

Administrative data for social impact in Canada

Progress Report

POWERED

BY

DATA

About Powered by Data

Powered by Data's mission is to maximize the availability and impact of data for public good. Through an approach that blends data policy and data strategy development, Powered by Data helps establish infrastructure and governance frameworks that will enable the social sector to better share, use, and learn from data. Powered by Data works with nonprofits and civil society groups, government, funders, and global data initiatives.

Powered by Data operates on Tides Canada's shared platform, which supports on-the-ground efforts to create uncommon solutions for the common good.

For more information, visit <http://poweredbydata.org>.

Acknowledgements

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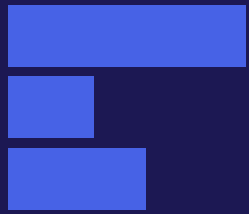
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PART 1

Background & Process

ADMINISTRATIVE DATA 101

Data can be a valuable tool for evidence-based decision making in the social sector. Nonprofits can use data to evaluate the impact of their interventions, understand the needs of beneficiary groups, support their advocacy efforts with evidence, and strategically plan their programs. Despite the immense potential of data to support the work of nonprofits, many nonprofits are working with data that are incomplete, inaccurate, or challenging to track over time.

Much of the data needed by nonprofits already exist as **administrative data**: operational records that government agencies and nonprofit service providers keep on the people they serve. Examples of administrative data could include: physician visit records, high school completion records, birth and death records, and tax returns.

Administrative data should not be confused with survey or census data. Unlike survey data, administrative data are not originally collected for research purposes.

Sharing and linking administrative data is also very different from publishing open data: administrative records can include sensitive person-level data which cannot be released to the public.

Administrative data sharing and reuse

Administrative data are often collected, stored, and accessed separately across different services or ministries. **Data-sharing is the practice of allowing more than one organizational body to access and reuse data for new purposes.** Sharing could occur within government, as well as between government and nonprofits. Data linking refers to the joining up of previously discrete personal records that results in a richer dataset; for instance, matching an individual's health records with their education records.

Because of the richness of information captured by administrative datasets, they can be repurposed in a variety of ways to support the work of nonprofits. Here are just a few examples of potential use cases Canadian nonprofits have expressed interest in:

- **OUTCOMES EVALUATION:** A youth court diversion nonprofit would like access to government recidivism data to better understand the long-term outcomes of youth participants who go through their programs.
- **SOCIAL RESEARCH & EVIDENCE-BASED ADVOCACY:** Data on the number of drug overdoses and fatalities among those incarcerated in Canada could help a human rights advocacy network make the case for immediate access to naloxone in prisons.
- **PROGRAM PLANNING:** A refugee/immigrant health service provider would like to anticipate how many people they will need to serve. Access to data on how many people have applied for OHIP in a given catchment area could support program planning.

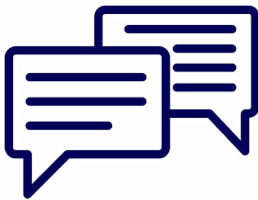
OUR INITIATIVE

Exploring a Canadian policy agenda on administrative data for social impact

In Canada, administrative data are already being leveraged by researchers to conduct social policy research. However, these data remain largely inaccessible to nonprofits, despite their untapped potential for supporting outcomes evaluation, evidence-based advocacy, and nonprofit program planning. Powered by Data is exploring the creation of a policy agenda around administrative data use—and sees an exciting opportunity for diverse members of civil society to help shape these efforts.

Over the last year, we have been building towards a multi-stakeholder coalition of Canadian advocacy groups, nonprofit service providers, and funders. The coalition will explore the potential for policy changes to enable ethical, effective, and responsible use of administrative data for social impact. Our work so far has involved a combination of stakeholder roundtables, community consultations, and preliminary policy research.

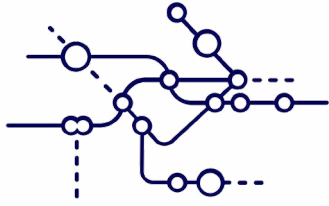
This document serves as a summary of our activities, progress, and learnings to date. We provide more detail on our process below.



CIVIL SOCIETY COALITION-BUILDING

In 2018, we convened civil society stakeholders in a series of roundtable discussions. These discussions helped us determine whether we had a mandate for moving forward with a policy initiative.

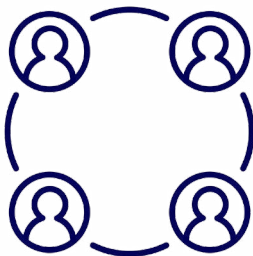
We have confirmed four co-convening partners who will help share this work: Philanthropic Foundations Canada, the Ontario Nonprofit Network, the Colour of Poverty-Colour of Change, and Dr. Janet Smylie from the Well Living House. In the coming year, we will be co-developing a coalition governance framework that centres stakeholder autonomy, transparency, and shared ownership over the initiative.



REVIEW OF DATA-SHARING LANDSCAPE

Preliminary research was conducted to compare existing infrastructure, resources, and initiatives around accessing, using, and/or sharing administrative data in Canada. An initial desktop review was conducted to document the types of data made available, the target users, policy and legislative, protocols, and governance frameworks.

The review encompassed government-led initiatives, such as Statistics Canada's Research Data Centres and their Social Data Linkage Environment, Indigenous-led initiatives such as the Nova Scotia First Nations Client Linkage Registry, academic research collaborations, and local health service provision networks. To deepen our understanding of the technical and policy issues around administrative data sharing, we also interviewed subject-matter experts currently engaged in leveraging administrative data for social impact:



COMMUNITY RESEARCH & CONSULTATION

In early 2018, Powered by Data held a series of roundtables, convening over 50 civil society groups to build a shared understanding of administrative data use amongst a range of social sector stakeholders. Three roundtable discussions were held in total; one for each stakeholder group: funders, nonprofit service providers, and advocacy groups.

During each roundtable, participants provided input on opportunities, risks, and the overall feasibility of the initiative. Participants were given the opportunity to express their interest or opposition in having a civil society coalition move this policy agenda forward.

To identify use cases for administrative data rooted in the Canadian context, we also conducted phone and in-person interviews with ten service providers and advocacy groups across a range of issue areas.

2018 in Review

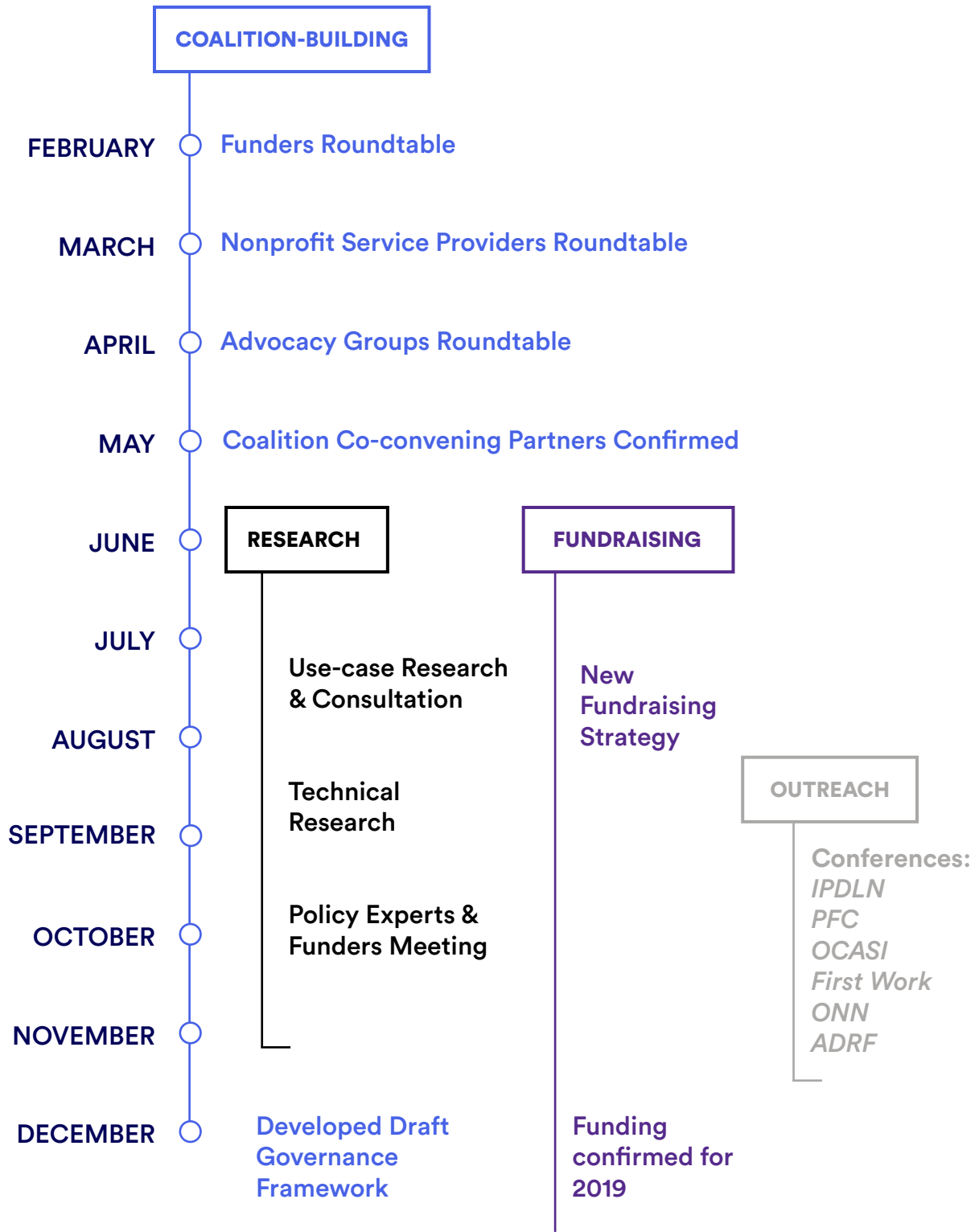
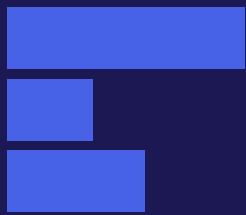


FIGURE 1. Timeline of Powered by Data's activities over the course of 2018.



PART 2

Opportunities & Use Cases

Administrative data offers new opportunities for evidence-based decision making in the social sector.

In early 2018, we anticipated most nonprofit use cases for administrative data would fall under the categories of: outcomes evaluation, research and advocacy, and integrated service delivery. Consultation with nonprofit service providers validated these categories, and also revealed an additional category—program planning—now included in our administrative data use case framework (Figure 2).

In the following section, we highlight potential use cases for administrative data in the Canadian context expressed by nonprofit service providers and advocacy groups.

KEY TAKEAWAYS

- A great many service providers and advocacy groups have clear ideas around how they could use administrative data to be more effective in their work. There is a strong appetite for making use of this data in new ways, under the right conditions.
- Many groups expressed that simply making existing data more available would not realize the full potential of administrative data. Rather, interventions would be needed to change the way data are collected during service provision. In particular, a number of groups expressed a desire for disaggregated race-based data as an advocacy tool for highlighting systemic inequities
- While stakeholders were broadly able to describe what government information they were interested in, it was difficult for them to name specific administrative datasets, or what department the data would be held in.
- Many interviewees shared that they were often already going out of their way to collect data currently inaccessible through government through other means (e.g. through intake forms, via anecdotes and media, through surveys)

Methodology

Our process for consultation and collecting these use cases involved:

- Stakeholder roundtables and conference workshops
- In person and phone interviews with nonprofit service providers and advocacy groups

Use Cases for Administrative Data Sharing and Re-use



FIGURE 2. Nonprofit use cases for administrative data typically fall under the categories of: outcomes evaluation, research and advocacy, and integrated service delivery.

USE CASES

OUTCOMES EVALUATION

It can be challenging for nonprofit organizations to track the health, economic, or educational outcomes of their beneficiaries over time. However, much of this information is already contained in administrative data held by government. By accessing these data, organizations could better track outcomes and more effectively determine whether services had a positive impact on users in the medium- to long-term. Administrative data are already being leveraged for outcomes evaluation in the UK: New Philanthropy Capital is a think tank developing a series of “data labs” to help nonprofits access and analyze government data on education, employment, and recidivism outcomes of their participants.

STAKEHOLDER: Youth justice court diversion nonprofit

CURRENT CHALLENGE: Nonprofit is unable to systematically measure whether court diversion programs reduce likelihood of future re-offending; and whether outcomes are different for racialized youth

HOW ADMIN DATA COULD ADDRESS THIS: Data on offending are already tracked by police for operational purposes. If shared securely and anonymously with nonprofits, it could help organizations measure their impact on reducing recidivism and to inform policy.



STAKEHOLDER: Education nonprofit for youth facing barriers

CURRENT CHALLENGE: Difficult to track long-term education and employment outcomes of beneficiaries after high school graduation

HOW ADMIN DATA COULD ADDRESS THIS: Data on education and employment outcomes are already tracked by government for administrative purposes (e.g. records held by the Ministry of Training, Colleges and Universities, or the CRA). A mechanism that allows nonprofits to access and analyze these data could support the evaluation of beneficiary outcomes in the long-term.



PROGRAM PLANNING

Government records could help nonprofit service providers better understand their beneficiary pool, helping to anticipate demands for services and strategically plan programs.

STAKEHOLDER: Organization providing health services to refugees and immigrants, including non-insured individuals

CURRENT CHALLENGE: It is difficult to anticipate how many people without health insurance will need to be serviced in upcoming months, hindering the ability to plan strategically in advance.

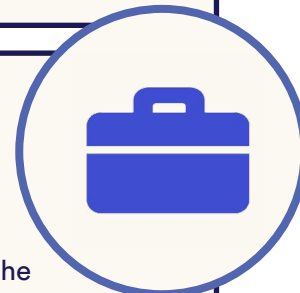
HOW ADMIN DATA COULD ADDRESS THIS: The organization would like access to OHIP data, aggregated by catchment areas. Knowing how many refugees, new immigrants, and returning Ontario residents in a given catchment area have applied for OHIP or are on the 3-month waiting list could help anticipate how many people they will need to serve.



STAKEHOLDER: Youth employment network

CURRENT CHALLENGE: It is currently challenging to determine estimates of how many people are in the labour pool, making it difficult to forecast what services will be needed by job-seekers, and the volume of demand.

HOW ADMIN DATA COULD ADDRESS THIS: Access to government labour market data would provide a more comprehensive picture of the labour pool - which could help plan what employment services will be in highest demand.



“ Knowing how many refugees, new immigrants, and returning Ontario residents in a given catchment area have applied for OHIP or are on the 3-month waiting list can help anticipate how many people we will need to serve.”

- Interviewee

“ Access to data could help us hold government to account. For example, data on the number of affordable housing units and addresses would help us map affordable housing, and hold government accountable on targets.”

- Coalition participant

RESEARCH & ADVOCACY

Because government administrative data contain rich information on social, economic, and educational outcomes (among others), their re-use allows researchers to address new research questions. These findings can, in turn, drive advocacy efforts for evidence-based policy making. A number of advocacy groups also expressed that increased access to government data could be a tool to hold government accountable and challenge positions that undermine human rights.

STAKEHOLDER: Advocacy group for Canadian youth in care

CURRENT CHALLENGE: Government is responsible for regularizing the immigration status of refugee crown wards while under government care—but this often doesn't happen, putting them at risk of being deported to a country which they may no longer have connections to.

HOW ADMIN DATA COULD ADDRESS THIS: Data on how many youth enter the care system without permanent status, and the number who continue to not have their status regularized while in care could keep government accountable to fulfilling their responsibilities.



STAKEHOLDER: Human rights advocacy network

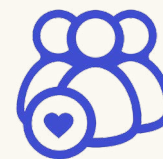
CURRENT CHALLENGE: The current opioid crisis is pronounced for people in prisons due to both the criminalization of opioid use and the significant lack of harm reduction services in prisons.

HOW ADMIN DATA COULD ADDRESS THIS: The Canadian HIV/AIDS Legal Network would like data on the number of drug overdoses in provincial, territorial and federal prisons and trends over the past 5 years, including number of fatalities. This would support advocacy efforts around urgency for immediate access to naloxone and opioid substitution therapy.



INTEGRATED SERVICE DELIVERY

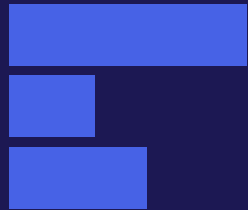
Individuals who have complex needs may be accessing multiple services concurrently. For example, survivors of interpersonal violence often require access to housing, mental health, and social assistance services. Navigating these on an individual basis can be a confusing and exhausting process. Linking administrative data across service providers would enable a more integrated approach to service delivery. Data sharing across agencies would allow for greater collaborative care, more streamlined referral processes, and increased consistency across services.



STAKEHOLDER: Multi-service provision, anti-poverty nonprofit

CURRENT CHALLENGE: The agency provides a number of services that reach require data to be inputted to discrete databases imposed by government. These databases are not linked to one another, making it difficult to measure how many clients they are serving. The organization says it's possible they are double-counting the number of people they service across the four databases.

HOW ADMIN DATA SHARING COULD ADDRESS THIS: By linking data between different databases, the nonprofit would avoid double-counting clients who access more than one service.



PART 3

Risks & Concerns

There are ethical concerns around increasing administrative data access and re-use.

Digital infrastructure planning often excludes communities at the margins who carry the greatest risks posed by these projects. Powered by Data is working in consultation with nonprofit service providers and grassroots advocacy groups to research and document the potential harms that could come with administrative data-sharing and re-use. The goal is to account for these risks and perspectives in any proposed policy agenda.

KEY TAKEAWAYS

- Participants at each stakeholder convening expressed concerns around the potential unintended consequences of sharing administrative data in new ways. These included the possibility of: amplifying systemic inequities, reducing non-profit autonomy, and violating consent around person-level data (Figure 3).
- Many grassroots advocacy groups, in particular, underscored the importance of an inclusive exploration of these risks. Stakeholders expressed open questions around how to prevent potential negative impacts of data-sharing—with an emphasis on building a diverse coalition, ensuring community involvement in decision-making processes, and centering the interests of marginalized groups.

Methodology

Our process for consultation and collecting feedback around risks involved preliminary desktop research, stakeholder roundtables, and feedback from conference workshops. There were no questions specifically about risk during the stakeholder use case interviews, but some interviewees elaborated on their concerns nonetheless. A priority for 2019 is to collect more feedback around risks from stakeholders in the Canadian context.

Risks of Administrative Data-Sharing and Re-use

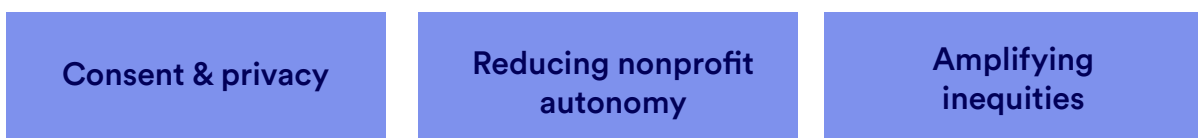


FIGURE 3. *Some of the risks of administrative data re-use identified so far have involved issues related to consent and privacy; reducing nonprofit autonomy, and amplifying systemic inequities.*

RISKS

CONSENT & PRIVACY

Central to administrative data sharing is the idea that data originally collected for operational needs can be used in new ways. What could happen when data is used for purposes beyond what the user originally consented to?

CASE STUDY

In the UK, frontline outreach workers collect nationality, mental health, and gender data of the homeless for the Greater London Authority in order to help policy makers identify the needs of the homeless population. In 2017, it was discovered that Home Office immigration officials were secretly using this nationality data to identify the location of illegal immigrants sleeping on the streets and deport EU nationals.

REDUCING NONPROFIT AUTONOMY

Top down imposition of evidence-based decision making could prevent service providers from exercising their local discretion, or shift incentive structures. This could result in programs that are less responsive to community context.

CASE STUDY

One nonprofit interviewee cautioned against a myopic focus on outcomes data. They referenced funding cuts to the Futures youth employment program during the Mike Harris Ontario government as an example. Futures was a program that had put young people in need into paid placements. When funding was cut, there was a shift in focus to outcomes—whether or not a young person stayed employed after the program ended. Due to the pressure to report successful outcomes, organizations began to only accept less disadvantaged youth into the program who were more likely to stay employed, pushing out marginalized youth most in need of the program.

AMPLIFYING INEQUITIES

Administrative data poses exciting opportunities to make evidence-based decisions on pressing social issues. However, administrative datasets themselves may reflect biases of the systems they are collected in. For example, one interviewee highlighted how the “Indian Register”, in Canada can be thought of as an operational, administrative dataset—but is also an inherently colonial data system. The register is an official record of people with “Indian status”—used to carry out the process of colonization in Canada. The register is also largely incomplete—it doesn’t capture Indigenous people without “status”, such as those who are Inuit or Métis.

CASE STUDY

In her book “Automating Inequality”, Virginia Eubanks highlights how administrative data-sharing has already facilitated new forms of modern inequities. She points to the Allegheny Family Screening Tool (AFST) as a case study in how data-driven tools can further profile poor communities and communities of colour. The AFST is a tool meant to help child welfare staff identify and prioritize the most “at risk” children in Allegheny County, Pennsylvania. The tool links data between twenty-nine different administrative data sources from the county’s Department of Human Services (DHS), including data on whether families have accessed or interacted with mental health services, child protective services, correction systems, drug/alcohol services, and more. This linked administrative data is fed into an algorithm used to flag which cases need “intervention” from General Protective Services—which often looks like separating a child from their family.

Unfortunately, many of the variables used to predict abuse in the model are simply measures for poverty (e.g. use of the SNAP nutrition assistance program), or reflections of systems that disproportionately affect poor & racialized communities (e.g. juvenile probation). The DHS also holds less data on affluent families—who are afforded more privacy simply by accessing mental health and drug treatment programs that are private, rather than public. Eubanks also points out the frustrating and heartbreaking paradox of parents being seen as greater risks to their children through the algorithm when they access public services to try and improve their situation.

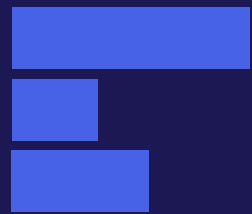
Despite its problematic nature, the AFST is often used as an exciting example of administrative data-sharing in action. **This underscores the need for an expanded, and more inclusive, conversation around the risks administrative data-sharing presents to marginalized communities.**

Open Questions

HOW TO BUILD AN INCLUSIVE COALITION, & EQUITABLE PLANNING PROCESS?

Some stakeholders have expressed concern that marginalized groups will be excluded in the coalition building, and policy planning process. Some open questions posed by roundtable participants included:

- How can we ensure communities are involved in each stage of the process?
- How can we prevent the potential negative impacts of administrative data-sharing and reuse on marginalized groups?
- How do we build a governance model that is racially diverse? That sets priorities in a way that centres groups most at risk? That is protective of the rights of the most vulnerable?



PART 4

Data sharing in Canada & Conditions for Success

DATA SHARING IN CANADA & CONDITIONS FOR SUCCESS

A preliminary desktop review was conducted to assess existing infrastructure, policy initiatives, and resources related to administrative data access and reuse in Canada. The goal of this preliminary scan was to better understand the existing momentum within government for administrative data reuse, as well as the policy, infrastructure, or programmatic conditions required for nonprofits to benefit from these data.

KEY TAKEAWAYS

- **Initiatives facilitating the reuse of administrative data are emerging at an increasing rate, at both the federal and provincial levels.** Statistics Canada, through their Social Data Linkage Environment and Research Data Centres, appears to be playing a leading role.
- Most resources for administrative data reuse target academic researchers and policymakers as their core users. There appears to be a gap in designing these resources for use by the nonprofit sector. The lack of data and research capacity in the sector may be a potentially significant barrier. **Coalition participants have articulated that capacity building will be necessary for meaningful engagement with administrative data.**
- **More research and consultation needs to be done with respect to Indigenous perspectives and how OCAP principles regarding ownership, control, access, and possession of data can be integrated into a broader administrative data policy agenda.** This would build on existing Indigenous-led initiatives around administrative data sharing for outcomes evaluation and advocacy—such as the Nova Scotia First Nations Client Linkage Registry.

Infrastructure

Our desktop review revealed a significant amount of existing digital infrastructure for administrative data access and reuse in Canada. These projects exist:

- **AT THE FEDERAL LEVEL:** Statistics Canada' Research Data Centres allow researchers to request access to government administrative datasets. The agency also runs a "Social Data Linkage Environment" which upon approved request, is able to conduct microdata linkages between datasets
- **AS COLLABORATIONS WITH PROVINCIAL GOVERNMENT:** the Child and Youth Data Lab is a collaboration in between five Government of Alberta ministries and Policywise to contribute to policy research on child well-being.
- **AS DATA-SHARING ARRANGEMENTS BETWEEN SERVICE PROVIDERS:** Reconnect Health's Community Business Intelligence initiative links data across 90+ service providers. This allows organizations to trace client journeys and access aggregate client data.
- **AS INDIGENOUS-LED DATA ACCESS INITIATIVES:** The Nova Scotia First Nations Client Linkage Registry links First Nations health records to Nova Scotia provincial sources, with the purpose of helping First Nations better monitor health outcomes their communities and support policy advocacy efforts.

Policy and Legislative Environment

We began this work with an assumption that changes to policy would be required to enable greater use of administrative data. **However, our preliminary research review indicated that existing privacy and/or health information legislation in Canada does already allow for some degree of administrative data-sharing and data-access.** There have also been some instances of legislative changes to enable greater administrative data-sharing for social impact. In 2018, The Data Matching Agreements Act (Bill 87) was introduced in Saskatchewan, and included amendments to The Freedom of Information and Protection of Privacy Act. Another exception is the Nova Scotia First Nations Client Linkage Registry (NSFCLR), which involved an amendment of the Personal Health Information Act.

There appears to be a recognized need from government for strategies that increase the impact of administrative data. The Federal 2018 Data Strategy Roadmap includes recommendations around enhancing "the rigor of analysis of program administrative data and increase the generation of new data to assess outcomes and strengthen performance measurement, program evaluation and policy development".

Research, Data, and Analytical Capacity

For data sharing initiatives to be impactful, nonprofit stakeholders need to have capacity to meaningfully engage with data. Currently, government and academic researchers are the primary users of most existing administrative data resources in Canada. Although some allow additional stakeholders to request data, significant research expertise is usually required for approval. For example, requests submitted to Research Data Centres are evaluated on the basis of “scientific merit and viability of proposed research”, methodological soundness, and “expertise and ability of researchers”. Many nonprofit stakeholders do not have this required expertise.

During our roundtable discussions, a number of participants provided feedback that **meaningful engagement in any data-sharing initiative will require capacity building around research and data**. Changes to data policy must be accompanied by data capacity-strengthening in communities whose data are being managed.

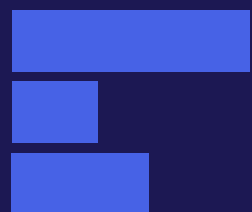
Indigenous Data Sovereignty and Governance

Only one of the initiatives in our preliminary desktop review focused specifically on administrative data-sharing with Indigenous communities in mind: the Nova Scotia First Nations Linkage Registry (NSFCLR). The registry’s purpose is to enable First Nations to better monitor health outcomes of their communities, and to reduce health inequities by targeting policy advocacy efforts. Governance of the data is in agreement with both provincial privacy legislation as well as OCAP principles.

A key theme that emerged from the advocacy groups roundtable is an obligation to consult with Indigenous groups on legislation that will impact them. **Indigenous participants emphasized the importance of a policy agenda that reflects “OCAP” principles— one that ensures Indigenous groups are able to have ownership of, control over, access to, and possession of, their own data**. This research should build on existing Indigenous-led initiatives around administrative data sharing for outcomes evaluation and advocacy, such as the NSFCLR.

“We can’t talk about Indigenous data sovereignty without talking about the need for Indigenous data capacity and expertise.”

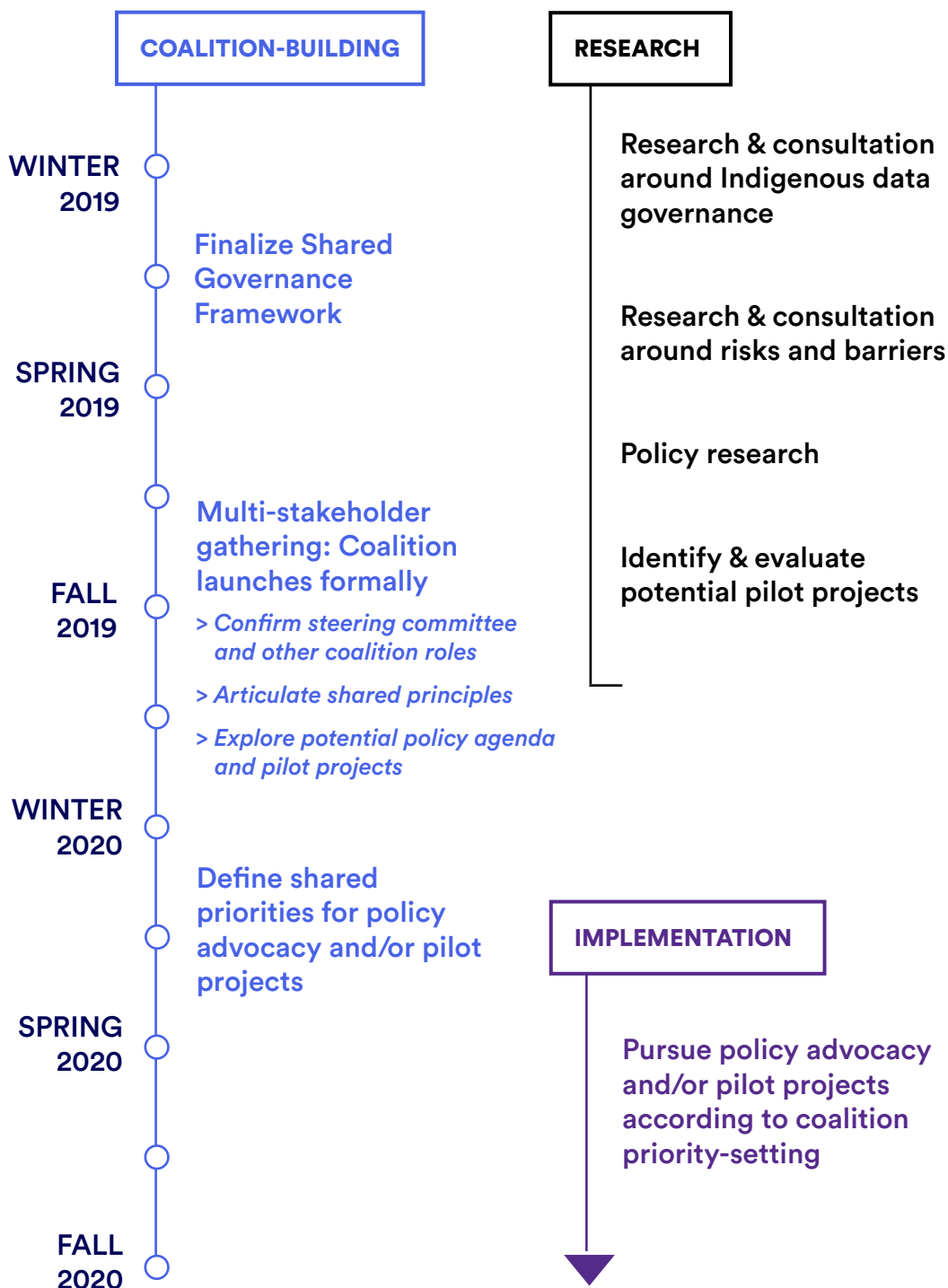
- Coalition participant



PART 5

Next Steps

2019–2020 Timeline



Opportunities to Engage in 2019

Prospective Coalition Members

In 2019, we will be engaging more deeply with the groups that have been participating this process - through a mix of individual consultation, group calls, and in-person convenings. Leading up to formally launching this coalition in mid-2019, we hope to work with participants to:

- Renew the core mandate for this initiative, align on a coalition governance structure, and develop a list of shared principles for carrying this work forward
- Explore risks and barriers in greater depth, with a focus on areas that were under-documented in 2018 (e.g. Indigenous data governance)
- Continue documenting potential use cases for administrative data-sharing in the social sector, and identify certain use cases that could be explored more deeply as pilot projects

Policy Experts and Government

Throughout 2019, we will continue to engage with public policy leaders to better understand existing opportunities and constraints around data sharing policy. We want to develop this coalition with full awareness of existing policy momentum around this issue, and establish a spirit of collaboration with government from the outset. **If you are working on questions of administrative data sharing from a public policy perspective, we would love to hear from you!**

Data-Sharing Practitioners

This past year, we have been grateful to learn directly from leading practitioners about the rapidly evolving state of administrative data sharing in Canada. We want to continue engaging with groups that leading this practical work, and paving the way for broader adoption. **If you are involved in a project that makes use of administrative data linking for social impact, please get in touch with us!**

Civil Society

For members of civil society (e.g. funders, nonprofits, advocacy groups, members of the general public) who are not currently engaged in this work, **we invite you reach out to us.** When we formally launch the coalition in mid-2019, and have a governance system in place, this will include a mechanism for bringing new members to the coalition. In the meantime, we can set up a 1:1 call to discuss our ongoing work with you.