

City of Toronto Black Data Governance: Literature Review

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May 2023

Wellesley Institute advances population health and reduces health inequities by driving change on the social determinants of health through applied research, effective policy solutions, knowledge mobilization, and innovation.

The Black Health Alliance is a community-led organization working to improve the health and well-being of Black communities in Canada. Using research, community engagement, and health promotion, the Black Health Alliance acts as a platform to dismantle systemic barriers.

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Acknowledgments

We would like to acknowledge the members of the Black Data Advisory Circle and the participants of the focus groups who provided rich and honest perspectives necessary to develop this groundbreaking Black community data governance framework for the City of Toronto.

Funding

This initiative was made possible through funding from the Data for Equity team and their partnership with the Confronting Anti-Black Racism Unit at the City of Toronto.



Report

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Executive summary

Strengthening the collection of sociodemographic data involves cultivating trust with racialized populations and ensuring accountability in the use, access and protection of data. Community data governance centres around how data is managed, exemplified by principles like OCAP® for First Nations' data and the Engagement, Governance, Access and Protections (EGAP) Framework for Black health data.

The City of Toronto received approval for the Data for Equity Strategy by Toronto City Council in November 2020, facilitating the collection of sociodemographic data to address inequities (1). The city has collaborated with Wellesley Institute and the Black Health Alliance to explore the development of Black data governance. The objective of this literature review is to contribute insights to the Black data governance, drawing lessons from local, national and international projects that prioritize leveraging data to promote equity.

Since community data governance is an emerging field, a comprehensive search strategy was utilized, inclusive of non-academic sources like toolkits, institutional policies and impact reports. A total of 78 results were included in this review. Through a thematic analysis of this literature, three themes emerged:

- Explaining emerging practices of community data governance
 - Community governance frameworks like OCAP®, EGAP, CARE Principles and Māori data governance centred on cultural perspectives and equitable outcomes to drive the generation of community-driven data practices.
 - Various methods of community involvement in data processes were explored, including tailored data literacy workshops, citizen advisory groups, citizen juries, independent third-party committees, institutional scorecards and quarterly bulletins.
- Establishing a data infrastructure for community-based data
 - Varied models of data sharing were explored based on scope and intended outcomes.
 - A key point of alignment has been recognizing that the data infrastructure and its components must drive improved outcomes for communities, thereby reinforcing the institutions' responsibilities to communities and fostering transparent and mutually beneficial relationships.
 - Building trust through partnership expertise facilitated effective data sharing, fostering productive discussions on funding, decision-making processes and sharing agreements that guided protections and access provisions through ethical principles and training.
- Introducing an equity lens into the data life cycle
 - An environmental scan spanning collection, access, algorithms, analysis, reporting, dissemination and technologies was proposed as a starting point.
 - By leveraging the insights of anti-racist experts and established guidelines from local bodies, various models for data collection, analysis and utilization emerged.
 - Ensuring accountability relied on standardized reporting mechanisms to maintain institutional commitment and employing data visualization methods to facilitate the accessible interpretation of data for communities.

This review has identified numerous resources and guides that can propel the City of Toronto's efforts to address inequities. As this initiative progresses in engaging city staff, external partners, stakeholders and members of the Black community, having an initial framework to guide Black data governance could facilitate the acknowledgment and implementation of sociodemographic data to enhance outcomes for Black populations in Toronto.

Introduction

In Canada, there is a growing interest in collecting and analyzing data based on factors like race, disability and sexual orientation (2-8). Sociodemographic data collection can be a valuable tool for tracking patterns and shaping policies that benefit marginalized communities (2, 7, 9). As sectors such as education, healthcare and justice strive to promote equity and human rights, it is critical to address the concerns related to data collection efforts caused by historical and present experiences (10-13).

Community data governance

Equity-informed data governance has gained significant attention from policymakers and researchers as an emerging and evolving field (14-16). This area of data governance centres on equitable oversight of data resources by various stakeholders, adhering to established protocols for engagement, decision-making authority and accountability (16). More specifically, community data governance involves a collaborative approach to managing data and engaging community members in decision-making processes related to data collection, analysis and utilization. The overarching goal of community data governance is to ensure that data practices align with the interests, needs and priorities of communities while upholding principles of ethics, privacy and equity (14, 16-18).

The longest-standing community data governance model in Canada was introduced by the First Nations Information Governance Centre in 1998, known as the First Nations Principles of OCAP® (19). This framework was designed to empower First Nations with ownership over their data, rooted in the context of nation-to-nation relationships. While this framework addressed the needs of First Nations, there was a gap in community data governance strategies for other populations. The Black Health Equity Working Group created a strong starting point in addressing this gap as it developed the Engagement, Governance, Access and Protections (EGAP) framework which aimed to model data sovereignty for Black communities, particularly in the context of the pandemic (20).

The City of Toronto

Toronto, as Canada's most populous city, stands as a hub of diversity with a significant proportion of racialized individuals (21). Advocacy from community stakeholders has underscored the need for sociodemographic data to comprehensively understand the experiences, diversity and potential disparities faced by Black communities (10, 22, 23). In response, the City of Toronto has shown its commitment to using data to address health inequities, such as those recently documented by Toronto Public Health (24).

However, the implementation of community data governance for Black communities surpasses these targeted efforts. This undertaking involves multifaceted considerations including the preparedness of institutions, legal frameworks, structural policies and equitable engagement practices. To truly establish effective community data governance processes, a solid grasp of local, regional and global practices that prioritize equity and community within data procedures is of utmost importance. This understanding can empower the City of Toronto to make strides in advancing its data governance initiatives.

The purpose of this literature review is to evaluate the body of evidence on existing models, frameworks and strategies relevant to the City of Toronto's goal to enact Black data governance.

Methods

The City of Toronto has partnered with Wellesley Institute and Black Health Alliance to conceptualize Black data governance through alignment with community members, stakeholders and the city. The primary objective was to review the existing evidence on how community data governance has been constructed from community, institutional and technological perspectives. Using local, national and international examples, the insights gained from this review aim to support the development of community data governance at the City of Toronto.

The search encompassed various sources beyond peer-reviewed papers including reports, toolkits, practical guides, institutional policies, news articles and funding award notices. In the construction of inclusion and exclusion criteria, certain parameters were established. These criteria included the necessity for data practices to have practical applicability, a requirement that publications should be dated after the release of the OCAP® principles in 1998, and the exclusion of topics that solely focused on technical aspects of data governance such as cloud architecture.

The findings were organized into thematic groups based on the record's purposes, goals and recommendations. For a more detailed description of the methods used in the literature review, see [Appendix 1: Literature review methodology](#).

Results

The literature search identified a total of 159 records. After removing duplicates and criteria evaluation, 78 records were incorporated into this review ([Appendix 2: Literature review flow chart](#)). Most examples were produced in the United States and Canada, with the remaining from the United Kingdom, New Zealand, Kenya and Australia as well as pan-European and -African initiatives. Seventy-four per cent of findings were published between 2019 and 2023, indicating the relatively recent emergence of topics related to community data governance.

The characteristics and summary of sources demonstrated a diversity of data frameworks, real-life cases, practical guides and organizational reports ([Appendix 3: Literature review findings table](#)). The systematic extraction process centred primarily on identifying findings that proved valuable for the collection, utilization and governance of sensitive data. It also considered structural aspects that were pertinent to the development of a framework.

The findings of the literature review were grouped into three overarching themes:

- Introducing an equity lens into the data life cycle: Empowering communities within data systems was explored across various domains, showcasing diverse engagement processes, practiced governance models and capacity-building strategies.
- Establishing a data infrastructure for community-based data: Successfully integrated data systems that facilitated community data sharing required stakeholders to select from a diverse range of structures, understand the developmental stages, incorporate areas of expertise and progress through implementation stages.
- Introducing an equity lens into the data life cycle: Strengthening equity-based initiatives involved the integration of frameworks and approaches that comprehensively addressed data across every stage of the data life cycle, including planning, use, analysis, access and reporting.

Explaining emerging practices of community data governance

This review also explored the state of evidence on the development of a technology system that incorporates equity or community governance. Among the 34 identified sources, there were examples of community data governance frameworks, data literacy and capacity-building guides, resources informing community governance models and real-life examples illustrating community-based decision-making in practice.

Governance frameworks

A total of seven distinct data governance frameworks were identified, each tailored to specific communities or equity concerns. These frameworks primarily aimed to address data governance gaps, respond to structural inequities and leverage data initiatives led by authoritative bodies. Indigenous groups, including First Nations (19), Māori (25) and an International Indigenous Data Sovereignty Interest Group (26), served as strong approaches that integrated historical and cultural viewpoints into data understanding. An international collaboration of civil and digital institutions formed the *Health Data*

Governance Principles to optimize the use of health data to drive equitable change (27). Canada showcased promising community-focused data frameworks such as the *Principles for Conducting Research in Jane Finch Community* (28), *Ontario Health Data Council Report: A Vision for Ontario's Health Data Ecosystem* (29) and the *Engagement, Governance, Access and Protections (EGAP) framework* (20). Notably, EGAP was the only identified framework supporting data sovereignty for Black communities.

Frameworks typically included vision and value statements, measurable outcomes, action-guiding principles and strategic implementation recommendations. Common principles included governance, community benefit, equity, ownership, engagement, responsibility, ethics, control, trust, expertise, stewardship and respect. A common strength of OCAP®, EGAP, CARE Principles, and the Māori data governance model was a community-generated foundation ensuring alignment with community priorities, epistemologies and values. A consistent theme was the need for explicit statements emphasizing data's equity-driven use and community benefits to foster accountability and transparency.

The theme of power was identified differently across frameworks. All endorsed community-led governance bodies to oversee data access, use and protection processes. Effective data management systems were essential for community data oversight, enabling operational control. Frameworks also outlined specific elements to consider such as classification definitions for community data, equity-focused metadata schemes, open access portals and decentralization through distributed models. Additionally, gaps were identified in conceptualizing privacy and consent at collective versus individual levels. Establishing community-level provisions was deemed vital to prevent improper data use and safeguard communities, particularly concerning data reuse, linkages, algorithms and security auditing.

Literacy and capacity

To establish governance structures, it was recognized that communities need accessible materials that encourage engagement and develop adaptable skills, especially for those unfamiliar with data (30). The Data-Pop Alliance, a non-profit think tank focused on advancing global use of data for change, aimed to define data literacy in the context of community empowerment, leading to the identification of four pillars of data: data education, data visualization, data modelling and data participation (30). They highlighted the importance of promoting flexible literacy that goes beyond technical skills by focusing on adaptive skills within these four pillars. The emphasis was on enhancing understanding and utilization of data relevant to their immediate environment which could indirectly foster social inclusion. This approach was proposed to tackle key challenges in data literacy initiatives.

Three distinct data literacy workshops and toolkits were identified to introduce data concepts including mapping, charts, addressing data collection biases, and techniques for data comparison (31-34). These resources targeted a diverse range of audiences, including individuals with no prior experience with data, non-profit staff and leaders, students and organizational stakeholders. These training materials featuring guides, checklists, slides, videos and interactive activities were applied across various data initiatives and are accessible to the public. Similarly, the *Guide to Tactical Data Engagement & Tactical Data Engagement: Data User Groups* workshops aimed to establish opportunities for communities to collaborate on open data projects (35, 36).

Mechanisms

After enhancing data literacy and familiarizing with community governance frameworks, this review identified specific procedures for determining governance practices, formal spaces for community involvement and effective community engagement. The Center for Health Strategies developed a step-wise guide to foster the inclusion of communities in specific data quality initiatives – from defining goals, collecting the data, collaborating through the interpretation, and steps for taking action (37)

Collaborative governance efforts were typically described as beginning with establishing a clear purpose in engaging with communities. For instance, at Monash University's Net Zero Precinct in Australia, participants gained awareness of how the data directly concerned them and they collaborated to design sessions on establishing data governance protocols (38). Through two activity-based workshops and multi-criteria mapping interviews, they arrived at several governance frameworks that prioritized engagement, equity, sensitivity, utility, impact and investment requirements. An additional approach, known as Data-Driven Knowledge Co-Production, was designed at Arizona State University, where stakeholders used an independent third-party organization to manage shared data while an advisory committee assumed the role of data stewards (39). Lastly, a United Kingdom-based government agency, Wilton Park, led consultations with youth to enhance proposed health data governance principles through questions on priorities, requirements for diverse inclusion and policy reforms (40).

The importance of diversity and independence in community governance was observed. A notable example was the Citizens' Summit in the United Kingdom, where public members contributed to defining health data usage, access, governance and management. The consensus emphasized the importance of a diverse citizens' advisory group reflecting the city's population (41). Similarly in British Columbia, while communities expressed interest in using data to combat racism and address inequities, African Canadians specifically emphasized the need for an independent third party to establish regulations regarding data collection, access and privacy (42).

Successful and sustainable initiatives relied on tangible demonstrations of commitment to social accountability (43). A compilation of studies examined community-level governance health structures in sub-Saharan African countries including Kenya, Uganda and Ghana (43-46). Approaches ranged from health committees, citizen report cards, organizational scorecards and the distribution of patient rights charters (43, 45, 46). Well-defined policies that mandated community involvement, funding allocation based on progress and staff training were identified as critical factors. An illustrative example of a policy was passed by the State of Washington's senate that required agencies to compensate individuals for community engagement in addition to gathering demographic data to analyze the impact of compensation on participation (47). Agencies were mandated to use this data to develop strategies to further enhance diversity and lower barriers.

Use cases

Lastly, this review identified nine initiatives that aimed to use data to reduce inequities and centre communities within data systems.

Canada: The Toronto Police Service's Race-Based Data Collection Strategy was developed through 69 community engagement events and featured robust participation from Black communities (48). This effort led to the prioritization of trust-building with communities, proposed training initiatives and the

establishment of a Community Advisory Panel to collaboratively analyze, interpret and report the outcomes of race-based data collections.

United States: The Learning and Action in Policy and Partnerships initiative produced case studies illustrating how data sharing between government agencies and community-serving organizations can advance health equity. In Arizona, individuals experiencing homelessness established a shared housing database and guidelines for access and consent (49). Similarly, in South Carolina, collaboration with youth living in poverty to jointly interpret data produced outcome measures and indicators to enhance the state's tracking of children's needs within schools (50). In Utah, the San Juan Aging Services team integrated data from hospitals and social care services through a referral system based on input from healthcare workers, local community members like Navajo nation members and case managers from social sector agencies (51).

Pursuing similar objectives, the Incentive Community Foundation collaborated with a community in central Wisconsin to enhance information sharing with residents and encourage its utilization in decision-making (52). They utilized a local public safety platform for distributing alert messages and employed it to disseminate information regarding community services such as education, health and well-being and community safety. This approach swiftly extended the reach of various services that had been identified as valuable by participants in focus groups.

Sierra Leone and Kenya: Two case studies from Sierra Leone and Kenya enabled mechanisms for community control of health information systems through multiple strategies (53). The distribution of data was facilitated through quarterly bulletins that were strategically placed in high-traffic locations, presenting the information in easily comprehensible formats. While the initial data quality was questionable, the act of disseminating the bulletin sparked discussions on improving data quality, leading to increased data reporting for subsequent bulletins. In addition, the introduction of District Health Information Software 2 (DHIS2) enabled online data access, even in areas with limited infrastructure, using internet modems and mobile networks. Offline data entry and analysis features were developed based on community feedback to address unreliable networks. Also integral to this approach were local review meetings, which brought together community members, health partners, religious leaders and officials to deliberate on health outcomes. Complementing this, chiefdom league tables enabled direct performance comparisons with neighbouring regions, compelling local leaders to make more effective use of the available data. This study effectively showcased how African communities can adeptly embrace data and information technologies at the grassroots level without requiring prior data-related expertise.

United Kingdom: Expanding on the topic of governance, this review identified the INSIGHT Data Trust Advisory Board in the United Kingdom, which was an independent body responsible for evaluating researchers' applications to access health data (54). The board's composition enabled the establishment of access criteria grounded in collective priorities such as patient safety, public benefit and potential implications for specific groups. Like a research ethics board, this group evaluates applications using five data principles, conducts thorough ethical assessments based on research intentions and advantages, and determines whether to approve or decline proposals.

Another instance of public governance involved the utilization of Citizen Juries (55). Participants in the Connected Health Cities' Citizen Juries lacked expertise in health or data. Instead, they received

presentations from experts, engaged in various group activities, deliberated on public health data usage topics and cast votes to authorize or reject data utilization based on hypothetical scenarios.

New Zealand: In the New Zealand government's Mana Ōrite Work Programme with the Data Iwi Leaders Group, an established data governance model recommended an appointed Māori Chief Data Steward responsible for aligning the government's data and statistical analytics with the preferences, values and decisions of Māori communities (56). They further advocated a standardized continuum of co-design to evaluate data systems' relationships between Māori communities and institutional data holdings.

Establishing a data infrastructure for community-based data

Comprehensive data ecosystems were important to enable proper management and safeguarding of sensitive data. This review examined 28 different sources, encompassing foundational insights into data-sharing systems, factors to consider during the development of an integrated data system and specific instances of relevant models in action. The following section aims to provide an overview and guidance on diverse data systems, the process of building data-sharing capabilities, the factors for fostering stakeholder partnerships and the practical implementation of these data structures.

Structure

There were six resources that examined the conceptualization and operationalization of data sharing, outlining different models, required skills and challenges. They focused on relevant data infrastructure topics, highlighting key elements for equity-focused data sharing: aligning data stewards' and community stakeholders' policies, exploring funding sources, enhancing digital resource capacity, learning from international experts and implementing evaluation methods (57).

Different data-sharing models – integrated data systems, data cooperatives, data collaboratives and data trusts – were shaped by purpose, use and stakeholder relationships (57, 58). Data cooperatives differed in that individuals whose data was being collected could voluntarily assume an equal role in making decisions about the data (57). The intention was to provide members with shared control and power over the data. Data collaboratives resembled cooperatives, with the distinction that they were confined to partnerships among organizations rather than involving individuals.

Data trusts emerged as legally independent entities delineating structures, participatory roles, responsibilities and data management practices under the purview of appointed data trustees. For example, a pilot by the Greater London Authority assessed a data trust's role in city-wide decision-making (59). Acting as an intermediary entity, the data trust oversaw the storage, management and access to sensitive data on behalf of data contributors. Two options for governance were discussed: a centralized trust body assuming complete responsibility and control over all data, or a data trust advisory acting as a liaison between data contributors and interested parties.

Integrated data systems sought to minimize redundancy both between and within organizations by constructing a comprehensive data ecosystem that houses all essential and pertinent data. Reports from Local Public Health Agencies (LPHA) and Youth Serving Organizations (YSOs) underscored data collection concerns, encompassing invasive questions and navigation difficulties across databases (60, 61). An inclination towards a single, accessible centralized database emerged (60, 61).

Furthermore, publicly available data was frequently seen as the optimal means of presenting information to communities and partner agencies (60). Open Data initiatives were often underutilized as an institutional resource despite the value of publicly available data by communities and partners (62). A shift in perception was proposed, advocating to view Open Data as community-based infrastructure addressing needs and enhancing community engagement (62). Enhancing the utilization of Open Data platforms demanded an enhancement of data literacy, a deeper comprehension of the information requirements of external stakeholders and the provision of multiple user interface options to cater to diverse audiences.

Development

The literature explored three main aspects in forming a data-sharing plan. It stressed the significance of strategic planning to start the process, leading to defining the scope of actions and responsibilities. Subsequently, it highlighted the importance of working through documents related to governance, privacy and ethics.

To begin, valuable insights and practical guidance on data system planning were explored through the National Neighborhood Indicators Partnership's *Guide to Starting a Local Data Intermediary* (63) and the *Resource Guide to Data Governance and Security* (64). Their creation aimed to assist organizations in carefully considering all the essential aspects required to launch a data initiative. These resources offered a systematic approach, encompassing the assessment of community acceptance, methods for securing funding, organizational management and capacity building.

After defining larger details, success stories elaborated on effective strategies that enabled institutions to progress in discussing specifics related to data access, governance, management and engagement. They emphasized understanding the data ecosystem comprehensively for identifying leadership and assigning responsibilities, establishing purpose-driven infrastructure, implementing adaptable standardized processes, consistently involving marginalized populations and planning for sustainable systems (65). Regarding community involvement in designing data sharing and governance initiatives, three examples emerged through the Connected Health Cities Programme (66), the Greater London Authority/Royal Borough of Greenwich data trust pilot (67), and the Open Data Institute's *Data Trusts: Lessons from Three Pilots* (68). They worked collaboratively to reach agreements on aspects such as scoping, model design, community decision-making about privacy, operations and evaluations.

Lastly, establishing data-sharing systems necessitated various types of documentation to facilitate the transfer, sharing and utilization of collective data. The Beek Center at Georgetown University and Actionable Intelligence for Social Policy at the University of Pennsylvania consolidated resources for various data sharing stages, covering purpose assessments, legal and organizational barriers, capacity, security, ethics and governance framework formation, data sharing practices, sustainability assessments and agreements (69-71).

Partnership

There was significant emphasis on effective data sharing through adept partnership building and skilled stakeholder management. This was particularly essential for ensuring the seamless flow of data in integrated systems and collaborative initiatives, requiring a delicate balance among benefits, control and trust (57, 58). Consistently, the literature emphasized key focal points: the inclusion of experts, the establishment of trust, the articulation of clear governance directions and the formation of agreements.

Successful data sharing was supported by diverse expertise spanning areas such as data governance, legal support, privacy, security and community engagement (58). The identification of stakeholders was systematically guided by key questions: who was essential for achieving success, who had the potential to either facilitate or impede success and who held a direct stake in the data of interest. This approach ensured a comprehensive understanding of the network of actors involved and their roles in the data-sharing ecosystem.

Trust-building emerged as a recurrent theme especially when initiating data sharing across organizations. Furthermore, the literature introduced considerations for building trust when initiating data sharing across organizations such as the Actionable Intelligence for Social Policy's privacy stakeholder engagement guide with worksheets, checklists and exercises (72).

Governance rules were identified as a crucial aspect in the context of collaborative initiatives. For instance, as the Data QUEST pilot connected community-based organizations and American Indian/Alaska Native tribes through cyclical engagement, they were able to establish four governance requirements (73):

- The authority to transfer approved data and halt data linkages.
- The capacity to approve or reject access requests.
- Respect for local contexts including cultural processes, resources and technical capabilities.
- Seamless organizational integration or termination processes.

Agreements were emphasized as fundamental to data sharing with the community across criminal, legal, educational, housing and health sectors (74). For instance, the Department of Medicine at the University of Alberta led the development of data governance agreements with Indigenous communities (75). These agreements signified funding, community engagement, cultural education and training, and adapting an institution's negotiation process to align with community-specific needs. Bright Hive, a non-profit focused on supporting data sharing, established data collaboration through agreements integrating ethical principles (76) such as involving diverse participants from marginalized communities, preventing community harm and leveraging data to promote equity.

Implementation

A total of seven sources presented ways that cities and other data-collecting institutions have successfully shared data for equity purposes. The implementation process typically followed a phased approach, commencing with small-scale initiatives, expanding and scaling up, harnessing networking and partnerships, and concluding with an evaluation.

As described, implementation commenced with the initiation of small-scale initiatives to demonstrate utility and elicit community interest. The City of Toronto presented three illustrative examples: participation in the *Community Data Program* (77), collaboration with the Toronto Child & Family Network to disaggregate outcomes by demographics (78) and the *Be Yourself See Yourself* initiative aimed to expand sociodemographic data collection in social service agencies (79). It was highlighted that sector collaboration improved data literacy and capacity, addressed staff hesitancy to collect data and provided a space for organizations to connect. The need for time and resources was specifically highlighted for efforts involving Black communities.

Following this, larger pilots were planned, contingent upon gaining stakeholder support and investment. As a specific instance, a case study of Rhode Island's Opioid Response emphasized the establishment of a foundation for the sustainability of cross-agency integration. This was achieved through a focus on data governance, conducting pilot tests before scaling, exploring funding opportunities and expanding partnerships (80). Similarly, the Western Pennsylvania Regional Data Center, a shared technological and legal data infrastructure, shared the resources used to develop data practices and engage communities such as a standardized data dictionary or terms of use agreement (81).

Lessons learned during these endeavours were shared within networks, enhancing the execution of governance activities. The *Equity in Practice Learning Community* was an identified network of public institutions aimed at establishing data infrastructures to empower communities (82). As an example drawn from this network, the Baltimore City Youth Data Hub was formed as a governance body to reduce disparities in outcomes for youth through community data guidelines. Legislation was passed to ensure management, use, reporting and liability related to the data aligned with the Youth Data Hub (83).

Finally, assessments were found to be important to evaluate the quality and magnitude of the impact on communities. The Data Across Sectors for Health initiative evaluated 193 community-centred data-sharing efforts through five levels of data-sharing readiness including planning, building, launching, scaling and innovating; two domain areas of organizational and technological data maturity; four levels of data use starting from knowledge generation, individual service provision, partnership development and strategy improvement; and two network strength indicators (84).

Introducing an equity lens into the data life cycle

In the process of developing a data infrastructure for community governance, the literature included an emphasis on clearly defining and standardizing procedures for managing data. This review, directed towards enhancing community inclusion in data, sought out specific resources supporting the adoption of equity-based data practices. As a result, 16 resources were identified that offered frameworks and approaches as guides for handling sensitive data in terms of collection, access, analysis, interpretation, management, dissemination and reuse. These resources also featured examples of institutions including equity in policies and processes to address specific community needs. This section delved into activities supporting planning stages to establish a robust foundation for equitable data processes and various activities integrating an equity-lens throughout the data life cycle.

Planning for collection

As general overviews, resources offered through a data and policy centre, Actionable Intelligence for Social Policy and by the Centers for Disease Control and Prevention (CDC) Foundation presented robust guidelines and activities to incorporate an equity lens in data practices (85, 86). To reduce organizational silos, contextualizing each data stage within the entire cycle was essential to avoid cultural gaps in technology across roles, departments or regions of an institution. A complete environmental scan involving collection, access, algorithms, technologies and tools, analysis, reporting and dissemination was suggested (85, 87, 88).

To balance data standardization with flexibility, it was recommended to dedicate time for the planning phase to define purpose and objectives. This strategic planning was supported by concurrent education to promote anti-racist workforce development and cultural competency, especially in data-related roles

(89). Diversity in leadership, specifically, was important in these activities including roles related to data, analytics, information technology, and privacy and security.

Strengthening equity-based data initiatives could involve leveraging directives of data provisions from local authorities, including the Ontario Human Rights Commission (90). For instance, Ontario's Anti-Racism Directorate provided specific considerations for data collection, access, use and protection to track inequities driven by systemic racism (91). Multiple components of the standards provided specific activities to be performed by data stewards such as the use of personal information and the release of data to the public.

Analysis and interpretation

To facilitate accessible discussions about data with community members, the Urban Institute created "Data Walks" for community interpretation of data which encourages individuals to engage with and reflect on data through stations in small groups (92). This method involved facilitators using dialogue to collaboratively interpret and analyze data points, drawing on participants' real-life experiences to generate action strategies. A successful example was highlighted in Houston, Texas, where African-American community members engaged in a Data Walk to discuss employment, housing and city planning issues (93).

Use and access

Moreover, community data utilization was approached from multiple angles. First, the Ngā Tikanga Paihere framework outlined conceptual principles for utilizing Māori data (94). This framework covered aspects like community benefits and respect for cultural customs. Organizations were encouraged to apply this framework to ensure the best standards and practices in data utilization. Furthermore, the exploration of social licences and prescriptive use guides, explored by the Health Data Research Network (95) and British Columbia's Ministry of Citizens' Services (96), advised potential data users to adhere to specific requirements regarding governance, language and data dissemination. In addition, Florida-based Broward Data Collaborative introduced adaptable use case categories that define data usage purposes: descriptive uses for assessing population dynamics, evaluation and research for comprehending the impact of interventions within populations, and care and service coordination(97). Data use was permitted for projects with objectives aligned with these predefined categories.

Reporting

Reporting processes were highlighted as an important way to demonstrate the impact of using equity data (98, 99). The benefits of creating standardized reports included understanding knowledge of the populations served, identifying and prioritizing heightening risks of outcomes or service provision, targeting training and education resources to the most appropriate institutional areas and tracking progress towards equity (99). Organizations were recommended to have clear communication channels that could be used to disseminate information within and beyond the institution. In addition, data visualization enhanced accessibility for audiences with limited time and data literacy capacities (100, 101). Forms like bar and pie graphs, geo-spatial mapping tools and report cards made data more approachable to equity-deserving groups. It was noted to undergo preliminary testing with small community advisory groups to ensure each visual's appropriateness.

Discussion

The City of Toronto has expressed interest in the potential of utilizing Black data governance as a tool to track and address inequities affecting Black communities and to empower Black communities to shape how the data is managed. The objectives of this review were to explore the evidence on guidance, frameworks and successful strategies related to community data governance based on real-world examples. These practices offered potential starting points for institutions across three areas: explaining community data governance, establishing a data ecosystem centred on equity and introducing equitable perspectives in data practices. A summary of implementation considerations from this literature review was provided ([Appendix 4: Summary of implementation considerations](#)).

The City of Toronto previously initiated efforts to disaggregate and disseminate demographic data. For example, internal entities like Toronto Public Health and the Toronto Police Services introduced dashboards that allowed community members to access information about health and justice involvement outcomes (24, 48). Also, community engagement and public consultation are consistently referenced across various city divisions including Toronto Police Services, City Planning, the Shelter, Support and Housing Administration (SSHA), and the Social Development, Finance and Administration division (102-106).

The city can strengthen its support for building data capacity within communities by actively engaging in the collaborative development of a governance framework with community stakeholders. Examples of community data governance varied in terms of their elements including vision statements, values, desired outcomes, principles and recommendations (19, 20, 25, 26, 28, 29). Significant emphasis was placed on clearly defining the purpose of collecting equity data and articulating how community members stand to benefit. It was crucial to align with data experts and institutional leaders to reflect on practical strategies for implementing community preferences on data access and protections (38, 39).

To expand the capacity for community governance and engagement procedures, this review pinpointed considerations and tangible actions for institutions to practically implement community-centric data governance. Emphasizing the significance of data literacy, the review highlighted its role as a crucial factor in fostering community inclusion in data governance (30). Through training materials and discussion guides, data stewards were instrumental in enhancing community capacity for data engagement and decision-making, particularly on topics relevant to data governance (31-34). Specific guidance was also outlined for Open Data initiatives (35, 36). Consequently, establishing a robust arm dedicated to data literacy and engagement within the city could be pivotal in laying the groundwork for community data governance as an infrastructure is developed.

The city can initiate the exploration of practical methods to implement community governance while engaging with Black populations. In the meantime, this review offered initial considerations for the city to test and identify potential areas willing to undertake and pilot this initiative. There were varied activities intended to implement community data governance: independent third-party governance table, oversight committees, citizen report cards, organizational scorecards, policies mandating community engagement, progress-based funding and participation honoraria (41-47). Success stories were also shared to demonstrate the impact of community governance across Canada, the United States, the United Kingdom, Sierra Leone, Kenya and New Zealand (48-56). By providing these foundational elements and sharing these stories with Black community members, the City of Toronto could adapt and refine these examples into a suitable Black data governance framework.

This review provided guidance to the city on data structures such as integrated data systems, data cooperatives, collaboratives or trusts to comprehensively understand and activate its current data holdings (57, 58, 107). Another viable starting point for exploring community governance could be through an alternative approach, such as Open Data, given its observed utility in presenting and sharing data with communities (60, 62).

Data sharing initiatives grounded in partnerships were identified, such as the Community Data Program, Be Yourself See Yourself, and Raising the Village Equity Toolkit (77-79). This review pinpointed practical insights essential for expanding this work towards governance including two guides by the National Neighborhood Indicators Partnership (63, 64). These guides were designed to encompass all the diverse components needed for building a robust data environment for equity objectives. Additionally, real-life examples of engagement processes were identified, illustrating how they supported consensus on data models, the purpose of data initiatives and decisions regarding data use and privacy. (66-68). In these initiatives, the central focus was on gathering data from diverse sources, demanding a strong foundation built on partnerships (57, 58, 72). These engagements required systematic inclusion of stakeholders, willingness to develop governance requirements and commit to data sharing agreements that incorporate community data governance (58, 73-76). These resources can contribute to the establishment of a unified data infrastructure among all partners and create the groundwork for the eventual creation of Black data governance.

Exploring examples of data usage, analysis, reporting and visualization could be beneficial for the city to evaluate and compare current practices and establish initial steps for developing specific data policies and practices aligned with the Black data governance. This review identified the initial steps to create an enterprise-wide data equity strategy, starting with gaining institutional agreement, planning and dedicating resources for equitable data practices (85, 86). Supportive factors were anti-racist education, diverse leadership and leveraging local support for using sociodemographic data to promote an equitable data culture (89-91). Various options for analysis, determining data use and access provisions, and reporting were provided in this review for the city to use once an environmental scan of current data practices is completed (92, 94-101).

Conclusion

In conclusion, this literature review provided insights, frameworks and strategies to inform Black data governance for the City of Toronto. Through 78 records, key findings encompassed the exploration of community data governance approaches, the creation of effective data infrastructure, and the integration of equity lenses throughout the data life cycle. The City of Toronto has the opportunity to leverage its ongoing initiatives and priorities by adopting the implementation strategies outlined in this literature review to realize Black data governance. Furthermore, engaging with internal city staff, sector experts and Black community stakeholders and leaders could contribute to refining and aligning these strategies with local contexts.

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Appendix 1: Literature review methodology

City of Toronto Black Data Governance

The City of Toronto has prioritized addressing inequities experienced by Black communities and other marginalized groups in Toronto through tracking disaggregated race-based data. Initiatives have been actively supported to strengthen their data ecosystem, including data governance and use of race-based data in ways that benefit communities.

The city has partnered with the Wellesley Institute and the Black Health Alliance to develop Black data governance given Wellesley Institute's focus on improving health equity through the social determinants of health and the Black Health Alliance's expertise in engagement with Black communities through research, thought-leadership and equity-oriented processes.

The project comprises five phases. In Phase 1, Wellesley Institute and the Black Health Alliance evaluated the project's scope, collecting city-related information and culminating in a detailed project plan. Phase 2's activities necessitated a literature review on community data governance and an internal scan of city staff. Phase 3 involved assembling an Advisory Circle of community experts to shape the Black data governance. Phase 4 entailed focus groups with representatives from local Black organizations, sector experts and Toronto's Black community members to enhance the Black data governance. In Phase 5, the finalized Black data governance integrated insights and recommendations from all phases, encompassing a holistic vision, objectives, principles, mechanisms and recommendations.

Literature review search strategy

The purpose of this literature review was to shape the development of the City of Toronto's Black data governance. Although the focus of this initiative was Black communities, evidence focused on data governance specifically for Black communities was limited. Due to insufficient data, the objectives of this review were expanded to community members in general. This broadened approach aimed to provide options from which community stakeholders and the city would be able to modify to develop a local Black data governance.

The primary objective of this literature review was to gather pertinent viewpoints, materials and instances of community data governance from local, national and international sources. The following secondary objectives have been outlined for the literature review:

- Discover frameworks, strategies, agreements, legislation, policies or approaches designed to offer guidance on handling sensitive data, particularly data related to race, encompassing its collection, analysis, management and dissemination.
- Explore effective strategies implemented by organizations collecting data to actively involve community members in the processes of data collection, governance and access which may include the development of data-sharing agreements.

- Identify instances that exemplify community members' participation in decision-making, planning, governance, access, management or data collection while also considering the allocation of time and resources devoted to supporting community engagement.

In this literature review's methodology, the focus on existing initiatives and practical guides required a broad search beyond peer-reviewed papers to include grey literature, news media, institutional websites, newsletters and networks. The search considered a variety of materials: reports, toolkits, articles, practical guides, protocols, policies, conference presentations, articles, commentaries and event notices. Search engines like Google Search and PubMed were used along with examining websites of organizations known for their emphasis on data and equity such as Alliance for Healthier Communities, ICES, CIHI and municipal government sites. Search terms included a combination of “data,” “information,” “technology,” “agreements,” “governance,” “sharing,” “use,” “collection,” “management,” “access,” “privacy,” “community,” “equity,” “Black,” “racialized,” “marginalized,” “vulnerable” and “public.”

Records were screened and selected based on the following inclusion criteria: published after 1998 when the OCAP principles were developed, available in the English language, and focused on community engagement or equity in relation to data life cycle components such as collection, analysis, management, use or governance. Exclusion criteria included: theoretical research without direct practical applicability and focus on technical or legal complexities of data governance such as cloud architecture or software development.

Data was extracted from each record through a data extraction sheet based on the record source (author or organization, publication or release date, geography, sector or document type), findings (equity or community focus; governance, ownership, or stewardship focus; summary; main findings) and themes based on the document's purpose and intended goals.

Appendix 2: Literature review flow chart

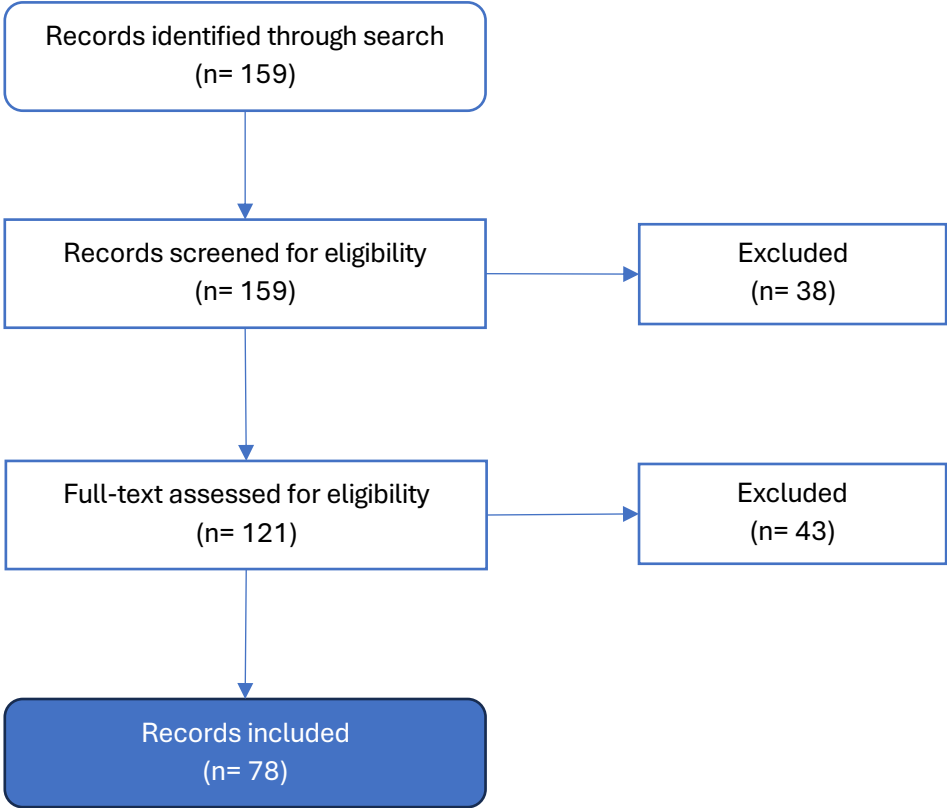


Figure 1 Flow chart of literature review search

Appendix 3: Literature review findings table

Title	Author	Year	Region	Sector	Type	Summary
Exploring community data governance						
Governance framework						
<u>OCAP Principles</u>	First Nations Information Governance Centre	2014	Canada	Advocacy Group	Framework	The First Nations principles of OCAP® assert that First Nations have ownership, control, access and possession of their data and information. OCAP® is a tool to support information governance on the path to First Nations data sovereignty, respecting their worldviews, traditional knowledge and protocols.
<u>Māori Data Governance Model</u>		2023	New Zealand	Government	Framework	The model provides guidance for the system-wide governance of Māori data, consistent with the Government’s responsibilities under te Tiriti o Waitangi. The model is intended to assist all agencies to undertake Māori data governance in a way that is values-led, centred on Māori needs and priorities and informed by research.
<u>The CARE Principles for Indigenous Data Governance</u>	International Indigenous Data Sovereignty Interest Group	2020	Europe	Advocacy Group	Journal Article	This is the first formal publication regarding the development and application of CARE principles. Principles were suggested by country.
<u>Health Data Governance Principles</u>	Transform Health	2022	International	Data-Centred Non-Profit	Framework	The principles aim to address a gap in standardized health data governance to improve population health and equitable change. They are intended to serve and apply to stakeholders including governments and international organisations.

<u>Principles for Conducting Research in the Jane Finch Community</u>	Jane Finch Community Research Partnership	2021	Canada	Non-Profit	Framework	This document outlines the Jane Finch Community Research Partnership's principles to ensure respectful and ethical research practices in the Jane Finch community. It aims to acknowledge and address the historical impacts of stigmatizing research, reduce emotional labor for community members and promote research processes that benefit the community.
<u>A Vision for Ontario's Health Data Ecosystem</u>	Ontario Health Data Council	2022	Canada	Government	Report	The Ontario Health Data Council emphasizes the need for a learning health data ecosystem to achieve a sustainable health system. Their report calls for integrating and using health data to improve care delivery, promoting health equity, establishing trustworthy governance for health data as a public good, respecting First Nations' data sovereignty and building data stewardship capacity for better health outcomes in Ontario.
<u>EGAP Principles</u>	Black Health Equity Working Group	2021	Canada	Advocacy Group	Framework	The EGAP Framework aims to achieve data sovereignty for Black communities by providing guiding principles in four areas: engagement, governance, access and protection. This framework advocates for genuine consultation with communities, community decision-making, the right to access collective data and protection of individual rights and data types.
Capacity and literacy						
<u>Beyond Data Literacy: Reinventing Community Engagement and Empowerment in the Age of Data</u>	MIT Media Hub	2015	U.S.	Non-Profit	Report	The article explores the concept of data literacy and its importance in promoting data inclusion, which empowers individuals to understand, interpret and use the data they encounter, and even produce and analyze their own data.

Data Literacy	Data Driven Detroit	2019	U.S.	Non-Profit	Use Case	This page provides resources including workshop recordings, blog posts and tool tutorials to help individuals learn how to use data in their work. It also offers free virtual consultation appointments with subject matter experts in a variety of fields through Co.act Detroit.
Data Driven Dialogue	Teacher Development Group	2019	U.S.	Education	Guide	This tool is a protocol for facilitating data-driven dialogue through the three phases of the protocol that involve making predictions, visualizing the data and engaging in observations and inferences. The tool is designed to help replace assumptions and hunches with data-based facts and generate root-cause discussions.
Data Literacy Trainings	Rice University Kinder Institute for Urban Research	2019	U.S.	Research Centre	Guide	This is a series of data literacy trainings designed for non-profit staff and leaders who want to facilitate community trainings on data and its applications. The curricula are based on equipping participants to understand the principles and challenges of data, use data to support their arguments or decision-making processes, and even produce and analyze their own data.
Data 101 Toolkit	Western Pennsylvania Regional Data Center	2018	U.S.	Government	Guide	The Data 101 workshop series is designed to introduce people to data literacy, with the goal of building participants' confidence and familiarity with data concepts. The toolkit includes everything needed to replicate or expand on the workshops, which are built around paper-based or low-tech activities and designed to be inclusive.
A Guide to Tactical Data Engagement	Sunlight Foundation	2017	U.S.	Research Centre	Guide	The guide introduces Tactical Data Engagement (TDE), a method based on human-centred design and tactical urbanism, aimed at facilitating community use of open data for local impact and making open data programs more transparent and participatory.

<u>Tactical Data Engagement: Data User Groups</u>	Sunlight Foundation	2017	U.S.	Research Centre	Guide	This excerpt explains the concept of data user groups, which are intentional opportunities for residents to collaborate on projects related to open data. These groups allow for feedback to be given to data providers and give community members a chance to learn about data and collaborate on local issues
Mechanisms						
<u>A participatory approach for empowering community engagement in data governance: The Monash Net Zero Precinct</u>	Monash Sustainable Development Institute	2021	Australia	Research Centre	Use Case	This workshop on community data governance for environmental/ecological community data used virtual post-it notes to capture ideas from participants about data use and data governance.
<u>Addressing Fragmentation of Health Services through Data-Driven Knowledge Co-Production within a Boundary Organization</u>	Arizona State University	2022	U.S.	Health and Social Services	Use Case	This paper introduces a novel approach to overcome challenges in healthcare data sharing by using a boundary organization and knowledge co-production practices to create an integrated multi-sector dataset and visualizations. The research demonstrates how this process can foster collaboration, align datasets and problem-solving efforts, and facilitate data sharing among disconnected and disparate social groups in the healthcare sector.
<u>Governing health futures: youth consultation on the principles of health data governance</u>	Wilton Park	2021	U.K.	Government	Report	This report describes a consultation process with young experts to construct an equitable health data governance framework as proposed by Transform Health.
<u>OneLondon Citizens' Summit</u>	OneLondon	2020	U.K.	Health and Social Services	Use Case	The OneLondon Citizens' Summit convened 100 Londoners in February and March 2020 to deliberate and provide recommendations on the uses of health and care data, covering topics such as expectations of the health and care service, access and control, de-personalised data for proactive care, research and development, and ongoing involvement in policy-making and oversight.

<u>Steps for Engaging Patients and Community Members in Data-Driven Quality Improvement</u>	Center for Health Care Strategies	2022	U.S.	Health and Social Services	Guide	This tool provides guidance for health care organizations to partner with patients and community members in their data-driven quality improvement efforts. It includes key steps, discussion questions and a practical example of using data to improve care.
<u>Community-Partner Led Engagement Findings Report: Anti-Racism Data Legislation Engagement</u>	Ministry of Attorney General: Multiculturalism and Anti-Racism Division	2022	Canada	Government	Report	A framework developed by the provincial government was used to help illustrate the importance of community involvement, the need to secure the communities data, and the need to see concrete action taken.
<u>Improving social accountability processes in the health sector in sub-Saharan Africa: a systematic review</u>	York University	2018	Sub-Saharan Africa	Health and Social Services	Journal Article	This paper examines the factors that lead to successful social accountability initiatives in sub-Saharan African countries, offering insights for community leaders and organizations aiming to enhance their impact in promoting accountability.
<u>Community participation in the health system: analyzing the implementation of community health committee policies in Kenya</u>	LCVT Health	2023	Kenya	Health and Social Services	Journal Article	This study examines the gap between policy intentions and the implementation of community health policies, focusing on factors influencing the execution of Community Health Committee (CHC) policies in rural and urban settings in Kenya.
<u>Participation in primary health care through community-level health committees in Sub-Saharan Africa: a qualitative synthesis</u>	LCVT Health	2022	Sub-Saharan Africa	Health and Social Services	Article	This paper explores the role of health committees in facilitating community participation in decision-making concerning primary health care in sub-Saharan Africa. It seeks to provide a comprehensive understanding of how community members engage in this process.

<u>How context influences the functionality of community-level health governance structures: A case study of community health committees in Kenya</u>	LCVT Health	2023	Kenya	Health and Social Services	Journal Article	This study focuses on Community Health Committees (CHCs) and their role in community participation within the governance of community health services in Kajiado, Migori, and Nairobi Counties in Kenya. They employed focus group discussions and interviews with community members, health professionals, and volunteers to understand how contextual factors influence CHC functionality.
<u>Second Substitute Senate Bill 5793</u>	Government of the State of Washington	2022	U.S.	Government	Legal Document	This Senate Bill mandates the compensation of lived experience experts in civic engagement and the collection of demographic data to inform more effective future engagement strategies.
Use case						
<u>In the Communities' Words: the Toronto Police Service's Race-based Data Collection Strategy</u>	Toronto Police Service	2020	Canada	Police	Report	Toronto Police Services collaborated with racialized communities to formulate a strategy for utilizing race-based data. The engagement process yielded significant insights across areas such as community involvement, data practices, and trust-building.
<u>Addressing the Health Care Needs of People Experiencing Homelessness in Arizona</u>	Center for Health Care Strategies	2022	U.S.	Health and Social Services	Use Case	Arizona LAPP team integrated data systems and expanded care coordination opportunities across state and local partners serving people experiencing homelessness, developing principles for data sharing, and obtaining written consent from individuals experiencing homelessness.
<u>Addressing the Health Needs of Children and Youth in Rural South Carolina</u>	Center for Health Care Strategies	2022	U.S.	Health and Social Services	Use Case	The University of South Carolina partnered with a local county to identify health inequities using microdata from the South Carolina Integrated Data System, and after community feedback, the team re-analyzed the data to provide clear measures for community leaders to track and prompt subsequent community-wide meetings to address the findings.

Supporting Aging Populations in Rural Utah	Center for Health Care Strategies	2022	U.S.	Health and Social Services	Use Case	Utah LAPP partnered with social and health care organizations to improve care coordination and health outcomes for San Juan County elders. They implemented a data exchange program using the Mon Ami Operating System to share patient records and received community feedback to develop a culturally appropriate referral system.
Realization in Central Wisconsin: How the Incourage Community Foundation Used Information to Build Hope and Speed Community Change	Incourage Community Foundation	2013	U.S.	Non-profit	Use Case	Incourage's community engagement efforts showed how sharing information can increase citizen engagement and lead to greater information consumption, as residents become motivated to use accurate and relevant information in their decision-making.
Developing decentralised health information systems in developing countries -cases from Sierra Leone and Kenya	WHO/Health Metrics Network	2013	Sub-Saharan Africa	Non-profit	Use Case	This study demonstrates how community-based health information systems in Sierra Leone and Kenya, integrated with modern ICT, empower communities to improve healthcare access and equity at the local level. By using simple information products, such as quarterly bulletins and league tables, communities engage in cultivating culturally appropriate health services.
The INSIGHT Data Trust Advisory Board: data access criteria	INSIGHT Data Trust Advisory Board	2021	U.K.	Health and Social Services	Use Case	The INSIGHT Data Trust Advisory Board (DataTAB) is responsible for assessing individual applications to access data through INSIGHT using their criteria. They provide recommendations to the INSIGHT Data Controllers to accept or refuse an application based on their assessment.
An evaluation of the impact of public involvement and engagement in the Connected Health Cities Programme	TwoCan Associates	2018	U.K.	Health and Social Services	Use Case	Findings from an evaluation of public involvement and engagement (PPIE) in Connected Health Cities (CHC), a UK Department of Health funded programme aimed at transforming healthcare by gathering data, experts and technology in secure data facilities, and highlights the different approaches of PPIE as well as summarising the lessons learnt to date through five case studies.

<u>Data Iwi Leaders Group (DILG) of the National Iwi Chairs Forum (NICE)</u>	New Zealand Government	2020	New Zealand	Government	Use Case	The MDG co-design process was co-led by the Data ILG and Stats NZ and resulted in two reports, Tawhiti Nuku and Māori Data Governance Co-design Review, which will inform ongoing refining, testing and implementation of the model.
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Establishing an equity-based data infrastructure

Structure

<u>Unlocking the Power of Digital Commons: Data Cooperatives as a Pathway for Data Sovereign, Innovative and Equitable Digital Communities</u>	University of Applied Sciences Konstanz	2023	Europe	Research Centre	Article	This review article emphasizes the role of digital commons and data sovereignty in providing communities with access to information and decision-making power. It highlights the importance of cooperative data governance and proposes a policy framework to support the practical implementation of digital federation platforms and data cooperatives for sustainable and inclusive development globally.
<u>Data Trust for the Royal Borough of Greenwich and Greater London Authority</u>	BPE Solicitors	2019	U.K.	Government	Report	The GLA and RBG are interested in testing a data trust as a solution to issues with data sharing. Possible alternatives include having individual data trusts for each borough or having the data trust act as an advisor.
<u>Introduction to Data Sharing and Integration</u>	Actionable Intelligence for Social Policy	2020	U.S.	Data-Centred Non-Profit	Guide	This resource provides guidance for partnerships and initiatives to repurpose administrative data and establish routine capacity for integrated data systems (IDS) with a focus on strong governance.
<u>Utilizing public health core competencies to share data effectively with community organizations to promote health equity</u>	Public Health Ontario	2019	Canada	Health and Social Services	Report	The article discusses the important role of Local Public Health Agencies (LPHAs) in sharing data more effectively with local community organizations to advance health equity, using an adapted model for research transfer.

Emerging Tensions in Data Work: Staff and Youth Perspectives in Youth-Serving Organizations	University of Minnesota	2022	U.S.	Health and Social Services	Framework	This study presents a framework for understanding tensions in data work in Youth Serving Organizations (YSOs). It highlights the need for nurturing local stakeholder involvement, setting specific goals linked to metrics, and considering ethical considerations in data system design to address these challenges effectively.
Actionable Open Data: Connecting City Data to Local Actions	Knowledge Media Institute	2020	U.K.	Data-Centred Non-Profit	Journal Article	This study explores why Open Data is underutilized, pointing out a misalignment between local actors, data use, and technology focus. The findings suggest a new approach: Open Data technologies acting as community infrastructure to better match data production with local development needs.
Development						
Guide to Starting a Local Data Intermediary	National Neighbourhood Indicators Partnership	2016	U.S.	Non-profit	Guide	This guide provides information on the role and establishment of a local data intermediary in a community, drawing on the NNIP model and the experiences of its local partners. It covers topics such as identifying a home for the intermediary, fundraising, and initial activities.
NNIP's Resource Guide to Data Governance and Security	National Neighborhood Indicators Partnership	2018	U.S.	Non-profit	Guide	This guide aims to provide resources and advice from the experiences of those in the NNIP network and other related organizations on developing a strong data governance program and protecting the security of confidential data.
Building + Sustaining State Data Integration Efforts: Legislation, Funding, and Strategies	Actionable Intelligence for Social Policy	2021	U.S.	Data-Centred Non-Profit	Report	This brief presents examples of states using legislation and executive orders for data integration, discusses funding opportunities, and outlines key strategies to ensure ethical and effective implementation.
Information Governance Report	Connected Health Cities	2020	U.K.	Health and Social Services	Use Case	The CHC Programme collected and analyzed data from various healthcare sectors to enhance patient outcomes. To ensure ethical data processing, the CHC Hub

						appointed a specialist to establish information governance protocols for lawful data sharing across all regional CHCs and host organizations.
<u>Greater London Authority/Royal Borough of Greenwich data trust pilot: Design of a decision-making process</u>	Open Data Institute	2019	U.K.	Government	Use Case	The Involve organization was tasked with designing a decision-making process for a pilot data trust for the GLA/RBG's Sharing Cities Programme. They developed a background assessment, insights into public perception of data trusts, and a generic design of a decision-making process emphasizing the importance of defining the problem and purpose, contextual decision-making, and early stakeholder analysis.
<u>Data trusts: lessons from three pilots</u>	Open Data Institute	2019	U.K.	Government	Report	The article discusses the key findings and recommendations of a report on the design of decision-making processes for data trusts, including the benefits of data trusts for data holders and the need for a multidisciplinary team, among other factors.
<u>Sharing Data for Social Impact: Guidebook to Establishing Responsible Governance Practices</u>	Georgetown	2020	U.S.	Non-profit	Guide	This Guidebook is part of the Digital Service Collaborative, a partnership between the Beeck Center and The Rockefeller Foundation that leverages the network of professionals working on data and digital services to scale solutions for greater impact. The Digital Service Collaborative brings together members of the data and digital service community to work together solving specific problems and sharing those solutions throughout the network.
<u>Quality Framework for Integrated Data Systems</u>	Actionable Intelligence for Social Policy	2021	U.S.	Data-Centred Non-Profit	Guide	This guide presents a quality framework for Integrated Data Systems (IDS), emphasizing governance, legal aspects, technical considerations, capacity building, and impact assessment. IDS enables the integration of diverse data sources to gain insights into public needs and optimize service delivery for clients, patients, students and taxpayers.

<u>Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration</u>	Actionable Intelligence for Social Policy	2022	U.S.	Data-Centred Non-Profit	Guide	This resource guides agencies to develop a robust legal framework for data sharing and integration. It offers key considerations, exemplars and practical tools to ensure compliance, ethical practices and effective implementation of Integrated Data Systems (IDS).
Partnership						
<u>Nothing to Hide: Tools for Talking (and Listening) About Data Privacy for Integrated Data Systems</u>	Actionable Intelligence for Social Policy	2018	U.S.	Data-Centred Non-Profit	Guide	The toolkit equips stakeholders involved in Integrated Data Systems (IDS) with the essential tools to facilitate privacy-sensitive and inclusive stakeholder engagement. It offers a comprehensive narrative guide for effective IDS communication and engagement, complemented by practical appendices that include worksheets, checklists, exercises and supplementary resources.
<u>Developing Governance for Federated Community-based EHR Data Sharing</u>	Data QUEST	2014	U.S.	Health and Social Services	Use Case	The Data QUEST pilot project facilitates data sharing among community-based primary care practices through an electronic health record infrastructure, incorporating governance requirements derived from partner organizations. Recommendations include controlled data access, query approval, adherence to local processes and resources and seamless addition or removal of partner organizations from the data sharing network.
<u>Collection of Example Data-Sharing Agreements: Health + Healthcare</u>	Urban Institute	2018	U.S.	Health and Social Services	Agreement	The MOUs on data sharing agreements between state Departments of Health and Human Services, healthcare providers, research intermediaries, non-profit agencies and municipal healthcare corporations cover a range of data sources that include health records, community surveys and Medicare data.

<u>Developing Data Governance Agreements with Indigenous Communities in Canada</u>	University of Alberta	2022	Canada	Research Centre	Article	This article discusses the importance of Indigenous data sovereignty and governance in public health research and programming. It shares experiences and lessons learned from developing and implementing data governance agreements with First Nations and Métis partnering communities in Canada for tuberculosis prevention and care.
<u>Data Trust Agreement: Canadian Member</u>	Bright Hive	2021	Canada	Data-Centred Non-Profit	Agreement	Bright Hive is a data-focused non-profit and developed data trust and sharing agreements that emphasize equity and community engagement.
Implementation						
<u>Community Data Program</u>	City of Toronto	2019	Canada	Government	Use Case	The Community Data Program provides municipalities and community sector agencies with access to customized data from Statistics Canada and other providers at reduced costs, allowing them to monitor and report on social and economic trends within their communities.
<u>Equity Analysis Toolkit</u>	Raising the Village	2020	Canada	Data-Centred Non-Profit	Guide	This toolkit provides disaggregated data on indicators to understand factors impacting children's well-being, aligning with the City of Toronto's Data for Equity strategy.
<u>Be Yourself See Yourself</u>	City of Toronto, Ontario Trillium Foundation, United Way Greater Toronto	2021	Canada	Health and Social Services	Program	The City of Toronto, Ontario Trillium Foundation and United Way Greater Toronto are funding a pilot program to collect standardized demographic information with service users in the community and social services sector.

How the Rhode Island EOHHS Ecosystem Leverages Federal Funding to Support State Data Capacity	Actionable Intelligence for Social Policy	2021	U.S.	Data-Centred Non-Profit	Use Case	This report describes how Rhode Island diversified funding for their state Integrated Data System (IDS), emphasizing starting with one use case to demonstrate value, focusing on data governance, seeking diverse funding and exploring matching potential, and building creative partnerships to increase capacity.
Western Pennsylvania Regional Data Center	Western Pennsylvania Regional Data Center	2022	U.S.	Government	Use Case	The Western Pennsylvania Regional Data Center is a shared technological and legal infrastructure to support research, analysis, decision making and community engagement by providing a legal infrastructure, technologies and capacity for managing information in a fragmented political environment.
Equity in Practice Learning Community	Actionable Intelligence for Social Policy	2023	U.S.	Data-Centred Non-Profit	Program	The AISP Equity in Practice Learning Community provides valuable guidance for those looking to integrate racial equity into data sharing efforts. They collaborate to create a more inclusive data infrastructure that shares power and knowledge with communities, particularly emphasizing health equity and racial justice.
Baltimore City Youth Data Hub	Baltimore Promises	2022	Canada	Non-profit	Use Case	The Baltimore City Youth Data Hub (the Data Hub) is an integrated data system that links data across youth-serving organizations into an anonymous system subject to community oversight and strict guidelines. The Data Hub brings communities, providers, policymakers and researchers together in partnership to make informed decisions as they create and implement programs and policies designed to eliminate disparities and achieve equitable outcomes for the success of Baltimore's youth and families.
Advancing Health, Well-Being, and Equity through Community-State Data-Sharing Partnerships	Center for Health Care Strategies	2020	U.S.	Health and Social Services	Report	The Robert Wood Johnson Foundation (RWJF) is partnering with the Center for Health Care Strategies (CHCS) to support an initiative called Data Across Sectors for Health (DASH) that will help communities

strengthen their relationships with state agencies for data-sharing efforts, ultimately informing inclusive policy and systems alignment at the community and state levels.

Introducing equity in data practices

Planning

<u>A Toolkit for Centering Racial Equity Throughout Data Integration</u>	Actionable Intelligence for Social Policy	2021	U.S.	Data-Centred Non-Profit	Guide	The purpose of this toolkit is to provide guidance for partnerships, collaboratives, agencies and community initiatives that aim to prioritize racial equity when utilizing, sharing, and integrating administrative data.
<u>Principles for Using Public Health Data to Drive Equity: A guide to embedding equitable practices throughout the data life cycle</u>	CDC Foundation	2022	U.S.	Health and Social Services	Guide	This excerpt emphasizes the importance of applying equitable practices, such as the data equity principles, throughout the data life cycle, which includes the planning, collection, access, analysis and dissemination phases.
<u>Leveraging Community Information Exchanges for Equitable and Inclusive Data: The CIE® Data Equity Framework</u>	Community Information Exchange	2021	U.S.	Health and Social Services	Framework	This framework provides a strategic visioning tool for institutions and initiatives to create more equitable and inclusive systems that support health outcomes. Its aim is to help build a robust data system of care that respects the people affected by the data gathering, sharing, and use processes.
<u>Surfacing Human Service Organizations' Data Use Practices: Toward a Critical Performance Measurement Framework</u>	University of Minnesota	2022	U.S.	Health and Social Services	Framework	This study proposes a framework of questions to facilitate a more critical, just and equitable approach to data work in youth serving organizations and community informatics. It emphasizes co-creating data collection systems with the involvement of young people and frontline workers, centering on trust, consent and data about systems and environments rather than solely focusing on young people themselves. However,

						implementing this framework requires education, authentic critique and a shift in perspective where data work is seen as an integral part of organizational functioning, rather than an add-on.
<u>Equity of Care: A Toolkit for Eliminating Health Care Disparities</u>	American Hospital Association	2015	U.S.	Health and Social Services	Guide	The Equity of Care Toolkit guides healthcare organizations to eliminate healthcare disparities and improve quality and equity in their communities by increasing REAL data collection, cultural competency training and diversity at the leadership and governance levels.
<u>Count me in! Collecting human rights-based data</u>	Ontario Human Rights Commission	2009	Canada	Health and Social Services	Report	The Ontario Human Rights Commission has found that data collection can help create strong human rights and human resources strategies for organizations in various sectors.
<u>Ontario's Anti-Racism Data Standards</u>	Anti-Racism Directorate	2018	Canada	Government	Guide	The Ontario Anti-Racism Data Standards (Standards) were established to identify and monitor systemic racism and racial disparities in the public sector. By setting consistent practices for collecting and using data, these Standards aim to support evidence-based decision-making, promote racial equity and help create an inclusive society for all Ontarians.
Analysis						
<u>Data Walks: An Innovative Way to Share Data with Communities</u>	Urban Institute	2015	U.S.	Health and Social Services	Guide	The article discusses the use of Data Walks as a tool to engage community stakeholders in the research process, highlighting their objectives, research questions and methods for maintaining integrity, recruitment and incentives.
<u>Taking residents on a data walk: An effective way to democratize community research findings</u>	Baker Institute for Public Policy	2020	U.S.	Non-profit	Use Case	The Kinder Institute's HCDC team partnered with the Sankofa Research Institute to host a data workshop at Blackshear Elementary School, using an interactive Data Walk to engage residents and stakeholders in interpreting

						research findings and collaboratively addressing community concerns in the changing historic neighborhood of Third Ward.
Use						
Ngā Tikanga Paihere: a framework guiding ethical and culturally appropriate data use	Stats NZ	2020	New Zealand	Government	Framework	The GCDS partners with New Zealand data leaders to develop and implement a stewardship framework to maintain a sustainable data system, while the Information Group provides governance for the data stewardship framework and leads the information management strategy for the public sector.
Social Licence For Uses Of Health Data: A Report On Public Perspectives	Health Data Research Network Canada	2022	Canada	Health and Social Services	Report	This report provides additional insights on the requirements for a use or user of health data to be within social licence, including perspectives from public and patient advisors and examples of acceptable and unacceptable uses and users
Broward Data Collaborative	Children's Services Council of Broward County	2017	U.S.	Data-Centred Non-Profit	Use Case	The Broward Data Collaborative (BDC) was established on December 14, 2017 to maximize the effectiveness of Broward's Integrated Data System (IDS). The goals of the BDC are to improve Broward County's human services system and its outcomes. The Broward Data Collaborative (BDC) agencies have worked together to create the proposed BDC use cases that are flexible and collaborative with the community of children and families we mutually serve in Broward County.
Report						
A Fairer NHSGCC	NHS Greater Glasgow & Clyde	2022	U.K.	Health and Social Services	Organization	The NHS Greater Glasgow & Clyde addresses inequities by collecting sociodemographic data on their workforce and patients to improve service delivery and provides public reports to share their progress towards equality outcomes.

<u>Creating Equity Reports: A Guide for Hospitals</u>	Massachusetts General Hospital	2008	U.S.	Health and Social Services	Guide	This guide provides a framework for equity data reporting and includes chapters on the rationale for equity reports, suggestions for leading the process, data collection, quality measures, presenting data and strategies for using the report to reduce inequalities.
<u>Data Consumption Guide</u>	Data Driven Detroit	2021	U.S.	Data-Centred Non-Profit	Organization	This guide identifies five important aspects of numbers to keep in mind when reading or reporting data, including scope, geography, availability, scale and source/methods. It emphasizes the importance of understanding the magnitude, location, availability, granularity and potential biases in data to ensure accurate and meaningful interpretation.
<u>Do No Harm Guide: Applying Equity Awareness in Data Visualization</u>	Urban Institute	2021	U.S.	Non-Profit	Report	This guide intends to support data practitioners in understanding and using data through an equity lens. It includes practical recommendations, a case study and a racial equity in data visualization checklist

Appendix 4: Summary of implementation considerations

Exploring community data governance	
Develop, refine and test community data governance framework	<ul style="list-style-type: none"> • Set framework objectives, including addressing data governance gaps, responding to structural inequities and leveraging relevant data initiatives. Explicitly state the use of data for equity purposes and community benefit. Include elements like vision and value statements, desired outcomes, guiding principles (governance, community benefit, equity, ownership, engagement, responsibility, ethics, control, trust, expertise, stewardship and respect) and implementation recommendations. • Align with community priorities, epistemologies and values. • Consider community-led governance bodies for decision-making. • Strengthen data management practices and define collective or community-level provisions.
Invest in data literacy for community empowerment	<ul style="list-style-type: none"> • Prioritize data education, visualization, modeling and participation. • Use examples of data that are relevant to their immediate surroundings. Utilize examples of data relevant to immediate surroundings. • Develop standardized training materials for data literacy in analysis, reporting, dissemination and engagement with open data platforms.
Understand facilitators and barriers to community inclusion	<ul style="list-style-type: none"> • Pilot data governance activities with both community members and stakeholder organizations. • Ensure advisory or governance groups reflect the diversity of the population of interest. • Establish an independent body to regulate data processes. • Demonstrate commitment to social accountability through visible mechanisms (e.g., health committees, citizen report cards, organizational scorecards). • Define policies incorporating community involvement and mention funding. • Compensate individuals for community engagement. • Use demographic data to monitor and expand engagement strategies.
Establishing an equity-based data infrastructure	
Structuring data systems for actionable sharing	<ul style="list-style-type: none"> • Consider and explore various models, such as integrated data systems, data cooperatives, data collaboratives and data trusts. • Develop a single, accessible centralized database to minimize redundancy. • Recognize Open Data as a community-based infrastructure, requiring data literacy and tailored interfaces for diverse audiences.
Process for establishing data sharing systems	<ul style="list-style-type: none"> • Initiate with strategic planning, encompassing community acceptance assessment, securing funding, organizational consensus and capacity building. • Define the scope of actions and responsibilities by conducting an environmental scan of the data ecosystem, identifying leadership and clarifying purposes. • Develop and pilot standardized processes, involve marginalized populations, and ensure institutional sustainability through funding commitments.

	<ul style="list-style-type: none"> • Generate documents and agreements, including purpose assessments, governance frameworks, sharing agreements, ethical reviews and legal and organizational requirements.
Factors fostering partnership among data contributors	<ul style="list-style-type: none"> • Employ skilled stakeholder management. • Include experts in governance, legal, privacy, security, community engagement and equity. • Establish trust between organizations and articulate clear governance rules, such as data approval processes and roles. • Formulate agreements covering funding, engagement, education, training, negotiation processes, and ethical principles like diversity, harm prevention and equity.
Practical implementation of data structures through a phased approach	<ul style="list-style-type: none"> • Begin with small-scale initiatives to demonstrate impact, gauge community interest and identify resource and time needs. • Expand and scale initiatives by exploring funding, building stakeholder support and specifying purposes or desired outcomes. • Leverage networks and partnerships to share lessons learned and set precedents. • Evaluate impact using identified domains and indicators and report findings.

Introducing equity in data practices

Planning for collection	<ul style="list-style-type: none"> • Situate all data processes, roles and departments within a comprehensive institutional data continuum. • Conduct a thorough environmental scan covering collection, access, analysis, reporting, dissemination, technologies and tools. • Allocate dedicated time for effective planning. • Define purposes and objectives, emphasizing their alignment with equity. • Promote anti-racist education and prioritize diverse leadership, especially in data, analytics, information technology, privacy and security. • Leverage directives and recommendations from relevant bodies and authorities.
Analysis and interpretation	<ul style="list-style-type: none"> • Engage in dialogue with community members to draw insights from their real-life experiences. • Develop actionable strategies based on insights gained from community engagement.
Use and access	<ul style="list-style-type: none"> • Determine appropriate options for data use and access, such as community principles, social licenses and prescriptive guides or use case categories.
Reporting	<ul style="list-style-type: none"> • Employ standardized reports to showcase impact, allocate resources effectively, and monitor progress. • Establish transparent communication channels for dissemination. • Promote data visualization for enhanced data accessibility. • Conduct preliminary testing with community advisory groups to ensure appropriateness and relevance.

Report

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