# Review Article

# Data, Power, and People: Toward Inclusive and Community-Led Governance in Health Research

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**Abstract**

Equitable research begins by examining who holds power in the research process, how that power is exercised, and whose voices are excluded or marginalized. Globally, visible minority and Indigenous communities have historically experienced research that was extractive, harmful, or conducted without meaningful participation or consent, shaping understandable mistrust toward academic institutions. Addressing these imbalances requires more than ethical intentions. It requires structured approaches that embed equity into how data is collected, governed, interpreted, and shared. Data governance offers a practical pathway for this transformation. Frameworks such as FAIR (Findable, Accessible, Interoperable, and Reusable), OCAP (Ownership, Control, Access, and Possession), CARE (Collective Benefit, Authority to Control, Responsibility, and Ethics), and EGAP (Evidence in Governance and Politics), along with models like Bruhn's spectrum, outline principles that balance access, accountability, autonomy, and community rights. When implemented collaboratively, these approaches reposition communities as partners and decision-makers rather than subjects of inquiry. Ethical data governance therefore strengthens research relationships by promoting equity, transparency, and inclusion, while preventing the reproduction of past hierarchies.

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## Introduction

Equitable and empowered research begins with recognizing power, and investigating who holds it, how it operates, and how its history continues to shape present-day health research. In Canada and elsewhere, marginalized communities have often been the subjects of extractive or harmful research practices. Confronting these legacies is not just necessary for ethical research; it is essential for building a healthier and more inclusive future for all. This paper introduces data governance as a practical approach to addressing these imbalances. "Data" refers to the factual information that supports reasoning and decision-making, while "governance" refers to the systems of authority and processes that guide how decisions are made. Together, data governance involves setting the principles, rules, and responsibilities that shape how data are: collected, managed, shared, and used throughout a project. It extends beyond technical or institutional processes and is influenced by culture, beliefs, traditions, and power.

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In health research involving visible-minority communities, data governance means being clear about who makes decisions and under what conditions. Through this lens, institutions can move beyond compliance, to communities leading across all aspects of data collection, storage, access, use, and benefit. When done well, data governance becomes a tool that redistributes power, builds trust, and aligns research with community priorities.

## Data Governance & Communities

Equity in research requires acknowledging and addressing existing power dynamics. In human and health research, these imbalances often stem from historical injustices and institutional hierarchies that continue to influence relationships and outcomes. In the example of Canadian health research, there have been severe cases of exploitation within visible minority and Indigenous communities. Indigenous children and adults were often used as research subjects without informed consent, meaningful consultation, or direct benefit [1]. Many studies in Indigenous communities were conducted without longitudinal follow-up, community involvement, or ethical oversight [2]. In many cases, researchers prioritized scientific discovery over human

wellbeing, and used racist ideologies to justify interventions. For instance, Indigenous people were considered "ideal subjects" due to the colonial injustices they faced- interpreted wrongfully as research-worthy natural or cultural phenomena [3]. Historically, many Indigenous health studies were structured through a deficit-based paradigm, which highlighted negative health indicators while giving less attention to strengths, protective factors, or community perspectives. This pattern has been criticized for perpetuating stigmatizing narratives and weakening community empowerment.

Likewise, marginalized communities and vulnerable individuals in Canada have faced unethical and exploitative research practices. One example is the MK-Ultra experiments, where marginalized individuals, including women, immigrants, and people with mental health challenges, were subjected to harmful psychological and medical interventions without consent [4]. Another is the work of Philippe Rushton, much of which has since been retracted, that misused scientific authority to promote racist ideas under the banner of academic research [5]. These cases show how research in Canada has often been guided by "white epistemology", a worldview that treats Western and colonial perspectives as the default standard for knowledge and ethics [6]. This way of thinking has led to research that ignores the lived experiences, cultural contexts, and priorities of racialized communities [6].

While much work and progress have been made in the field of ethical research since the previously mentioned examples, there are still systematic inequalities in our society which reinforce hierarchical, oppressive, and inequitable research practices. Forces such as racism, sexism, classism, and colonial power persist, which play a role in knowledge and research authority [7,8]. Inequity continues to be reproduced when these dynamics are ignored, and has grave ethical, moral, integrity, and legal violations. As such, communities and researchers have worked to create more transparent pathways for research conduct, data governance being chief among the avenues of change.

**Definitions of Data Governance**

To start, there must first be a distinction made between data and information, which are often used interchangeably. Data in specific, is defined as factual details used for arguments, reasoning or calculations [9]. That is to say, an ingredient list, geographical coordinates, or daily temperature readings are all examples of data. However, that data can transform into information when an individual uses them- to organize ingredients into a recipe, to map out an itinerary, or to prepare a weather report. This distinction can be guided by the need to answer a question, and synthesize information to form knowledge- the foundation of science [10]. This data however, must meet certain requirements of quality, in order to be used well. Proposed dimensions of data quality include its: completeness, correctness, concordance, plausibility, and currency, and are achieved through improvement of data quality and quantity [11]. To achieve well-developed data, a well-developed data governance strategy must be designed.




Figure 1. Dimensions of Data Quality

Governance in specific, is defined as controlling or exercising authority over something [12]. While this definition aligns well with the traditional views of control and regulation, theorists in the field of constructivism move away from governance as previously understood through the lens of institutionalism and rational choice, and instead develop a broader understanding of governance [13]. They argue that governance is a socially constructed process, and while it can include formal structures, it is also an interpretative process guided by beliefs, power, traditions, and culture [13]. With this understanding, data governance can be viewed as a socially embedded practice that transcends corporate, technological, or organizational boundaries. In fact, there is much need to understand how data governance impacts everyday individuals, and especially individuals whose data historically and presently has been compromised, stolen, misused, and misrepresented. This is also a crucial step in reducing social reproduction, and investigating inequitable power and privilege dynamics in health data [14,15].

Table 1. Definitional Components of Data Governance

| | |
|---|---|
| Data | Factual details used for arguments, reasoning or calculations |
| Governance | Controlling or exercising authority over something |
| Data Governance | The interpretative process of controlling or exercising authority over factual details used for arguments, reasoning or calculations |

Based on the definitions outlined above, we can understand data governance as the process of controlling or exercising authority over factual details used for arguments, reasoning or calculations. In other words, it is the interpretative process of designing rules, processes, and standards that determine how data is used for all capacities. Typically, data governance considerations appear at all stages of a project, from the planning to dissemination.

**Data Governance Components, Principles, and Models**

Depending on the needs of a study and the nature of its data, the spectrum of data ownership and governance that participants and/or their community holds can vary. Projects involving data often reference a 'data lifecycle', which covers the stages of accessing data, ranging from generation, collection, processing, storage, management, analysis, visualization to interpretation [16]. Other models include a focus on usage, archives, and destruction [17]. These lifecycles have been merged and presented in Figure 2. They can be powerful models to visualize the places and people data will come into contact with and help with planning data-based projects. However, they do not directly address or support governance for equity-deserving populations.

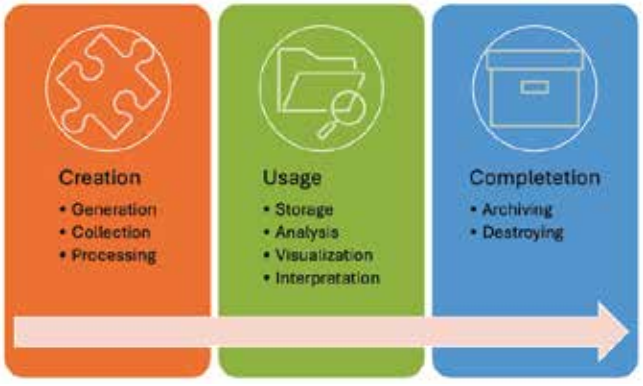



Figure 2. Integrated Model of Data Lifecyle

**Key Principles of Interest**

Many principles have been developed to support better data governance. Principles such as FAIR, OCAP, CARE, and EGAP have highlighted standards for community data governance, and can be leveraged to guide data governance strategies [18–21]. These principles have been summarized below:

Table 2.

| |
|---|
| FAIR |
| • Findable, Accessible, Interoperable, and Reusable (FAIR)<br>• Developed to improve human and machine access to data<br>• Helps organize data considering the volume and speed of scientific research genesis |
| OCAP |
| • Ownership, control, access, possession (OCAP)<br>• Developed by the First Nations Information Governance Committee<br>• Provide groups, researchers, & institutions guidance on interacting with First Nations data |
| CARE |
| • Collective Benefit, Authority to Control, Responsibility, and Ethics (CARE)<br>• Developed with the Global Indigenous Data Alliance<br>• Presents principle people oriented principles for data governance |
| EGAP |
| • Developed through emerging equity-focused frameworks in health/social research<br>• Emphasizes community participation and decision-making in the research process<br>• Promotes transparency, accountability, and inclusion in how data are governed |

These frameworks reflect the growing work in the field of data governance. Some projects draw from multiple models rather than relying on a single one. FAIR emphasizes accessibility and usability, ensuring that data can be efficiently found and shared. OCAP and CARE extend this conversation by centering the rights and authority of Indigenous and equity-deserving communities, often pairing the model with FAIR [22]. EGAP emphasizes participation and accountability, underscoring that equitable governance depends on communities acting as active partners rather than passive data providers. Although some academics do not typically classify EGAP as a data governance framework alongside FAIR, OCAP, or CARE, this distinction is not entirely accurate. EGAP contributes meaningful guidance on transparency, community engagement, and ethical practice — elements that are integral to effective data governance.

A key strength of these frameworks is their flexibility. Their broad and principle-based nature allows them to be applied across diverse contexts and fields. However, this generality can also be a limitation. In practice, the lack of specific direction can make it difficult to translate these principles into concrete actions or governance structures. Together, these frameworks show that ethics, efficiency, and innovation can work in balance within data governance.

**Governance in Action: Hierarchy Models**

In addition to data lifecycle models and governance principles, it is also important to note the arrangement of authority in the data governance framework. One approach postulated by Bruhn describes a spectrum of models, which varies in the level of centralized vs de-centralized data governance authority [23]. In this structure, centralized and decentralized data governance models exist on opposite sides of the spectrum, and denote the differences in how power is distributed [23]. A brief description of the roles mention has been prepared below:

- Single-Organization Data Hierarchy: a centralized model of data governance where an executive body can make policies, decisions, and standards, serving a strategic purpose
- Outsourcing: mechanism used by a single-organization data authority to outsource some delivery of services to third parties, retaining full control
- Data Partnership: a model of data governance whereby parties with similar goals interact on a horizontal power level to achieve mutual benefit
- Advisory Bodies: consultation-based mechanism where external groups provide input or feedback on data processes, but have no formal decision-making power.
- Data Commons: a collaborative model where data are openly shared within a community or network, guided by shared rules and accountability

While this continuum discusses several models of governance, it is largely absent of process that question the role of people, power, and traditions. We can see the shift of

vulnerability across this spectrum as well, where power and control guide what collaboration looks like. Project goals and institutional aims also guide these relationships, and whether communities have the freedom to choose how their data is governed and by whom. While the collaborative frameworks support meaningful community governance of data, they still carry a risk of replicating exploitative social dynamics if root causes are not addressed. In contrast, centralized or single-organization governance models typically concentrate authority within one institution. If this central authority is held by the community itself — rather than by an external organization — such a model can play a meaningful role in reducing inequities. However, for community-led centralized governance to be effective, it must be supported by adequate infrastructure, resources, and expertise to sustain long-term control.

## Conclusion

When done collaboratively and with inclusivity, data governance can serve communities, by treating them not as subjects but as partners and leaders. Institutions are increasingly recognizing that scientific merit cannot rest solely on authority and control. Instead, data should be understood as both a technical and social resource, which individuals and communities have a stake in. Through frameworks such as FAIR, OCAP, CARE, and EGAP, and models like Bruhn's spectrum, we see that ethical and effective data governance requires balancing access, accountability, and autonomy. Data governance is not only about managing information; it is also about managing relationships between researchers, institutions, and the communities whose data make research possible. When communities have a voice throughout the data lifecycle, research outcomes become more ethical, relevant, and sustainable. Embedding community priorities and shared accountability into governance processes can transform how research is done, ensuring that data stewardship advances equity rather than reinforcing existing hierarchies.

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