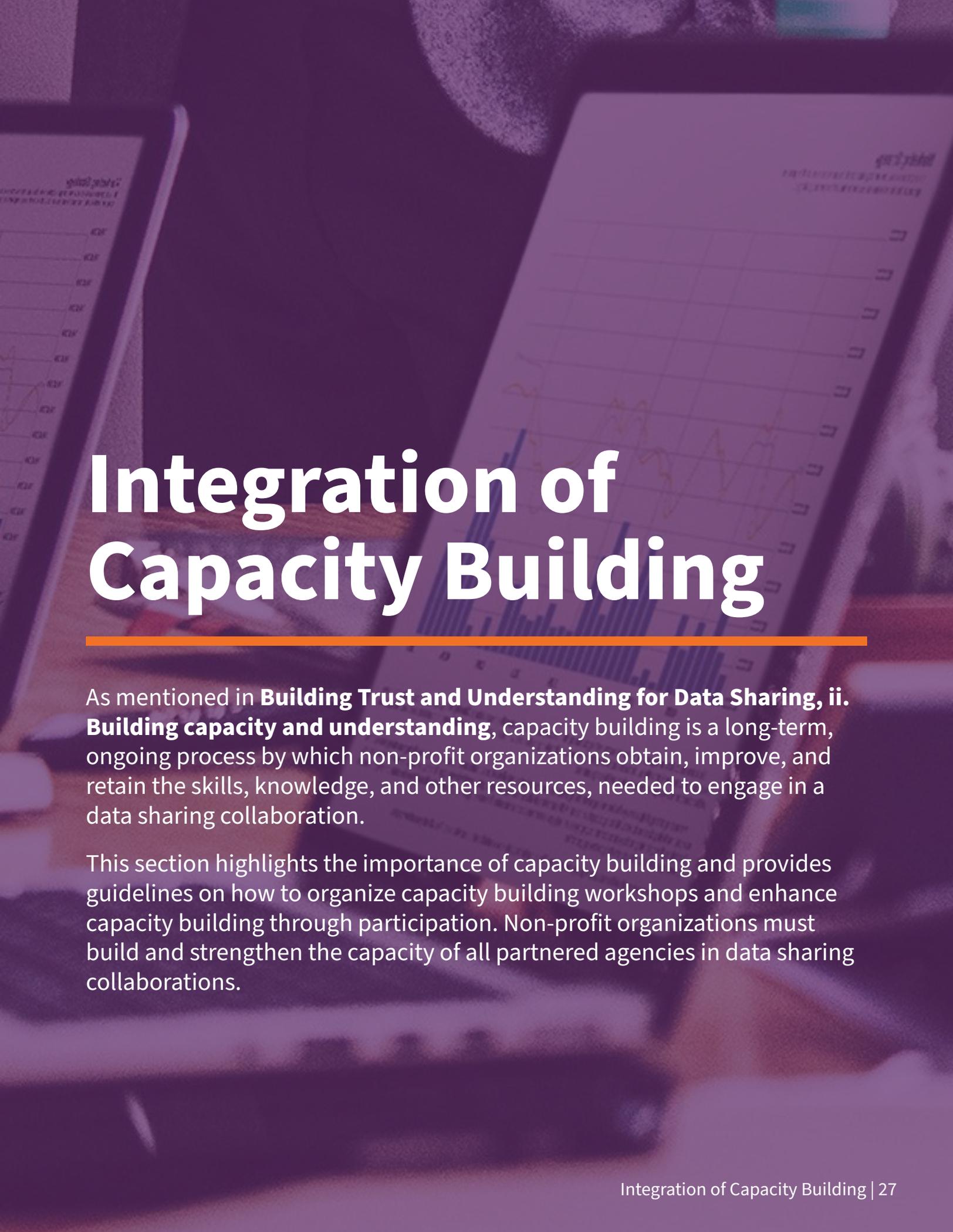
- Addressing uncertainties about data ownership by ensuring organizational ownership of data, reviewing the privacy and confidentiality legislation enforced within Canada, and developing a data transfer agreement.
- Reinforcing trust and empowering partnered agencies through stakeholder engagements to maximize the value of data (e.g., trust building, sharing resources and expertise).
- Showcasing benefits of shared data pooling and analysis to provide operational

Data Ownership

insights to compensate agencies for their concerns (e.g., empowering unprecedented collaboration, data-driven decision-making, informing policy, amplifying social impact).

The above strategies are interrelated. For example, trust can be reinforced by empowering partnered agencies to address the risks of enhanced access and sharing. Data ownership is the act of retaining complete power over a data sharing collaboration, thus, the issue of power demands agencies' further considerations.





Integration of Capacity Building

As mentioned in **Building Trust and Understanding for Data Sharing, ii. Building capacity and understanding**, capacity building is a long-term, ongoing process by which non-profit organizations obtain, improve, and retain the skills, knowledge, and other resources, needed to engage in a data sharing collaboration.

This section highlights the importance of capacity building and provides guidelines on how to organize capacity building workshops and enhance capacity building through participation. Non-profit organizations must build and strengthen the capacity of all partnered agencies in data sharing collaborations.

Integration of Capacity Building

i. Importance of capacity building

Capacity building is the term commonly used by non-profit leadership to ascertain the ability of an organization to achieve its mission in an effective way. Many community agencies have expertise and capacity in service delivery, but not necessarily in data analysis. Therefore, agencies need to build capacity towards data management, data use, and their abilities to extract evidence from the data they collected to support service planning and service improvements.

For instance, some of the SDI project's environmental scan participants demonstrated a gap in knowledge regarding what service delivery data was collected regularly at their organization and how they would access that data in a manner appropriate for analysis. One participant said, "I don't really understand what a part of the knowledge base is."

The participants also noted that they lacked an understanding of what information their data was capable of providing them, one noting "Our biggest problem is we don't really know what to make of the data we have." As a result, the TEQ LIP implemented capacity building workshops as an essential part of the project immediately after conducting the environmental scan. It is evident from the S.N.N.T Evaluation Report that the integration of capacity building was well received by the participants.

ii. Capacity building workshops

Capacity building workshops that build and enhance organizations' capacity to utilize their own data, and other data sources, for service planning can greatly enhance the success of a data sharing project. The general workshop topics should be based on a needs assessment of participating agencies to identify specific project-focused needs. Topics covered in the SDI S.N.N.T. project included preparing to begin a data sharing project, reviewing privacy and confidentiality legislation, asking relevant research questions, how to create surveys, and how to use Microsoft Excel for data collection and analysis.

It is evident from the S.N.N.T Report Evaluation that the SDI project participants were satisfied with the capacity building workshops. Everyone indicated that the workshops were interesting, relevant, and well-presented, and the great majority felt that the workshops were of benefit to them. See **Appendix iii** for the charts demonstrating the positive outcomes as a result of the workshops.

The learnings from the SDI project informed the project team to make a few changes to the workshops. Practical case studies and examples that are relevant to the particular data collaborative can be extremely useful in building the capacity of participating agencies to benefit from the data sharing initiative, as well as group work such as bringing their own data and working with it in teams.

Integration of Capacity Building

iii. Capacity building through participation

Since capacity building is a long-term, ongoing effort to promote and support an environment that is conducive to data sharing, non-profit organizations could enhance their capacity and ability to use data effectively through active participation in data sharing collaborations.

In this context, we focus on capacity building examples at three different levels (“Examples of Capacity Building Activities”):

- **Individual level:** successful implementation starts at this level, where capacity building activities increases an individual’s knowledge and skills (e.g., one on one, or group, trainings, and mentorships).
- **Organizational level:** capacity building activities at the organizational level concentrate on supporting collaboration, establishing governance structure, and shoring up sustainability (e.g., collaborating with post-secondary institutions, forming an advisory committee, developing the data lifecycle).
- **Systems level:** capacity building activities at the systems level tend to be more complex. They involve the allocation of resources and the development of policy (e.g., data sharing decision matrix, reviewing legislation and the Privacy Commission of Canada regulations, developing data transfer agreements).

Capacity building is an investment in a data sharing collaboration’s success. In addition to the capacity building workshops that took place during the SDI SNNT project, the Research Partnership Lead met one on one with agencies to provide feedback and make concrete suggestions and recommendations on individual agencies’ data collection and management practices, following the learnings from the data uploads. This, in turn, helped agencies improve their data collection and management practices in the SDI project.



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Sustainability Plan

The sustainability plan of a data sharing collaboration is a roadmap for achieving long-term data sharing goals. In this context, we focus on agencies pooling together service delivery data they collect as part of their client services, for the purpose of shared analysis. This has the potential to create learnings that better inform service planning and improvements.

This section provides a practical framework for non-profit organizations to develop a sustainability plan for data sharing collaborations through data lifecycle management. The data lifecycle refers to the sequence of stages that service delivery data goes through from its capture to its distribution and reuse.

Sustainability Plan

i. Data lifecycle

There are six general stages of data lifecycle in a data sharing collaboration.

Although these stages are ordered in an ideal sequence, non-profit organizations do not necessarily have to go through all stages below:

- **Capture:** Agencies collect service delivery data as part of their client services, usually through data entry, acquisition from external sources and signal reception such as transmitted sensor data.
- **Maintenance:** Service delivery data are subjected to processes prior to its use in data sharing collaborations, which involve tasks such as cleansing, enrichment, and retrieval of changed data, also known as extract-transform-load.
- **Active use:** Service delivery data are used to support the data sharing collaboration (e.g., TEQ LIP and UTSC conducted statistical analyses on the contents of agencies' uploaded reports combined with the reports from other participating agencies).
- **Distribution:** Research reports are assembled when the analyses are completed and presented to the participating agencies, which help identify patterns and trends for future service delivery improvement initiatives and funding applications.
- **Archival:** Service delivery data and research reports are no longer processed, used or distributed, but are stored for future applications.
- **Purging:** Service delivery data and research reports are deleted if necessary.

Furthermore, data lifecycle management is the catalyst that flows data from one stage to the next ("Data Lifecycle"). When engaging in a data collaborative, participants should apply data lifecycle management to maximize the utilization of their service delivery data and to set out what happens with the data once the project has run its course. Successful data lifecycle management enables the availability of clean, accurate, and useful data to all stakeholders. Thus, providing operational insights that would enhance community services.



Appendices

Appendices

i. The SDI project environmental scan survey questionnaire

- What data management system(s) does your organization use for data input?
- Who inputs data at your organization?
- Where does your organization store your data?
- Are you using additional encryption or security software for your organization's data?
- Who or what system analyses your data?
- What support does your organization have analyzing data?
- What do you most commonly use your organization's data for?
- What are your biggest challenges related to using data effectively?
- If given the opportunity to request analysed data, what would your organization want to know?
- If TEQ LIP and UTSC had the resources, what supports would your organization most need in relation to data analysis and capacity-building related to data use?
- If TEQ LIP and UTSC had the resources, what supports would your organization most need in relation to data analysis and capacity-building related to data use?
- What public/open data sets does your organization utilize?
- What do you most commonly use open/public data sets for?
- What challenges do you encounter when using open/public data sets?
- If the open/public data sets your organization is using are missing important data points, can you think of any specific data you would like to get from official data sources?
- What concerns do you already have within your organization in relation to data collection?
- What is your role at your organization?
- TEQ LIP and UTSC would like to better understand what variables are already being collected in Scarborough to avoid creating extra work for organizations. Given instruction on how to do so, would you be willing to provide TEQ LIP and UTSC with a blank copy (no client information) of the variables or fields your staff is inputting into your system?
- Would you be willing to provide TEQ LIP and UTSC with a copy of your client confidentiality/use of data agreement?
- If you are interested in learning more about this project and/or would like to participate, please leave your contact information below so we may provide you with additional information.

Appendices

ii. Sample data transfer agreement

DATA TRANSFER AGREEMENT

This agreement is made between

[Agency Name]
(the “Provider”)
and
[Agency Name]
(the “Recipient”)

Effective the last date of execution below (the “Effective Date”).

WHEREAS the Recipient intends to perform a project entitled “[The Scarborough Newcomer Needs and Trends Report Project]” as generally described in Appendix “A” (the “Project”);

AND WHEREAS the project ends on {date xxx} unless otherwise extended by written agreement of all parties and pending funding availability;

AND WHEREAS the Recipient requires certain information as more fully described in Appendix “B” (the “Data”) that is owned by, or under the control of the Provider for use in performance of the Project;

AND WHEREAS the Provider wishes to provide the Data to the Recipient in order for the Recipient to perform the Project;

NOW THEREFORE the Parties agree as follows:

- 1. Data Provided.** The Provider shall provide the mutually agreed upon Data to the Recipient, and by such means, as described in Appendix “B” or as may be agreed to by the Parties in writing. Participation in any data collection as requested by the Recipient will be at the discretion of the Provider. There will be several data collection points undertaken in the course of the project. The Provider may opt out of any request for data. The content of any data collection and focus of analysis will be a joint decision between all parties.
- 2. Withdraw.** Should the Provider wish to opt out of any data collection or discontinue their participation in the Project, they will do so by providing written notice to the Recipient 30 days in advance of that data collection. All previously contributed data will remain in the platform and as part of the Project.
- 3. Purpose.** The Recipient shall only use the Data for the purposes of the Project, or other purposes as may be agreed from time to time by the Parties.
- 4. Future use of Data:** The use of the Data for purposes outside of the scope of the Project, such as academic research, will be agreed upon by the Parties on a case by case basis. The goal of any such purposes would be clearly in the interest of the populations served by the Provider.

Appendices

- 5. Acknowledgement.** The Recipient agrees to acknowledge the source of the Data in any publications resulting from the use of the Data.
- 6. Further Distribution.** The Recipient will not distribute the Data received from the Provider to third parties outside of the scope of the Project without the Provider’s written consent, and shall refer any request for the Data to the Provider.
- 7. Copies.** The Recipient shall only make such copies of the Data as is necessary for the purposes described in this Agreement. Unless otherwise agreed by the Provider, all such copies shall, upon request, be promptly returned to the Provider with the original or destroyed upon termination or expiration of this Agreement.
- 8. Terms and Termination.** This Agreement shall enter into force as of the Effective Date and shall terminate concurrently with the termination of the Project. The Project end date is {xxx date} unless otherwise extended by written agreement of all parties and pending funding availability.
- 9. Confidentiality.** The Recipient agrees to maintain the Data in confidence with the same degree of care as it normally takes to preserve its own confidential information of similar grade, but in any event, no less than a reasonable degree of care.
- 10. No Personal Information.** The Data will not contain any personal information as defined under the Freedom of Information and Protection of Privacy Act.
- 11. Independent Parties.** The Parties are independent parties and nothing in this Agreement shall constitute either party as the employer, principal or partner of or joint venture with the other party. Neither party has any authority to assume or create any obligation or liability, either expressed or implied, on behalf of the other.
- 12. Governing Law.** This Agreement shall be governed by and construed in accordance with the laws of Canada and the laws of the Province of Ontario applicable therein.
- 13. Entire Agreement.** This Agreement is the entire agreement of the Parties and no change or modification shall be valid unless it is in writing and signed by both parties.

IN WITNESS THEREOF, the authorized representatives of the Parties have executed this agreement in two original counterparts as of the Effective Date.

- A. {AGENCY NAME} The Provider
- B. {AGENCY NAME} The Participant

A. NAME:

B. NAME:

TITLE:

TITLE:

DATE:

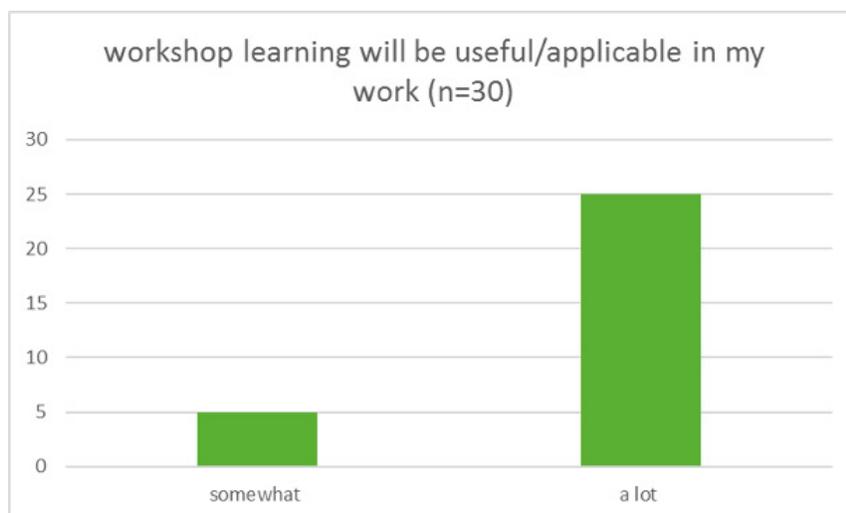
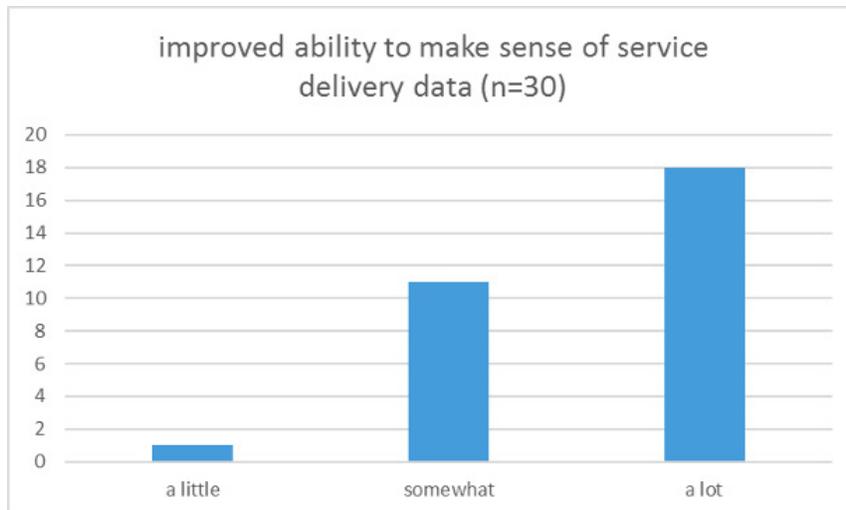
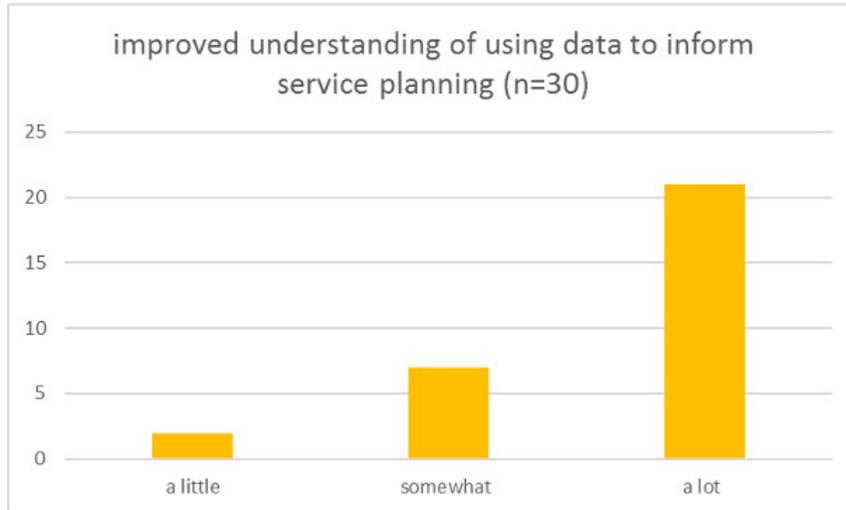
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Appendices

iii. The SDI project workshop feedback charts





Works Cited

Works Cited

- “8 Examples of Capacity Building Activities for Health Service Organizations.” Capacity for Health, Asian & Pacific Islander American Health Forum, 2 Apr. 2019, capacity4health.org/examples-of-capacity-building-activities/.
- Canada Revenue Agency. “What Is the Difference between a Registered Charity and a Non-Profit Organization? - Canada.Ca.” Government of Canada, 23 June 2016, www.canada.ca/en/revenue-agency/services/charities-giving/giving-charity-information-donors/about-registered-charities/what-difference-between-a-registered-charity-a-non-profit-organization.html.
- “Data Sharing (or Transfer) Agreements: What Are They and When Do I Need One?” Research, University of Waterloo, 18 Jan. 2016, uwaterloo.ca/research/office-research-ethics/research-human-participants/pre-submission-and-training/human-research-guidelines-and-policies-alphabetical-list/data-sharing-or-transfer-agreements-what-are-they-and-when.
- Government of Ontario. “Freedom of Information and Protection of Privacy Manual.” Government of Ontario, Queen’s Printer for Ontario, 14 July 2020, www.ontario.ca/document/freedom-information-and-protection-privacy-manual.
- “Group Decision Making: Methods and Techniques.” The Lecturio Online Medical Library, Lecturio GmbH, 2 Aug. 2019, www.lecturio.com/magazine/group-decision-making/.
- Nestor, Hope. Environmental Scan Report. 23 Aug. 2018, Toronto East Quadrant Local Immigration Partnership.
- Raza, Muhammad. Newcomer Insight Collaborative (NIC) Participation and Template Guidebook. Nov. 2019, Toronto East Quadrant Local Immigration Partnership.
- Reeb, Brenda. “Data Governance Roles: Steward, Owner and Custodian.” IData Insights Blog, IData Incorporated, 21 Mar. 2019, blog.idatainc.com/data-governance-roles.
- Shainblum, Esther. “Why Charities and Not-for-Profits Should Comply with PIPEDA.” The Canadian Bar Association, The Canadian Bar Association, 16 Jan. 2019, www.cba.org/Sections/Charities-and-Not-for-Profit-Law/Articles/2019/comply-with-PIPEDA.
- “Summary of Privacy Laws in Canada.” Office of the Privacy Commissioner of Canada, Office of the Privacy Commissioner of Canada, 31 Jan. 2018, www.priv.gc.ca/en/privacy-topics/privacy-laws-in-canada/02_05_d_15/.
- Toronto East Quadrant Local Immigration Partnership, University of Toronto Scarborough. Scarborough Newcomer Needs and Trends Report Project Brief. Aug. 2020.
- Weston, Dorene. SNNT Evaluation Report. 16 Mar. 2020, Full Circle Consulting Inc.
- Wigmore, Ivy. “Data Life Cycle.” WhatIs.com, TechTarget, 31 July 2017, whatis.techtarget.com/definition/data-life-cycle.



