Community Data Sharing
A Flash Review of Related Literature

Summary
A flash review of collection, storage, and sharing strategies for community data.

Findings
There is very little Saskatchewan-specific research addressing the data collected by community organizations in a Saskatchewan context. Drawing on both research and practice related to community-data storage and mobilization, we demonstrate that the development of data tools for Saskatchewan community organizations would enhance the benefits associated with data sharing and access while minimizing the risk.

About the team
This project was supported by a working group made up of Chuk Plante, Brea Loewenberger, Taryn McLachlan, and Rachel Loewen Walker and supported by the Social Sciences and Humanities Research Council.

Question

Saskatchewan community organizations face a number of challenges when considering the implications of sharing collected data with researchers or partners. Data collected by community organizations has incredible potential for research to benefit both the organization and the community at large. However, organizations must consider responsible stewardship of the data, including factors such as privacy, uptake and distribution, and the perceptions of data use in the community. A comprehensive data strategy can aid organizations in making informed decisions about the appropriate use of community data for valuable research. However, developing such a strategy can prove to be very difficult.

This flash review surveys the existing landscape of policies, initiatives and literature concerning community-based data collection and sharing in hopes of setting a path forward for Saskatchewan's community-data landscape.

Review/Research Strategy

A literature review and environmental scan was performed of research related to data sharing and access to community organization's data. Additionally, a survey was conducted of existing community-based policy initiatives, guides and reports concerning the use of data. The primary method of the environmental scan included a search of internet search engines (Google and Google Scholar), as well as searching citations of previously identified documents. The search terms used in the course of the search include "data privacy non-profit", "charity data and research privacy", "cross sector data sharing Canada nonprofit", "cross sector data sharing Canada charity", "privacy cross sector data sharing canada", "privacy and charities", "privacy community organization research", "(Privacy or information) and (charity or "community organization") and (research or university or researcher)" and "cross sector data sharing Canada charity". Search terms were chosen in acknowledgement of the wide variety of phrases used for the subject matter.

Findings

There is little research specifically addressing the data collected by community organizations in a Saskatchewan context, but a growing body of literature in a national context. Considerable benefits have been identified in utilizing community organization data in a variety of contexts. This includes for the community organizations own use, research purposes and partnerships with private business. Community organization data has significant potential to have incredible benefit to community organizations and the people they serve. The utilization of community organization data can aid in effective program development and evaluation for the specific community organization, as well as providing wider benefits in assessing the efficacy of a wide range of programs.

Although there is considerable benefit to the utilization of data from community organizations, there are risks that must be considered carefully. There are both real and perceived ethical issues with the management of individual's data, it is important for data to be appropriately shielded in order to maintain public trust in the organization. The legal framework concerning community organizations is sparse, although PIPEDA has the potential to impact community organizations that are engaged in commercial activities and organizations that deal with healthcare services may be subject to The Health Information Protection Act (HIPA). This lack of legal framework causes confusion among organizations of their responsibilities under the law and can create a chilling effect in the access and data sharing.

The development of data tools for Saskatchewan community organizations has significant potential to aid organizations in clarifying roles and responsibilities.

Recommendations and Conclusion

Data governance for Saskatchewan community organizations is a complex problem with many considerations of the potential benefits, as well as significant risks. The development of data tools for Saskatchewan community organizations would enhance the benefits associated with data sharing and access while minimizing the risk. Data tools should be practical, drawing on examples of practical guidance for community organizations. This could include templates, FAQs on data privacy policy and legislation, as well as step-by-step guides.

Appendix: Community Data Research Scan

Title	Summary	Benefits associated with data sharing and access	Risks associated with data sharing and access	Practical advice or guidelines	Province/ Region	Link
Collaborating for Greater Impact: building an Integrated Data Ecosystem	Discusses how charities, funders, governments, and academic institutions in Canada and the UK can create a more enabling environment for data collection, analysis, and sharing. The report provides a comparative perspective on the charitable sector data landscape in both countries and offers recommendations to address challenges related to data infrastructure, collaboration, and legislative and regulatory environments.	Can be used to assess local needs and identify service gaps, inform organizational decision-making, understand trends over time, advocate for policy change, evaluate the outcomes and impact of programs and services and provide accountability and transparency to service users and the general public	Charitable organizations must improve their privacy practices as they collect, access and share data on a larger scale. For small organizations, improving data practices should be an incremental process that is proportionate to the organization's capacity. Power dynamics are also inherent in data collection and use, Ethics, privacy and security must is also a concern	High level policy recommendations for governments	Ontario	https://munksch ool.utoronto.ca/ mowatcentre/w p-content/uploads /publications/16 1_EE_collaborati ng_for_greater_i mpact.pdf
Report #2 of the Advisory Committee on the Charitable Sector - April 2021	The report focuses on three areas: the relationship of Indigenous peoples and organisations with the Charities Directorate, and the impact of the Income Tax Act (ITA) and regulations on Indigenous peoples and organisations; the need for a federal data strategy with respect to data relevant to the charitable sector, and improvements to the data collection managed by the Charities Directorate; and the simplification of categories of charities within the ITA. The ACCS also addresses the impact of the COVID-19 pandemic on the charitable sector in Canada, highlighting the urgent need to examine the impact of federal regulations and systems on	1. Coordination, standardization, integration, and accessibility of data on the charitable sector, which would enhance evidence-based programs, policies, and practices; 2. Improved completeness, timeliness, and accuracy of data reporting by leveraging existing data sources and technologies; 3. More rapid and accurate verification of data through online filing, which would make data publicly available in a timelier way; 4. More appropriate identification and analysis of charities through updated category codes; 5. Collection of diversity information on directors, paid employees, and volunteers, which would lead to more	Unclear messaging around reasons for collecting diversity data; lack of overall resources that organizations can use to collect diversity information on their volunteers in an appropriate and consistent way (e.g., templates); repetitive self-identification occurs when multiple data collection points are not aligned	Recommendations for policy development in non profits. Recommendation 5, 6 and 7 discusses the potential development of a national data strategy for non profits. This includes goals of supporting coordination and standardization.	Canada	https://www.can ada.ca/en/reven ue-agency/program s/about-canada-revenue-agency-cra/corporate-reports-information/advi sory-committee-charitable-sector/report-advisory-committee-charitable-sector-april-2021.html

	charities serving vulnerable populations.	accurate interpretation of diversity data and better representation of diverse voices; 6. Reduction of the burden on the charitable sector by reducing the need for repetitive self-identification and providing resources for consistent data collection.				
Towards a Data Strategy for the Ontario Nonprofit Sector	Exploring models for data strategies in Ontario non profits	Aids in creation and monitoring of responsible initiatives, creating stronger and more stable partnerships between community organizations or	Cautions data sharing and access must include: Effective use: Nonprofits should put data to effective use to serve their communities - not just collect it, but proactively use it. 2) Responsible use: Data should be created, collected and accessed responsibly and ethically, with attention to power dynamics that could mar the use of data and with respect to the privacy and safety of those involved. 3) For public benefit (not for profit): Nonprofits and governments should be committed and able to access data for public benefit use.		Ontario	https://theonn.ca/wp-content/uploads/2015/07/Towards-a-Data-Strategy-for-Ontario-Nonprofit-Sector_ONN_Final_2015-07-13.pdf
Building a Knowledge-Driven Nonprofit Sector	Increasing ability of non profits to appropriately use data				Alberta	https://policywise.com/wp-content/uploads/2020/06/2019-2020-Alberta-Nonprofit-Data-Strategy-Final-Report-and-Project-Plans...-1.pdf
Consultation Response on Open Data Directive	Feedback on Ontario Open Data Directive concerning Aboriginal specific data	collection and analysis of program data that we can make informed decisions about program administration, delivery, and enhancements,			Ontario	https://theonn.ca/wp-content/uploads/2022/01/2015-07-20-OFIFC-

		and it is a critical tool for community-based planning decisions				Open-Data-Submission.pdf
Information sharing guide for social-based service design and delivery	Recommendations for policy development in Alberta non profits	Information sharing facilitates more comprehensive, coordinated or integrated service delivery as well as planning, monitoring and evaluation, enabling shared case planning without compromising privacy.	Confidentiality, Privacy is about an individual's control over the collection, use, and disclosure of information that relates to that person. Security refers to the controls implemented to safeguard an individual's information from unauthorized access, use, and disclosure.	Provides toolkit for organizations - including forms and FAQs for specific legal/policy questions	Alberta	https://open.alberta.ca/publications/9781460136812#summary
Data driven social partnerships: Exploring an emergent trend in search of research challenges and questions	Explores public, private and non governmental partnerships aggregating data different sources of data. Proposes term of data driven social partnerships	data based social partnerships can be key for continually tackling social problems	Lack of consistent laws, guidelines and policies creates ambiguity for organizations also organizational, data-related, and societal			https://www.sciencedirect.com/science/article/pii/S0740624X17302708
Cross Sector Data Sharing: Necessity, Challenge, and Hope	Existing data sources have huge potential but there are legal and logistical impediments to data sharing efforts. Considers a data-sharing initiative in Peoria, IL that was able to overcome challenges to set up a cross-sectoral data system to coordinate mental health, law enforcement, and healthcare services.	Public data is critical to identify problems early, react quickly, and assess interventions in a timely manner	identifies the patchwork of laws as confusing and inconsistent, creating real and perceived barriers to data sharing. There is a chilling effect on data sharing.		USA	
GovLab Data Collaborative Toolkit	American resource that provides a practical step by step guide of the considerations that should go into establishing data sharing agreement			Practical step by step guide in creating a data sharing agreement with extensive resources	USA	https://datacollaboratives.org/canvas.html#phase-1