The Data Dissemination Spectrum

**Best Practices in Open Data and
Other Data Sharing Strategies in Health Data**

June 2019

Executive Summary

Data dissemination consists of the distribution or transmission of statistical or other data to an end user.[1] Governments, agencies and other organizations have used data dissemination and related communication activities to extend the utility of their data to a much wider audience to maximize the value and use of data holdings, encourage inquiry and debate within society, increase transparency and accountability, and provide valuable information to spur innovation. Successful data dissemination strategies do not simply release data; they are designed to transmit information to defined user groups. Therefore, one strategy does not necessarily fit all audiences.

This environmental scan explores the application and considerations of open data, data exploration tools, data services, data sharing agreements and secure data access programs as each relates to health data. Each data dissemination strategy is defined by a number of key principles, which in turn impact the ease and effectiveness by which a target audience can access and use information. The different approaches to data dissemination as reviewed in this report are not new and have been used by many different organizations across multiple jurisdictions. What is relatively new is the increasingly large shift toward a more open approach to sharing data. While the public sector, including government, has been one of the earliest adopters of open data strategies, many private sector organizations have also begun to benefit from this approach to data dissemination.

Data dissemination strategies exist on a spectrum from closed to shared to open. Factors that position a strategy within this spectrum are primarily centred around access, availability and associated supports; the strategy is impacted by the nature of the underlying data and the purpose for which it is being shared. However, the data spectrum is not linear, as access to and use of data can be restricted to varying levels within each category.[2] While open data is freely available, shared data may be restricted to specific or ranges of groups that meet defined criteria or have specific licences. Closed data is characterized by restrictions (i.e., technical, legal, institutional) that limit distribution to a select group of data users.

While many data dissemination strategies exist, each is associated with its own strengths, weaknesses, and ability to meet institutional and user requirements. This report provides a detailed introduction and overview of five data dissemination strategies, their application and associated considerations.

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An Overview of Data Dissemination

Data-driven systems have quickly become the new paradigm for innovation, economy and government. Data—that is, any fact, number or text that can be processed by a computer—are accumulated by public and private organizations and can be harnessed to develop meaningful insights and provide information for decision-making. An IDC study predicts that overall data will grow by 50 times from 2012 to 2020.[3] Clearly, the role of data will continue to proliferate in all sectors to drive growth and development.

In health, data collected from traditional records, as well as innovative sources such as mobile health applications, can transform the healthcare landscape. Health data can help clinicians to make cost-effective decisions, improve chronic disease research, inform policy decisions in government and more fully engage consumers in managing their health.

Data dissemination consists of distribution or transmission of statistical or other data to an end user.[4] Governments, agencies and other organizations have used data dissemination and related communication activities to extend the utility of their data to a much wider audience to maximize the value and use of their data holdings, encourage inquiry and debate within society, increase transparency and accountability, and provide valuable information to spur innovation in the private sector.

Data dissemination activities have been used in a wide range of domains including but not limited to government and public sector, financial, health, infrastructure and agriculture. Within each sector, data sources can range from data held by the organization itself or a compilation of data from a wide range of different sources such as that held within national statistics repositories through to government administrative data, surveys, transactional data, machine data and research outputs.

The effectiveness of a dissemination strategy depends on a number of factors including the characteristics and value of the data being shared, the target audience, the channel or mechanism through which it is shared and the level of associated support services. Successful data dissemination strategies do not simply release data; they are designed to transmit information to defined user groups and typically follow the model of one size does not necessarily fit all. For example, the needs and sophistication of the general population differ significantly from those of the research community or private sector. A successful approach would therefore need to take these differences into consideration and ensure the use of relevant and accessible data formats and channels that will enable timely and impactful use of shared data.

Why is Data Not Shared?

One of the more effective ways of improving the efficiency and quality of programs, policies, and services using data to discover gaps or areas that require change. However, the data necessary to discover and act on these areas might not always be available to an organization or audience segment. While data sharing and improved access from alternate sources can typically enable this, there are many obstacles that often slow the sharing process or prevent it completely. Barriers can fall into three broad categories: knowledge, technical obstacles, and conflicting values and obligations.

Knowledge Barriers

Despite the absence of an integrated system, Canada has access to individual data sources that can provide information on populations across the country. Use of publicly held data sets, and sharing of privately held data, is limited by lack of knowledge and awareness of data collected and methods of accessing this data.

The lack of cohesive infrastructure and data user community activities act as barriers to data sharing and exchange, and are obstacles to using data to promote the acceleration of data-driven innovation. Changes to knowledge and awareness of data require investment in social and organizational infrastructure.

Technical Obstacles

Generally, technical obstacles to sharing computer-readable data can be reduced to a matter of machine and software incompatibilities, data preparation, documentation and retention practices. To overcome incompatibilities of machine and software systems, data must be transformed, organized and re-structured into compatible formats. Though technically possible, the process is elaborate and time consuming, and therefore resource heavy.

Differences in data documentation and retention, such as undocumented codes, coding conventions and inadequate documentation, can result in data that can only be used with difficulty or that is completely unusable. The absence of standards for data preparation, documentation and retention practices is often due to resource limitations rather than individual practices.

Conflicting Values and Obligations

Intellectual property, confidentiality concerns and lack of requirement are often cited as reasons for not sharing data.[6] Premature release of data might allow another person or organization to publish first, and any sharing could deprive the original data collector (or associates) of longer-term opportunities to mine the data. Moreover, while agencies that fund data collection projects have the potential to devise and enforce data sharing standards, no such requirements have yet to be developed or recognized across jurisdictions or data consuming communities. Other considerations in data sharing of privately held data sets are limited by stakeholder interests such as cost, ease of access, privacy, confidentiality, interpretation and use.
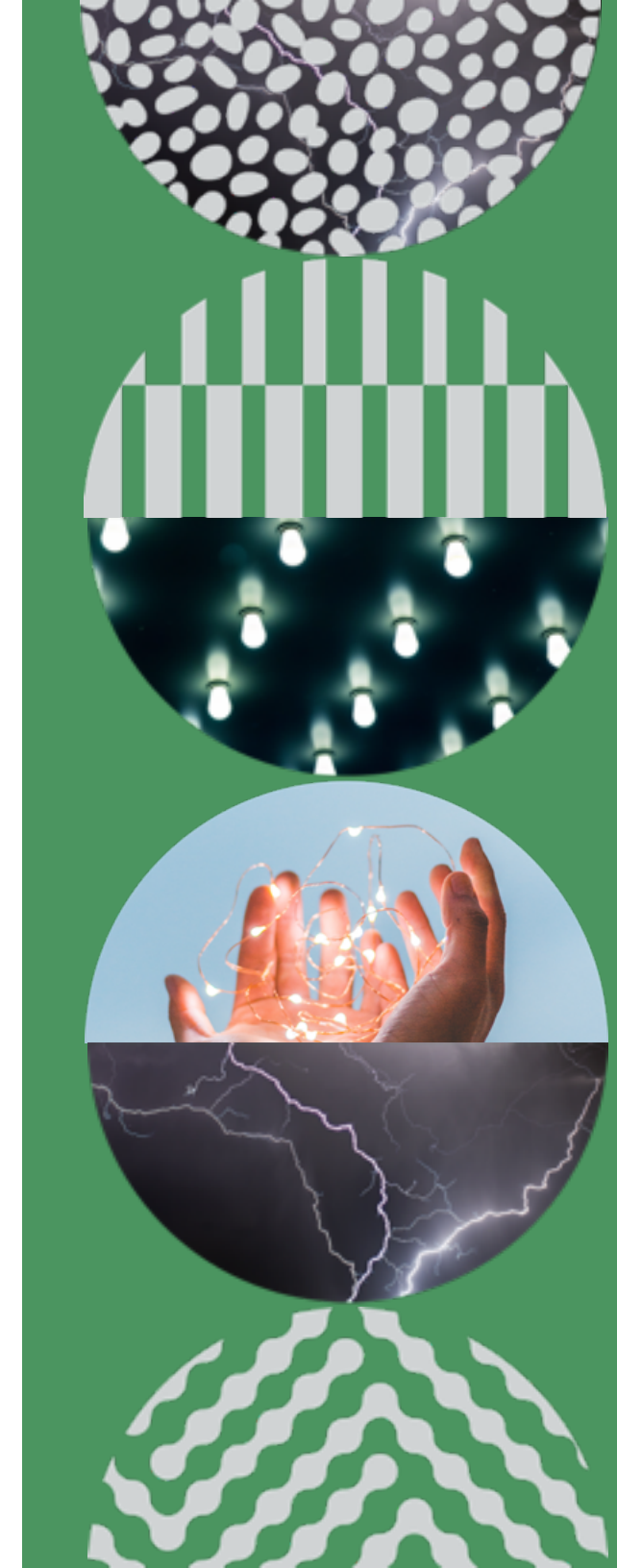
Impacts of Sharing Data

An effective data dissemination strategy that shares information with a wider set of end users has the ability to positively impact a number of different areas and can create new value for society, the economy and the organization sharing the data.

A more open approach to data in the public sector (both governments and agencies) has been found to result in a variety of downstream societal benefits, such as improved participation in and interactions with the government, increased self-empowerment and a greater ability to support one's own physical, mental, and financial wellness, impacting overall quality of life.

Making data more widely available and open also has the potential to generate significant economic benefits. Open data across multiple sectors provides private sector entities with the ability to compare and benchmark themselves against peers, identifying areas where operational efficiencies can be achieved and spurring improvements to productivity. The use of open data and analytics also enables organizations to more effectively understand consumer preferences and identify previously unknown needs, enabling the creation of new and better designed products and services. A McKinsey study found that improving the availability of public data and shared data from private sources in seven sectors (education, transportation, consumer products, electricity, oil and gas, healthcare, and consumer finance) could generate in excess of $3 trillion USD per year in additional value to the global economy.[5]

At an organizational level, benefits include increased efficiency, effectiveness, transparency, deeper engagement with stakeholders and improved public perception. The dissemination of data to a wider audience can also raise awareness of an organization's strengths and capabilities supporting the development of innovative new national and international partnerships and collaborations.

While the creation of a well-designed and effective data dissemination strategy can require significant time and resource commitments, regional and national governments, as well as the private sector, have already recognized the potential benefits of a more open approach to data; many have already instituted their own initiatives and programs.

Goldstein's Data Commons Framework[2] has been summarized into four layers – technology, data and format, institutional and organizational, and human – by the The Global Partnership for Sustainable Development Data:

- The technology layer addresses the standards needed to make data accessible on the Internet;
- The data and format layer focuses on data structures, metadata standards, and vocabularies;
- The institutional and organizational layer covers process standards needed to keep data accurate and consistent, as well as high-level policies such as data sharing agreements ; and
- The human layer emphasizes the need for common understandings among those who produce and use the data.

Together, these layers show the elements that are needed for successful data interoperability.

The Data Dissemination Spectrum

Data dissemination strategies exist on a spectrum from closed to shared to open. However, the data spectrum is not linear, as access to and use of data can be restricted to varying levels within each category.[7]

The Open Data Institute (ODI) defines closed data as data that can only be accessed by its subject, owner or holder. Shared data is subdivided into named access (data shared only with named individuals or organizations), attribute-based access (data available to specific groups meeting certain criteria) or public access (data available to anyone under terms and conditions that are not "open"). Open data, on the other hand, can be accessed, used and shared by anyone.

The openness with which data should be disseminated must align with the underlying data and the purpose for which it is being shared. Data that are shared, but not open, might be restricted to specific groups that meet certain criteria or specific licences. Examples of this are data that require role-based approvals (e.g., epidemiologist, policy makers), or data sharing agreements (e.g., between primary investigators who collected data and secondary researchers who have interest in mining it). Shared data ranges in access, based on the nature of data and organizations. Shared data becomes increasingly closed with the addition of layers of approvals and conditions required for access. Data sharing agreements, data services and data exploration tools work to make data more accessible for a spectrum of shared to closed data by reducing barriers to access, use and understand data.

Closed data, on the other hand, is characterized by restrictions (i.e., technical, legal, institutional) that limit distribution to data users for a variety of reasons (e.g., privacy). In some instances, information extractions can be made from closed data using data exploration tools. Where appropriate, these tools enable data users to extract information in a way that maintains the safety (i.e., anonymity and confidentiality) of data.

While many data dissemination strategies exist, each is associated with its own set of strengths, weaknesses, and ability to meet institutional and user requirements. This report provides a detailed introduction and overview of five data dissemination strategies, their application and associated considerations:

- Open data
- Data exploration tools
- Data services
- Data sharing agreements
- Secure data access programs

Open data makes data available to all users; however, it might not be appropriate for all data types or user skill levels. Data exploration tools aim to improve data users' self-service ability while mitigating risks to data privacy and security. Data services (i.e., offline data user support) reduce knowledge barriers to accessing data. Data sharing agreements provide access to shared data for authorized and approved users. Secure data access programs rigorously control access to data due to the sensitive nature of individual microfile data.

The Data Spectrum
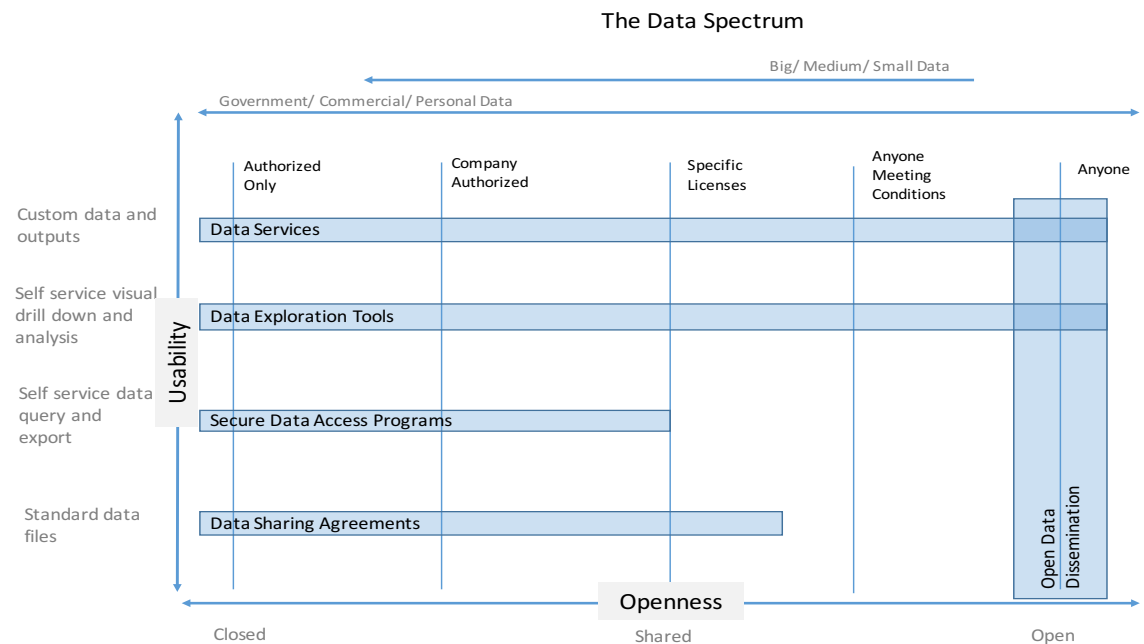
Open Data

Overview

Open data dissemination purposefully releases data in any number of formats for any party's free and non-exclusive use. Usability of data released via an open data approach is primarily limited by the data user's skills and ability. When designed effectively, open data strategies can be applied to any data with little to no privacy or confidentiality risk and can be widely used to create opportunities for innovation in government, industry and society.

Open data is characterized by data that are free to access, use, modify and share, subject at most to measures that preserve provenance and openness.[8] Data are considered open if they are both technically (in machine-readable standard format) and legally (explicitly licensed in a way that permits commercial and non-commercial use and reuse without restriction) available to users.[9] Open data can be held at any level including multinational, national and municipal, and might focus on any number of sectors including finance, health, education, environment and others.

Acknowledging the importance of data availability, primarily governments, agencies and not-for-profit organizations have adopted open data initiatives to make information available to the public to facilitate transparency and accountability, support development and innovation, and improve citizen access, engagement and participation.[10,11,12] Moreover, through the use of open data analytics, organizations are able to uncover consumer preferences that enable the development of new applications and better-tailored services.[13]

Internationally, interest in open data has led to the development and promotion of open data dissemination channels to improve governance and spur innovation. In June 2013, leaders of the G8 (now G7) signed on to the G8 Open Data Charter that recognizes the role of open data in promoting innovation and government transparency.[14,15]

The G8 Open Data Charter underlines five key principles about open data:
1. Release open data by default,
2. Ensure high quality and quantity of data,
3. Make data usable by all,
4. Release data for improved governance,
5. Release data for innovation.[16]

Fifteen different national and international examples of an open data approach to the dissemination of government and/or health data were examined (summarized in Table 1). A comparison of the different open data initiatives identified a number of common features and functionalities that were implemented to ensure that the value inherent to these data sets is easily accessed and used.

The common features and trends in open data examined include:
- Terms of Use and Licensing
- Sectors
- Data Format Classification
- Dissemination Supports (Services and Tools)
- Social Media Presence
- Community Engagement

Jurisdictions with Open Data Reviewed

Program Name	Administrative Level	API Available	Useable Format Assessment	Social Media Presence
European Union Open data Portal	Inter-governmental	✓		
Global Open Data Index	Inter-governmental	✓		✓
Health Data (USA)	National	✓		
Data.gov.ie (Republic of Ireland)	National	✓	✓	
Data.gov (USA)	National	✓	✓	✓
Data.gov.au (Australia)	National			
Open Data Estonia	National			✓
Government Open Data Portal (Republic of Moldova)	National	✓		✓
Kenya Open Data	National	✓		✓
Data.gov.tw (Taiwan)	National	✓		
Open Data (Canada)	National	✓		✓
NYC Open Data	City	✓		✓
Data SF (San Francisco)	City	✓		✓
Open data Catalog (Vancouver)	City			

Open Data: Key Trends and Observations

Term of Use and Licensing

Open data licensing is the cornerstone of an open data dissemination strategy, and must be carefully structured to promote the benefits of open data while limiting liability and risk to the organization releasing the data. Terms of use and licensing impact the legal openness of data, thereby affecting the likelihood of use by audiences. While there are no common approaches to compliance and monitoring of open data licences, principles of open data encourage freedom to access, use, modify and share data.

Seven of the 15 examples provide notice of creative commons, terms of use or jurisdictional open data licences. The remainder did not have explicit limitations to use.

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Data.gov.uk Open Data Portal

Data.gov.uk in the United Kingdom provides open data broadly categorized into 10 categories: environment, mapping, towns and cities, government, society, health, government spending, education, transport, and business and economy.
Over 99 percent of data sets have APIs available to data users. Moreover, to support use of linked data sets, the initiative features 390 third-party developed applications. Any user can submit an application that uses data.gov.uk open data via the associated API.

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Sectors

Open data can be an instrument to address information gaps across industries and allow companies to share benchmarks and spread best practices. Linking data from multiple sources and enabling open access can propel innovation and help organizations to replace traditional decision-making approaches with data-driven ones.

While there are currently no examples of linkages by governments for government-held data sets, there is a trend to expand the variety and complexity of data to include multiple sectors. A number of jurisdictions have made dissemination tools that support linkages between data they expose and those existing in other data sets, nine of 15 examples examined provide links to third-party developed applications to link, visualize or interpret data. In the context of open data, linked data is possible by publishing unstructured data that can be associated. Provided that no data sets being linked have identifiers, data sets can be related with no increased risk to personal privacy.

Application Program Interfaces (APIs) support the development of applications that use, manipulate and interpret open data sets. Jurisdictions that do not provide linked data can provide APIs to support third-party development of applications that link data. Using these APIs, there is a trend toward using resource description frameworks to expose data over the web so that it can be linked and queried.

Open Data: Key Trends and Obervations

Data Format Classifications

There are no standard minimum requirements for "machine-readability".[17] Moreover, data that are not in a machine-readable format (and therefore technically inaccessible) are limited in impact and usability. Rating the openness of data provides an empirical and high-level method to quantify the openness of open data. The most widely adopted scale for rating the openness of data is the five-star deployment scheme for Open Data.

One Star

Available on the web in any format with an open licence (e.g., image scan)
- User benefits:
  - Can be viewed, printed, and stored locally
  - Data can be entered into another system and changed
  - Data can be shared
- Publisher benefit:
  - Simple to publish

Two Stars

Available as machine-readable structured data (e.g., Excel)
- User benefits:
  - All one star benefits
  - Ability to directly process data with proprietary software
  - Ability to export into other structured formats
- Publisher benefit:
  - Simple to publish if readily available

Three Star

Available in machine-readable, structured and non-proprietary formats (e.g., CSV)
- User benefits:
  - All two star benefits
  - Ability to manipulate data without owning proprietary software packages
- Publisher benefits:
  - Simple to publish if readily available
  - *May require conversion from proprietary formats

Four Star

Allows use of Uniform Resource Identifiers to denote data so others can make reference
- User benefits:
  - All three star benefits
  - Ability to link to it from other places on the web or locally
  - Ability to bookmark
  - Ability to combine data safely with other data.
- Publisher benefits:
  - Fine granular control over data items and can optimize access (e.g., caching)
  - Other data publishers can link to data

Five Star

Linked data to other data to provide context
- User benefits:
  - All four star benefits
  - Ability to discover related data while consuming data
  - Ability to directly learn about the data schema
- Publisher benefits:
  - Data more easily discovered, thereby increasing the value of available data
  - Organization gains the same benefits from any data linkages made by consumers

Open Data: Key Trends and Observations

Dissemination Supports (Services and Tools)

Services provided to data users are a fundamental component of many successful open data strategies and can include tools, training and other applications that promote data dissemination. Dissemination support and services enable the use of data and work to mitigate misuse and misinterpretation.

The type of services and tools offered range widely from how to link data sets, education regarding research methodologies and standards through to links to readily available third-party applications. Linked third-party applications include data visualization tools, linked data sets, and tools to support analysis and interpretation of data. Training is also provided through many channels (e.g., worksheets, e-learning modules, in-person workshops) and cover a variety of topics, including data privacy, API use and data analysis.

Of the 15 data jurisdictions examined, 14 provided a minimum of one service, tool or support for open data use and dissemination. Of the 14 examples, 12 provided API developer supports or links to third-party-developed applications; two jurisdictions provided training beyond application development.

Community Engagement

BLOGS AND FORUMS

Blogs and community forums are used to provide detailed information on open data initiatives and support active engagement with stakeholders. They are also used to provide detailed reports on data availability, data use and updates to initiatives. Blogs drive traffic to websites by increasing the number of indexed pages. Topics covered can include detailed information and instruction on use of available data, updates regarding improvements to data sets and the data catalogue, changes to policies that affect the open data initiative, and best practices on the use of tools and services provided by the initiative.

Community forums were used to engage data users in the detailed use, manipulation and interpretation of data. Community forums in jurisdictions with open data dissemination strategies provided a platform to support interaction among users. These community forums were provided on the same site as data catalogues, increasing visibility as well as use. Messages submitted by forum users are available for public viewing. Common topics include comparisons and free discussion about use and interpretation of available data. All forums required registration to participate, and agents of the open data administration provided moderation. Four of 15 open data dissemination catalogues reviewed featured community forums.

MEETINGS

Open data can be promoted through complementary and innovative approaches, including events and technology support, to promote collaboration, increase visibility as well as innovative use of data. Conferences, summits and other in-person meetings provide an opportunity to discuss barriers in the field, identify opportunities for collaboration and design collective solutions. While many jurisdictions support online collaboration, one organization hosts regular in-person collaboration events.

Making APIs available for data sets within data catalogues provides the opportunity for innovation and development of data exploration tools in developer and stakeholder communities. Five of the 14 had APIs available for developers, and 10 of 15 advertised or linked applications developed by third parties on the website of the open data initiative.

SOCIAL MEDIA PRESENCE

While data itself is not posted on social media, this medium has been used as a channel to inform audiences and users of new data sets, publications or opportunities to participate in data use. Eleven of the fifteen jurisdictions examined utilize a minimum of one social media platform.

Data Exploration Tools

Overview

Data exploration tools support the controlled dissemination and use of data by allowing users to access aggregate level data using specifically designed tools aimed at supporting the data user's self-service abilities.

The usability of data exploration tools is affected by their suitability for their target audience. A well-designed user interface and the availability of appropriate supporting reference materials can greatly improve uptake and use of data available through data exploration tools.

These tools can be used where reporting of aggregate level data does not pose a risk to the privacy or confidentiality of data, and where the information required can be generated via descriptive and exploratory data analysis rather than more complex processes.

Data exploration tools (e.g., online analytic processing tools (OLAP) or data cubes) enable users to analyze multi-dimensional data interactively and from multiple perspectives. Data inputs into these exploration tools can come from a variety of sources including open data and sensitive data held in central repositories. The basic functions of data exploration tools (e.g., for data cubes: slice, dice, drill down/up, roll up) limit complex analysis, but provide an opportunity to share data from non-open sources in a controlled manner and ensure the privacy and protection of personal information.

Data exploration tools take a variety of forms to increase the self-serving abilities of data exploration tools for users. Online analytic processing systems often present as data cubes that consist of numeric measures categorized by dimensions. Data exploration tools can also output visual formats such as maps or graphs. Many data exploration tools require an understanding of data use and analytics. In some instances, complex data can be presented with interpretations in the form of analytical publication or analytic reports.

Data exploration tools are capable of minimizing the demand of minor data requests on organizations and improve data users' self-service abilities through the reduction of approvals processes otherwise required to access data sets. As a result, data exploration tools can provide a means through which to achieve the outcomes of open data without risking privacy or personal information.

Organizations might require permission to access data sharing tools to ensure the skill level and potential purposes of data use and to mitigate data misinterpretation and misuse. Data exploration tools vary greatly in format, and skills required to use and interpret data.

Six data exploration tools were reviewed for this scan; the common features of each that were further examined include:
1. Types of data
2. Usability (including format of output and support services to support the format of output)

Jurisdictions with Data Exploration Tools Reviewed

Program Name	Jurisdiction	Type of Data	Format of Output	Support Services Available
Canadian Health Institute for Health Information	National (Canada)	Administrative Health Databases, Hospital Registries	Interactive Reports, Analytical Tools, Analytical Publications	Support request form
Public Health Ontario	Ontario	Health Services, Infectious Disease, Environmental Health, Health Behaviour, Infectious Disease, Injury and Substance Misuse, Lab-based data	Interactive map-based dashboards, dynamic data exploration query tool, Decision support tool	Support request form
Better Outcomes Registry and Network Ontario	Ontario	Administrative data	Data Cubes	Peer-reviewed publication library
The Canadian Atlas of Child and Youth Injury Prevention	National (Canada)	Survey, administrative data	Time graph of potential years of life lost, interactive dashboards map-based dashboards	Administrative Health Databases, Hospital Registries
Insitute of Health Metrics and Evaluation	Multi-national (USA Lead)	Survey, Administrative health data, disease registry	Analytical Publications, Data visualization tools	Help page Methods and process page
Authoritative information and Statistics to Promote Better Health and Wellbeing	Australia	Administrative Data, Health Survey, Disease Registry, Nursing Minimum Data Set	Data Cubes	None

Data Exploration Tools: Key Trends and Observations

Type of Data

Data exploration tools can use administrative, electronic health records, health survey, disease registry and claims data. Data exploration tools examined reported metrics at an aggregate level, and suppressed values that could lead to deductive disclosure. In this manner, findings from data that would have been otherwise accessible only through rigorous approvals are made public.

> ### Exploring Canadian Institute for Health Information Data
>
> Canadian Institute for Health Information provides an Indicator Library that contains an alphabetical list of indicators and associated definition, description, interpretation in plain language, geographic origin and coverage, reporting level/disaggregation and Health System Performance Measurement Framework. Information was consistently and accurately used throughout data exploration tools and also readily accessible while in use. Canadian Institute for Health Information's wait time interactive report allows comparison of like indicators across jurisdictions in colour-coded bar graphs.
>
> Canadian Institute for Health Information data holdings span all Canadian jurisdictions. Data used in Canadian Institute for Health Information data exploration tools include hospital care, community care, specialized care, pharmaceuticals, patient & safety, health workforce, spending, international comparisons, access & wait time administrative data.

Useability

Data exploration tools are affected by ease of access, which can be influenced by technological limitations, institutional limitations, and the availability and quality of accompanying information. Support services, including guidance documents and functionalities, can improve the usability of data exploration tools. The usability and subsequent value of a data exploration tool is defined by the design of its interface as well as the availability of guidance documents or training. Successfully adopted applications are aimed at a specific audience rather than a one-size-fits-all approach and tailor the data and features available to meet their needs. Many employ user experience design and undergo multiple user testing cycles to ensure effective user-tool interaction and navigation. A user-friendly and well-designed interface can enable intuitive use of a tool, enhancing its utility to the target audience.

User accessibility to data can be limited by the highly technical nature of some data exploration tools. Data analytic technology without training increases the likelihood of mismanagement and misinterpretation of data; despite the nature of these tools, organizations generally do not offer additional services to support users. Those that do provide data users with information on how to use the tools and interpret data outputs of data exploration tools. This ensures the effective dissemination of data holdings held in data exploration tools.

Data Services

Overview

Data services provide a means by which data users can access, understand and extract value from data that would otherwise be technically or legally unavailable to them.

Data custodians or stewards typically provide data analysis services to data requestors from a variety of backgrounds.

Data services are used in situations where analysis of secure data is required by organizations not approved for its use, but where the results of the analysis can internally or externally disseminated and used.

For a variety of reasons, data users might not have the access, time or background required to obtain, analyze and interpret the complex administrative, linked survey or administrative data sets. Data services (available through offline consultation and support) provided by custodians, stewards and owners of data provide a means to use this otherwise unattainable resource. Data requesters work with the data holder's agents to negotiate and purchase data services. Data holders, with appropriate access to the data holding, access, analyze and interpret the data on behalf of the data requestor. Data services facilitate the analysis and interpretation of data and might include data set creation, analysis and reports.

Data service programs require formal data requests outlining the research to be completed, the rationale for the request, the data required and the justification for use of this data. Requests are then reviewed by a board, prior to proceeding with the project.

Timelines and turnaround time between request and analysis are often a limitation to data service requests. Depending on the nature of the data (e.g., health data), privacy risks might require multiple approvals (e.g., ethics, institutional) that can be onerous or time consuming to obtain. For health data services in Canada, there are regulations in security, privacy and use among provincial or territorial health systems, as well as differences in governance structures between jurisdictions; data services are predominantly held at the provincial level. Six data service programs in Canada, and two international jurisdictions, were reviewed for this scan.

Common features of data services examined include:
1. Type of data available
2. User and community restrictions
3. Data procressing and services provided
4. Additional Training
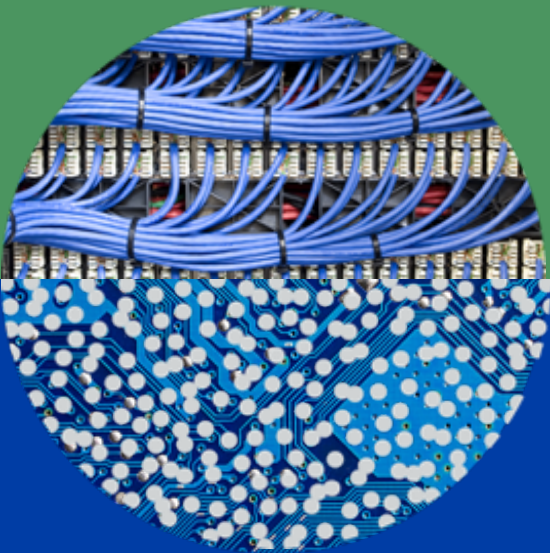
Jurisdictions with Data Services Reviewed

Program Name	Jurisdiction	Type of Data	Services Provided	Data Owner/ Custodian	Approved Uses
Canadian Health Institute for Health Information	Canada	Comparable, pan-Canadian health data	Sampling; De-identified record-level clinical and administrative data; Identifiable data – with approvals.	Owner and Custodian	Academic, hospital-affiliated researchers, government, publically-funded non-profits only
Institute for Clinical Evaluative Sciences	Ontario	Comprehensive linked, encoded Ontario health-related data	Research-ready linked health administrative data and analytic tools; Data set creation; Data Analysis and Reports.	Custodian	Academic, hospital-affiliated researchers; limited services for private sector
Ontario Cancer Data Linkage Project	Ontario	Administrative data related to cancer health services research	Data set creation of research-ready linked and de-identified data.	Custodian	No commercial interests
Manitoba Centre for Health Policy	Manitoba	Administrative health and health-related data of Manitoba health and agencies	Data extraction, processing, and analysis. Physical workspace and computer.	Custodian	Project-by-project basis
Population Data BC	British Columbia	Individual-level de-identified longitudinal data	Linked administrative research data; Consultation on data needs and data analysis plans; Data preparation; Data Analysis	Custodian	Academic and government only
Analytical Services - UBC Centre for Health Services and Policy Research	British Columbia	Access to Population Data BC Data catalog	Consultation on data needs and data analysis plans; Preparation of data for analysis; Data analysis; Preparation of data for analysis; Data analysis ; Research	Custodian	Academic and hospital-affiliated research or students only
UK Health and Social Care Information Centre	United Kingdom	Information, data, and IT systems for health and social care	Data set preparation. Data extraction, tabulations, status and tracking.	Custodian	Requests reviewed by independent data access advisory group
Mount Sinai Hospital (NY) Data Warehouse	USA - Private Organization	Clinical, operational, financial data	Data set preparation. Data analysis.	Owner and Custodian	Affiliations with the Teaching Hospital and approved projects only

The Data Dissemination Spectrum

Data Services: Key Trends and Observations

Type of Data

While the data holdings in the reviewed examples primarily store and link administrative health data sets, some are able to incorporate data from other sectors (e.g., demographic data) or jurisdictions to bridge information gaps. Leading data services integrate education, justice welfare and other data sets to better understand the social determinants of health and early indicators of disease for surveillance and intervention., Access to data from extra-jurisdictional sources and linkage to data from local sources typically requires multiple approvals, which increases the time it takes for analysis. Despite current barriers to making data from other sectors available, the value of coordinating monitoring and interventions is more timely and cost effective.

User Community and Restrictions

Across the organizations and examples examined, government (to support policy-focused research and to inform decision-making) and academic researchers are the primary users of data services. To safeguard the privacy of data, many data services restrict access by private, for-profit organizations. While restriction of the user base for data services is intended to protect data, it minimizes the value of the data and impact of the services provided. To further safeguard the data, several organizations have implemented service review processes or other mechanisms, such as anonymization or separation of data service providers into separate corporate entities with differing access to information

Data Services: Key Trends and Observations

Data Processing and Services Provided

Data services can range from basic data extractions to complex analytics (including descriptive, predictive and prescriptive analytics), as well as interpretation and review of publications using the data. Beyond providing access to data, data services provide technical expertise required to understand complex data. In this manner, data services provide technical abilities to organizations or researchers that would not otherwise have it.

For the majority of jurisdictional examples reviewed, data service providers work with the data requestor to determine the project's precise needs. Service providers then perform data set extractions and build data sets for these specific projects. Data holders process the data to suit the data requestor's needs while complying with security, privacy and ethical standards. Information that could result in an individual's identification is separated from the content data. Identifying information is replaced with a random code identifier to enable linkage. Data sets are stored in a central repository, with extractions made as required for approved projects.

Depending on the service agreement, service providers might also be responsible for linkages to other data sets, a range of analysis and report generation for projects. Service needs and costs for projects are determined on a case-by-case basis. Cost for access and analysis depends on the institution. While some institutions bill based on request type and complexity, others bill based on time and the requestor's organization category. Consultations are available to discuss potential cost of data and analytic services.

To complement data services, organizations might offer additional services such as training and dissemination tools to enhance the understanding and use of data in a research setting. Types of additional services included education regarding available data sets, research methodologies and standards, data use and ethics, and data reporting. Training is provided through many channels including web-based, e-learning and in-person workshops.

Data Services at The Institute for Clinical Evaluative Sciences

The Institute for Clinical Evaluative Sciences (ICES) data holdings can be made available to academic and hospital researchers or students, publicly funded not-for-profits and policy makers, and for use in development of evidence-informed policy and practice. Recently, ICES has begun to provide data analytic services to private sector researchers. Under this initiative, private sector organizations (that have received ethics approvals) can request results reports that include statistics, such as the total number of people identified as having a condition in Ontario at a specific time or the number of hospitalizations associated with a condition. ICES staff will perform the analyses that generate these results reports. ICES will not provide analytic services for studies primarily or solely for commercial purposes.

Data Sharing and Data Partnerships

Overview

Data sharing agreements through contracts or partnerships provide authorized institutions and individuals with access to secure data collected or generated by other organizations. Data sharing agreements might include a variety of conditions and supports that affect their value to a recipient organization. In general, data sharing agreements provide raw data, limiting usability to individuals or organizations with the relevant technical and analytic skills.

Data sharing agreements are generally utilized to obtain and use data that is unique, requires high privacy and security, and that is not intended for widespread dissemination.

Data sharing is used to make data collected for research available to others for further analysis or use for collaborations or independent research. Although supplemental information that is necessary to understand or reproduce findings is often required by funding agencies and peer-review journals, data sharing is at the discretion of the data owner.

Data sharing agreements are important as unique data (which is often onerous or difficult to obtain) cannot be readily replicated. Data sharing, conducted properly, reinforces open scientific inquiry, encourages diversity and methods of analysis, supports multiple studies on data collection methods and measurements, and enables exploration of topics outside the expertise of initial investigators. Moreover, data sharing agreements permit the creation of new data sets when data from multiple sources are combined.

Due to the high flexibility and variations among data sharing agreements, and that data sharing agreements are negotiated on a case-by-case basis based on organizational regulations, data owners and users are able to determine agreements that best suit the projects' needs. The drawback of the high degree of flexibility is that data sharing agreements often undergo many iterations to meet all organizations' needs. Moreover, the ad-hoc nature of data sharing agreements results in a lack of coordinating structure and catalogue of data holdings within or across jurisdictions. As such, awareness of data collected might limit access to, and dissemination of, data.

There are no minimum standards to what and how data are shared in data sharing agreements. Researchers often cite intellectual property or confidentiality concerns around data that prevent sharing.[18] This might be attributed to an individual sense of ownership and publication rights over data. Consequently, there is repetition and overlap of data collection efforts. This increases the burden of research on participants, research teams and funding agencies. Considerations must be made when organizations interested in sharing data that are held by an organization that is not the data's primary or sole owner or custodian. While this does not limit data sharing, it contributes to the complexity of data sharing agreements due to approvals required from all stakeholders and data owners. In the absence of overall governance, standards or requirements, methods of handling data sharing and approvals vary by organization.

When data are shared, the resulting data sharing agreements negotiated between data owners and data users can vary greatly. This scan examined seven data sharing agreement guidance documents, templates and reviews that address data concerning health or personal information.

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Data Sharing and Data Partnerships Reviewed

Source Program	Jurisdiction	Article Type	Data Type
Data Sharing to Advance Global Public Health: Ethical Challenges and a Principled way Forward	International	Meta-analysis (n=26)	Health Data
Data Sharing: Creating Agreements	USA	Guidance Document	General Data
Sample Inter-Agency Data Sharing Agreement	USA	Template	Health Data
Treasury Board of Canada - Guidance of Preparing Information Sharing Agreements Involving Personal Information	Canada	Guidance Document	Personal Information
Information Sharing Agreements for Disclosure of EHR Data within Canada	Canada	Jurisdictional Scan and Guidance Document	Health Data
Toronto Agencies and Clients integrating Care to End Chronic Homelessness	Toronto	Guidance Document	Health Data
Toronto Central LHIN Data Sharing Guidelines	Toronto	Guidance Document	Health Data

A review of the documents identified a number of common components and elements present in data sharing agreements (frequency indicated in parentheses):
- Applicable Reference Legislation (5)
- Purpose of Data Sharing Agreement (5)
- Processes for Privacy, Confidentiality, and Disposal of Data (5)
- Description of Data to be shared (4)
- Data users (4)
- Custodial Responsibility (4)
- Signatories (3)
- Consent and notices (3)
- Limitations to Data Use (3)
- Method of sharing (3)
- Background (2)
- Period of Agreement (2)
- Justification for Access (2)
- Resources and Costs (2)
- Risk Assessment (2)
- Conditions that trigger agreement reviews (1)

There are no federal, provincial or sector authorities on data sharing agreements, nor a consistent framework, guidance or method. As a result, the contents and format of data sharing agreements are at the discretion of the data owner and data requesting institutions.

Secure Data Access Programs

Overview

Secure data access programs provide approvals-based access to securely held data. The usability of secure data access centres varies based on the data user's skills and abilities as they typically only provide access and lack analytic support or other associated services. Secure data access program can be used for data that would otherwise be inaccessible due to legal, institutional or privacy restrictions.

Secure data access programs can be comprised of physical and/or secure web-based locations that provide data users with access to data in a controlled setting. Data held in secure access centres are sensitive in nature due to the availability of individual-level and identifiable data. While this allows users to work with data at a granular level and link it across a variety of data sets, the process requires a high level of security to ensure privacy and confidentiality.

Data holdings in secure data access programs are not always owned by the organization providing the service and might come from a variety of sources. Depending on the level of approval required for data collection projects, data added to secure data access programs can be treated differently (e.g., level of de-identification, terms of use). Specific projects might require removal of identifying information prior to storage, linkage and use in these programs.

Secure data access programs with physical locations allow qualified users to analyze the data using statistical software. In these physical environments, potential risks to data security and privacy are minimized through control of the environment and removal of devices (e.g., phones, memory sticks, cameras, pen and paper) that could copy, download or disseminate the data in any way. Facilities are protected by multiple firewalls and data are stored centrally on servers located in high-security data centres with strict access controls and security surveillance.

Remote access (i.e., web-based access) risks are mitigated through data processing and security around computing environments. To use data remotely, data users write and send queries into the secure data sets held by secure data access programs. The queries are processed and produce outputs that are then retrieved by the data user.

Other models, limited by jurisdictional and data governance policies, maintain data holdings with original data owners and stewards. These programs facilitate researchers' data access and use by pulling the relevant information directly from the source rather than a central repository. This provides a single point of entry for both data users and data providers.

Due to regulations in security, privacy and use, as well as differences in governance structures between national jurisdictions, secure data access programs from two jurisdictions were reviewed and compared to Canada's Research Data Centres.

Common features of data access programs include:
1. Security features and control mechanisms
2. Dissemination support features including training and services

Jurisdictions with Secure Data Access Programs Reviewed

Program Name	Jurisdiction	Type of Data	Data Owner	Central Data Holding	Physical Locations	Remote Access	Project Based Access	User Certification Requirements
Canadian Health Institute for Health Information	Canada	De-identified Administrative Health Data			✓	✓	✓	✓
Institute for Clinical Evaluative Sciences	Ontario	Disaggregated microfile statistics data	✓	✓	✓	✓	✓	✓
Ontario Cancer Data Linkage Project	Ontario	Linked health data	✓	✓		✓	✓	✓

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Secure Data Access Programs: Key Trends and Observations

Security Features and Control Mechanisms

Due to the sensitive nature of individual-level data, secure data access programs invest in numerous measures to safeguard data including:

- Intensive criteria and training for data users to become eligible for access
- Rigorous and individualized review processes for access requests
- Pricing structures to encourage minimal data susceptibility
- Staff to process and build data sets for users in a way that minimizes risk
- Review and vetting of analyzed data and completed findings

All three secure data access programs reviewed provide access to secure data for qualifying and approved data users on a project-by-project basis. Data users are required to undertake training in privacy and ethics, receive certification, and meet security requirements. In one examined jurisdiction, only researchers of accredited and approved universities or equivalents can request access to data.

Programs reuire a formal request outlining the research to be completed, the rationale of the request and data required. Data centres do not provide support services to facilitate drafting of requests. Review committees, comprised of academic, research ethics, legal and privacy experts, scrutinize the project proposal to ensure that the project meets specific requirements, and that all requested data are in fact required for the project. All secure data access programs reviewed and approved data access on a project-by-project basis.

All pricing structures encourage minimal exposure and use of data. Users purchase access, based on their type of organization purpose of data access and skill level. Using a tiered pricing model, lower risk data users, including students for the purpose of academic research, and government agents are provided with more economical solutions. Programs can also structure fees for access based on type and amount of data use.

In two secure data access programs, staff build data sets for user analysis using the minimum number of variables required for the project. This approach reduces the risk to privacy by minimizing the type and amount of data available to only that which is required to answer the proposed research question. Within the secure environment, a complete audit trail of all information and entries is maintained. Once a research project is complete, the data set created for that project is securely destroyed.

In physical secure data access points, results of data analysis are reviewed and vetted for privacy, sensitivity and security prior to leaving the location for interpretation or reporting. Moreover, any articles, papers or materials developed as a result of data analysis done at secure data access programs are examined and cleared by the program staff prior to publication.

Dissemination Support Features

While training and support services provided to data users are not a fundamental component of secure data access programs, two jurisdictions offer training through partner organizations beyond that which is mandatory for privacy, security and ethics needs. Training courses include general methods as well as specific topics and data sets available in the data holding.

Data Dissemination Strategy Considerations

Data dissemination strategies explored in this scan differ in strength and each is associated with a set of unique limitations. While many function to support participation by a variety of users and sectors, others work to minimize risk to data privacy and security. As a result, the opportunity exists to combine strategies to balance the protection of privacy, sensitivity and confidentiality of data while supporting effective use.

The review of the five strategies in this scan surfaced a number of common considerations that an organization must make when selecting and designing an appropriate data dissemination strategy including:

- Privacy and confidentiality
- Timeliness
- Usability and training
- Engaging the audience

Privacy and Confidentiality

Stripping data sets of personal identifiers (e.g., name, address, contact information) is the first measure to ensure the privacy of data subjects in any data set. Furthermore, indirect identifiers that could lead to deductive disclosure such as small sample sizes or unusual characteristics of occurrences must also be carefully considered. Samples drawn from specific sub-populations, geographic areas and linked data sets (association of data to one individual, thereby increasing the risk of identifying individuals) can present challenges to the protection of subject identities. Many data dissemination strategies undergo suppression of values in an effort to minimize risks to privacy.

Access to data is hindered by various legal structures and differing interpretations of the terms identifiable and de-identified across jurisdictions. Instead of rigidly classifying data as either identifiable or non-identifiable, identifiablility can be considered as a continuum and access can be controlled accordingly.[19] One spectrum for consideration in data dissemination includes the range aggregate, depersonalized, personal non-confidential/non-sensitive, personal confidential/sensitive, confidential.[20] Risk management strategies must be proportional to and appropriate for the risk.

While privacy applies to the individuals within a data set, confidentiality pertains to the data itself. As data and data holdings might take a variety of formats across data dissemination strategies and jurisdictions, ensuring that all data are handled, transferred and used in a manner that maintains confidentiality is important to ensure ongoing confidence in data sharing and use.

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Usability and Training

Statistical data should be presented in a manner such that the main results are understandable absent any expert knowledge of statistics and in a form that ensures correct interpretation and meaningful comparison. Usability depends greatly on data users' skills and proficiencies. As such, data dissemination strategies must be tailored to specific audiences. Format impacts usability, and can be supported using support tools such as guidance documents, training and individual support mechanisms.

Training and support services are complementary to all data dissemination strategies and enable data users to minimize the risks of data misinterpretation and misuse. Training can also be tailored to data users' varying skill levels. Certification programs can be used as incentives to participate in data use training, while at the same time ensuring that users meet a minimum standard of knowledge and technological proficiency when using and interpreting the data. Where possible, compliance measures and enforcement (such as vetting data outputs prior to use and publication) can be used to manage and mitigate potential misuse of data.

Timeliness

The value of data often depends on timeliness, with the specific timeframe influenced by the nature of data collected. While data from smaller studies can be analyzed and disseminated relatively quickly, data from large epidemiological or longitudinal studies are collected over several discrete time periods or waves. In the latter scenario, it is reasonable to expect that data would be released in waves as data become available. In disseminating data, every effort should be undertaken to ensure that data are as timely as possible, and dissemination of meaningful data is not hindered by prolonged exclusive use.

Engaging the Audience

Awareness of data availability has direct impact on users and potential users of data. While social media is not an appropriate method of data dissemination, social media platforms can be used to raise awareness of changes to data catalogues and updates to data or data dissemination strategies, and to highlight and demonstrate uses of data. Many jurisdictions reviewed in this scan use social media platforms to increase awareness of and engagement with open data initiatives. In Canada, 69% of the nation's population is active on social media, with activity growing by 3% in 2013.[21] Fifty-nine per cent of Canadians use Facebook, 30% use LinkedIn, 25% are on Twitter and 16% use Instagram.[22] The broad reach of social media and high penetration rates into Canadian society provide an easy and near real-time mechanism that can be leveraged to raise awareness of available data and better engage with the public at large.

Other engagement methods might include active, in-person engagements. Events such as conferences or hackathons provide an opportunity to share innovations in data dissemination and use or develop a platform for feedback on data dissemination. Hackathons, which are often short events that address single issues, bring together innovators to crowdsource the development of an approach to a topic or to answer a question. Challenges (i.e., longer-term competitions) provide similar benefits to hackathons; however, they allow for more in-depth exploration and refined outputs that respond to the issues identified for the challenge. All described events have the added benefit of increasing connectivity and collaboration between and among stakeholders. For engagement events that include use of data, consideration must be given to how the data are provided to users to ensure that data are available in a format that is appropriate for the context.

Conclusion

Open data is only one of a number of strategies and approaches that can be applied to extend the value and increase the usage of an organization's data holdings. In general, there is no single data dissemination approach that can generate value equally to all end users. The selection and application of a data dissemination methodology requires balancing many factors, such as an organization's values and objectives, the mode and technical feasibility of data sharing, and the type and level of support that can be provided to end users. While there are a number of criteria that must be considered when selecting a data sharing approach, two important considerations are the type of data to be shared and the target audience for the data.

The type of data to be shared plays a large role in determining the optimal dissemination strategy. The volume, content, sensitivity and format of the data determine whether the data can be shared and consumed in an open fashion or whether there is a need for the implementation of security protocols or other types of access control. Moreover, the sources, associated terms of use and licensing restrictions inherent to the data can directly affect the mechanism by which data can be disseminated.

Another critical component in the selection of a data dissemination strategy is the identification of the target audience segment(s) or intended end users of the data. Each audience segment will have a different purpose or objective for the data as well as varying levels of technical sophistication.

Prioritization of a target audience segment, combined with analysis of that group's needs and how data can meet those needs, is critical to ensuring the selection of an effective data dissemination strategy. A one-size-fits-all approach, while convenient, might not have the desired impact across multiple segments. For example, while an open data approach where users can freely download and analyze large data sets will be of value to the research community or data innovators, this approach and the format of the data might not be easily consumable by a non-expert audience. It is therefore important to identify the end user(s) and select an appropriate approach (including the provision of support mechanisms) to ensure that the target group is able to extract maximum value from the shared data.

As the proliferation of data continues to grow, there is a significant opportunity for data owners and stewards in Canada to consider strategic enablers for delivering information to a wider set of stakeholders in Canada and globally. New insights developed from improved data accesses will serve to advance healthcare, improve outcomes, spur innovation, increase transparency, and engage policy makers, citizens, and consumers in evidence-informed decision-making.

Annex 1: Methods and Limitations

Multiple sources informed the research phase of this review document. A preliminary global environmental scan and long list of data dissemination strategies applied to health and other sectors in comparable jurisdictions was compiled under the advisement of content experts and consultations with stakeholders in the public and private sectors.

Using a number of criteria, and further consultation with stakeholders and content experts, this list of data dissemination strategies and associated jurisdictional examples was distilled to the five strategies detailed in this report.

Sources:
1. Academic and grey literature: Taking a broad approach to the literature provided local, regional and international perspectives on data dissemination methodologies and associated strengths and weaknesses. Academic and grey literature were collected through hand-searches, while additional sources were volunteered by key informants and content experts.

2. Content experts: Experts in data access and use in the health, public health, and other sectors were consulted on current and past dissemination of data sets, and exemplar cases of applications of data dissemination strategies.

3. Jurisdictional websites: To inform how other jurisdictions have approached data dissemination, websites of jurisdictions employing identified data dissemination strategies were reviewed for common characteristics, leading practices and emerging trends.

Each dissemination strategy presented in this report includes a description of the strategy, as well as trends and observations identified through a review of relevant national and international examples. A summary table for each strategy provides key information for each example reviewed, as well as trends and other relevant observations. While the options highlighted in this report for each strategy are not a comprehensive list of all global examples, they do represent successful or unique models.

Moreover, few data dissemination strategies are formally evaluated. As such, this jurisdictional scan does not include assessments of reach, impact, user participation, audience penetration or user experience. When selecting and designing a data dissemination strategy, it is important to also consider and evaluate these factors through further study and qualitative assessment.

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Acknowledgements

Karen Deng
MaRS Discovery District

Shahab Shahnazari
MaRS Discovery District