

The background of the top half of the page is a photograph of a meeting, overlaid with a semi-transparent orange filter. Two women are seated at the front of a room, facing a group of people whose backs are to the camera. The room has large windows with blinds in the background.

# Doing Data Ethically

**HOW THE SOCIAL SECTOR CAN USE DATA ETHICALLY AND SAFELY**

**A Transform the Sector Report**

## Transform the Sector 2017 Series

*Doing Data Ethically* is part of a series of reports written by Powered by Data that aim to summarize some of the key topics covered at Transform the Sector 2017. Transform the Sector 2017 was a one-day conference about revolutionizing the Canadian social sector's use of data. Held on February 23rd 2017, the event was organized by Powered by Data in partnership with the Ontario Trillium Foundation and the Stanford Digital Civil Society Lab.

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## About Powered by Data

With the goal of enabling the social sector to benefit from the rapidly changing way society handles information, Powered by Data works with leaders in nonprofits, governments, and foundations to help them better use, share, and learn from data. Powered by Data also works with key stakeholders to open up their data for social impact. 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, visit <http://poweredbydata.org>



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# CONTENTS

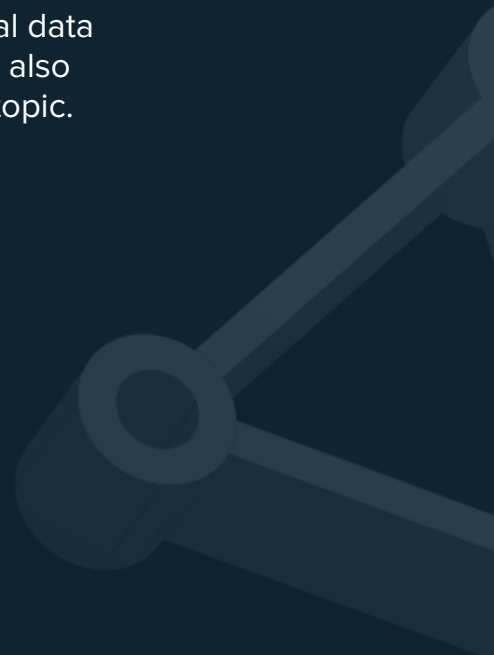
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<b>OVERVIEW</b>	<b>4</b>
<b>HOW DATA INCREASE RISKS AND VULNERABILITIES</b>	<b>5</b>
Privacy	5
Community Stigma	5
<b>THE ADVANTAGES OF DATA IN THE SOCIAL SECTOR OUTWEIGH THE RISKS</b>	<b>6</b>
<b>WHY THE SOCIAL SECTOR SHOULD CARE ABOUT DATA ETHICS</b>	<b>6</b>
<b>FRAMEWORKS FOR USING DATA ETHICALLY</b>	<b>7</b>
OCAP Principles	8
Digital Impact's Four Principles	8
<b>CONSIDERATIONS FOR USING DATA ETHICALLY</b>	<b>9</b>
<b>CONCLUSION</b>	<b>10</b>
<b>ADDITIONAL RESOURCES</b>	<b>11</b>

# Overview

Using digital data is crucial for the social sector to provide the best services and care to communities. Digital data use in the social sector has many advantages, but it can also expose organizations and governments to new risks and vulnerabilities. Data collected or used unethically can enable discrimination or further marginalize already vulnerable populations. There's a growing body of strategic approaches that help reduce these risks.

This report provides an overview of the discussions at Transform the Sector 2017 that focused on how digital data practices in the social sector can be done ethically. It also provides additional context and background on this topic.



# How data increase risks and vulnerabilities

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The data collected by the social sector is primarily about the people served by the sector. They can be exposed to a number of threats if that data is mismanaged or collected, used or stored improperly. Moreover, data used by social sector organizations typically contains information on marginalized and vulnerable people. This information needs to be dealt with ethically and safely to ensure that these people are not put at greater risk.

## **PRIVACY**

Social sector clients often share personal information with organizations, and in the wrong hands, that data can do harm. When unintended audiences obtain information about a person, that person may face threats for holding certain views, or be discriminated against because of their identity. For example, a person without legal status could face deportation if their data is shared with the wrong government department, or someone fleeing domestic violence could be located by their abuser. To mitigate personal threats, sometimes data is stripped of personally-identifying information before being shared. However, there are instances where de-identified personal data contains enough unique information to re-identify anonymized people and expose potentially sensitive information.

## **COMMUNITY STIGMA**

Data can be as imperfect as the humans who collect it. While good data used properly can empower a community and address inequalities, data that is biased and misused can perpetuate stereotypes and further marginalize a community. A community that has been disproportionately policed, for example, may be additionally stigmatized by data that paints community members as dangerous and requiring restrictions on their freedoms. Another example is when emerging software solutions that claim to use data to predict crime, use data that is biased in the first place. The results can pose threats to civil liberties and perpetuate community stigma.

## The advantages of data in the social sector outweigh the risks

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New ways of sharing and using digital data can bring many advantages to stakeholders in the social sector. Data can help funders better understand community needs, access funding landscapes, and communicate more effectively. Data can help nonprofit organizations evaluate their impact and improve their services. Data can help governments make evidence-based policy decisions and pay for outcomes. Like many new technologies, the adoption of digital data can be slow-paced due to unfamiliarity, fear or uncertainty. However, the potential benefits of digital data use outweigh the risks. With the proper support and leadership, the social sector would be able to keep up with developments in data technologies and make informed decisions about how to use data safely and ethically.

## Why the social sector should care about data ethics

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Data can offer the social sector the best available evidence to inform its work, but data also comes with a responsibility. As a sector focused on respecting individual rights and dignity, these values need to be carried forward in the sector's approaches to dealing with data. The sector has an opportunity to lead by ensuring that people's rights are protected during every step of its data processes. Organizations stand to gain trust and build integrity with ethical approaches to data. By not caring about or lacking the capacity for ethical data use, the sector could cause harm to others, create legal trouble, and damage the trust they have built with the communities they serve.



# FRAMEWORKS FOR USING DATA ETHICALLY

Social sector organizations do not need to figure out how to approach data ethics on their own. Sets of principles have already been created. Adopting such principles can help guide organizations in their efforts to use data ethically.



## OCAP PRINCIPLES

One set of principles was established in 1998 to guide how Indigenous data should be collected, protected, used, and shared. The four principles, known as OCAP®, were designed to bring benefits to a community while minimizing harm, and have been implemented across Canada, with each community interpreting the principles in their own way. Briefly, the principles are:

- **Ownership:** A community or group owns information collectively in the same way an individual owns personal information.
- **Control:** First Nations, their communities, and representative bodies have rights to control research and information management that impact them.
- **Access:** First Nations must have access to information and data about themselves, and can make decisions about access to their collective information.
- **Possession:** Physical control of data is the mechanism by which ownership can be asserted and protected.

## DIGITAL IMPACT'S FOUR PRINCIPLES

In 2016, the Digital Civil Society Lab at Stanford University launched [digitalimpact.io](https://digitalimpact.io) to help social sector organizations share and develop data practices that align with their missions. Digital Impact has four guiding principles for ethical data use:

- **Consent:** Collecting data from constituents is a voluntary relationship. Organizations need to ask permission to collect and use someone's data for specific purposes. Their data must also be treated with integrity.
- **Privacy:** Organizations must collect only the necessary data and put safeguards in place to protect data donors from being identified personally. The sector's most valuable resource is trust, so it is important the sector does not collect what can't be protected.
- **Openness:** Social sector organizations serve a public purpose. As such, data practices should be designed with openness and sharing in mind. Consent and privacy practices can then be developed accordingly.
- **Pluralism:** The social sector's digital data use should be designed from and for diversity. The data tools should be made by and for people as diverse as society and its interests. The people represented in the sector's data should have a say over how their data are used. People should be able to see and understand the methods used to make decisions about data.



# Considerations for using data ethically

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Data ethics are evolving just as the technologies that necessitate data ethics are expanding. Different insights and strategies exist for social sector organizations to do data ethically. The following are considerations for how the social sector can build data ethics into their processes, while refining its approaches along the way.

- **Build data ethics into organizational culture:** Social sector organizations need to build internal cultures that regularly highlight the need to be responsible with data, discuss inherent risks and solutions with stakeholders, and foster data literacy across the organization.
- **Engage communities:** Communities served by the sector need to be consulted when designing data policies. Community needs and concerns related to data need to be understood. Data literacy within communities needs to be built, including an understanding of the inherent risks of data.
- **Assess data risks and develop mitigation plans:** Social sector organizations need to ask what could be done with any of their organization's data if it fell into the wrong hands. As such, organizations need to collect the minimum amount of data necessary. Before adopting any new technology, organizations also need to ask what data they will collect. They need to ask how data can be stored securely, whether it should be eventually destroyed, and if so, when and how. Organizations need to minimize risks before any new data practices are adopted rather than after.
- **Create standards for sharing data:** Organizations need to set policies for how they will share data with other organizations. For example, they need to ask how data can be safely anonymized before they share it, with no risk of re-identification.
- **Understand the legal obligations that apply to the organization and its data:** Different countries have different laws about data security, which could affect data stored in international servers, or data kept about people in different countries.
- **Be transparent before collecting data:** The sector needs to ensure that anyone from whom data is collected understands how it will be used and shared, any limitations on its use, how it will be stored or destroyed, and when. They need to be informed if they can access the data themselves, or request it be returned or destroyed. They need to be communicated with clearly and given time to consider what has been discussed. Informed consent is essential.

# Conclusion

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The approaches and considerations for the ethical use of data that have already been developed provide enough of a framework for the sector to overcome its trepidation and build its capacity to use data ethically.

Nevertheless, there is still work to be done to further develop the processes and implementation of these frameworks. In the meantime, please see the following resources section for additional reading and knowledge.

# Additional Resources

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Digital Impact - Digital Impact's Four Principles

<https://digitalimpact.io/digital-data/four-principles/>

Digital Impact - Privacy

<https://digitalimpact.io/policies/privacy/>

Digital Impact - Consent

<https://digitalimpact.io/policies/consent-for-data-use/>

First Nations Information Governance Centre - OCAP Principles

<http://fnigc.ca/ocap.html>

Responsible Data - The Handbook:

<https://responsibledata.io/resources/handbook/>

Responsible Data - Reflection Stories:

<https://responsibledata.io/reflection-stories/overview/>

ELAN - Data management and protection starter kit

<http://elan.cashlearning.org/wp-content/uploads/2016/05/Data-minimization-tip-sheet.pdf>