Modernize the Healthcare System: Stewardship of a Strong Health Data Foundation

Modernisation du système de santé : la gérance de solides sources de données sur la santé

COMMENTARY

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ABSTRACT

The Canadian Institutes of Health Research – Institute of Health Services and Policy Research (IHSPR) has published its Strategic Plan 2021–2026 *(CIHR IHSPR 2021) and, as members of the Expert Advisory Group for a Pan-Canadian Health Data Strategy, we are providing commentary on the second strategic priority of IHSPR's Strategy related to health data and digital health. Systemic barriers have prevented the timely and effective collection, sharing and use of health data in Canada. Many of these systemic barriers relate to the fragmented health data foundation, lack of coordinated data governance and a risk-averse culture. As IHSPR mobilizes its strategic plan, it will be important to consider and address these factors head-on to contribute to a stronger health data foundation that would help achieve both IHSPR's strategic objectives and meaningfully contribute to elevating Canada's health data ecosystem.*

RÉSUMÉ

L'Institut des services et des politiques de la santé (ISPS) des Instituts de recherche en santé du Canada a publié son Plan stratégique 2021-2026 *(CIHR IHSPR 2021) et, en tant que membres du comité consultatif d'experts pour la Stratégie pancanadienne de données sur la santé, nous commentons la deuxième priorité stratégique du Plan relative aux données sur la santé et à la santé numérique. Des obstacles systémiques empêchent la collecte, le partage et l'utilisation opportuns et efficaces des données sur la santé au Canada. Bon nombre de ces obstacles systémiques sont liés à la fragmentation des sources de données sur la santé, au manque de gouvernance coordonnée et à une culture d'aversion au risque. Alors que l'ISPS déploie son Plan stratégique, il est important d'examiner et d'aborder ces facteurs pour favoriser des sources de données sur la santé plus solides qui permettraient d'atteindre les objectifs stratégiques de l'ISPS et contribueraient à améliorer l'écosystème des données sur la santé au Canada.*

Introduction

The Canadian Institutes of Health Research – Institute of Health Services and Policy Research (CIHR IHSPR) has published its *Strategic Plan 2021–2026* (CIHR IHSPR 2021). We were asked to provide commentary on the second strategic priority of this strategy – modernizing "the health care system with digital health solutions and data science" (CIHR IHSPR 2021: 14) – from our perspective as health data researchers and as members of the Expert Advisory Group (EAG) for a Pan-Canadian Health Data Strategy (PCHDS) (Government of Canada 2021d).

We are excited by the boldness and strength of the strategy that IHSPR has put forward. In particular, we are excited to see the emphasis on adopting the Quadruple Aim as a consistent method of evaluating health systems and improving health equity, driving digital health solutions, enabling aspects of a learning health system and building health workforces to support the digital age.

From the work that we have done on the PCHDS, there are some lessons and learnings that will be relevant for IHSPR as it gets its work under way. Specifically, we note systemic barriers that have prevented the timely and effective collection, sharing and use of health data in Canada – many of which were made more apparent during the pandemic.

The majority of these systemic barriers relate to the fragmented health data

foundation, a lack of coordinated data governance and a risk-averse culture. As IHSPR mobilizes its strategic plan, it will be important to consider and address these factors head-on to ensure IHSPR's success and to contribute to the permanent remediation of those barriers to support Canada's success. In this article, we provide several ideas for consideration in line with strengthening Canada's health data foundation while addressing those barriers.

Background

The COVID-19 pandemic has shone a bright light on the essential requirement for Canada to use its health data better to improve outcomes for all Canadians. This is being acknowledged at senior levels of the government with recognition in the November 2021 Speech from the Throne as "[t]here is work to be done … on improving data collection across health systems to inform future decisions and get the best possible results" (Government of Canada 2021b) and in the December 2021 Mandate Letter for the Federal Minister of Health as "... expediting work to create a world-class health data system ..." (Prime Minister of Canada 2021).

IHSPR has developed a bold strategy for the next five years with a vision to "Accelerate Health System Transformation through Research to Achieve the Quadruple Aim and Health Equity for All" (CIHR IHSPR 2021: 1). One of the strategic priorities to achieve this vision is to "modernize the health care system with digital health solutions and data science" (CIHR IHSPR 2021: 14). This strategic priority, as well as the overall vision, is about the production, organization and use of timely and trusted data to (a) measure the Quadruple Aim, (b) drive new digital and data science solutions and (c) implement those solutions for care, safety, continuous improvement, planning and research.

Since December 2020, we have been developing advice for governments on a PCHDS through an EAG. Through that work, we are proposing a vision and principles for Canadian health data (Government of Canada 2021a, 2021c).

Furthermore, we note that Canada's (now largely digital) health data are systemically fragmented without a coherent foundation of governance, policy, standards or engagement. This systemic fragmentation is caused and exacerbated by several barriers that impede progress. These barriers primarily relate to culture and policy.

As IHSPR embarks on its strategic plan, it will be important for it to consider its role in strengthening the foundation of health data and tactics to overcome the relevant systemic barriers. It is on this basis that we provide this commentary.

Vision to be World-Class

While there is no definitive definition of a world-class health data system, several countries have data systems that support individual empowerment, clinical access and advanced analytics. Notably, health digital and/or data strategies have been advanced in the last two years by the UK, New Zealand, Australia and the Netherlands (Australian Digital Health Agency n.d.; Department of Health and Social Care 2022; Ministry of Health 2021; OECD 2022).

A "world-class [digital] health data system" (Prime Minister of Canada 2021: 3) will have several attributes that are consistent with the EAG's advice, IHSPR's strategic plan and data strategies being advanced by other countries. In one possible definition, such a system would:

- establish individuals as partners in health while achieving their health outcomes;
- foster a loop of continuous improvement through a learning health system; and
- be measured in its outcomes through the Quintuple Aim (Nundy et al. 2022), including reporting outcomes by

socio-demographic factors to identify opportunities to improve equity.

Significantly, with the tools now available, such a system does not need to be a monolithic single national database. With appropriate governance and accountability mechanisms, data can be integrated through distributed networks to enable clinical uses and population and public health, health services management, research and individual use.

Research will be a partner in achieving this, supporting the production and use of data that are timely, usable and connectable. Those data can generate necessary insights today and be flexible and responsive to new questions and capabilities that arise in the future.

To that end, IHSPR should lead work with partners across Canada and around the world to establish an objective framework for a research-enabling world-class (digital) health data system. This would define a clear framework for what success looks like and easy-to-understand metrics that will measure its success.

Culture of Data Stewardship

Achieving the objectives of the PCHDS and IHSPR's strategic plan will require adoption of a culture and practise of data stewardship. Data stewardship will help overcome the risk-averse health data culture that impairs timely data collection, sharing and use.

The risk-averse culture is the result of data custodians incented to reduce or eliminate risk of data misuse from data sharing, without consideration of the risks and consequences of not sharing data. This impacts research through (1) cumbersome processes to gain access to data, (2) data shared with only a high level of aggregation limiting its use in analysis and/or (3) data governed in siloes without use of standards or consideration of how data sets may later be integrated to answer future questions. Side effects of the risk-averse culture include bespoke data-sharing arrangements where clinical data are manually rekeyed for their analysis and a proliferation of smaller research initiatives that miss the opportunity for broader collaboration in Canada or globally.

The systemic barriers – short-term investments and lack of governance – negatively influence pan-Canadian health data research cohorts. Dozens of health cohorts, established for longitudinal studies, are designed for targeted purposes such as child development or aging. These cohorts include more than a million Canadians and are rich sources of research data on diverse populations; however, these cohorts were designed independently. Without commitment of ongoing funding, they are neither comprehensive in their population coverage nor always linkable to other health data, including other cohorts. This limits their current ability to generate cross-cohort insight.

Overall, the current health data culture causes insights to be late, lack sufficient granularity to have the desired impact and/or disproportionately consume limited budgets on administrative tasks rather than insightful research.

A culture of data stewardship would establish a clear *code of conduct* for uses of data, including expectations to:

- reuse data assets (standards, data sets);
- contribute data assets for others to reuse easily;
- simplify data linking to common master data;
- adhere to prescribed privacy law and understand health data policy;
- define scenarios where data must be shared and how new scenarios are reviewed;

- and others as agreed by the health data user community (Paprica et al. 2020).

Furthermore, this code of conduct would clarify the incentives for failing to adhere to the code of conduct, such as penalties for malicious data re-identification.

A consistent code of conduct will simplify negotiations between data collaborators as the expectations of all parties would align with the expectations in *data collaboration (sharing) agreements*. In addition, the code of conduct would articulate a consistent expectation of how to "encourage and promote the use of data sources and platforms … including SPOR's Canadian Data Platform" (CIHR IHSPR 2021: 16).

Canada has an opportunity to lead the world in research with our diverse population and the willingness of Canadians to participate in these types of studies. There is an opportunity for IHSPR to make it easy for researchers to do the right thing in designing and implementing their research studies to achieve their objectives on a timely basis and to support the future exponential value of networked data.

Efforts to establish types of this "code of conduct" are already under way in many communities. To that end, IHSPR can help catalyze and lead efforts to develop a consistent code of conduct across data organizations. When in place, this would radically simplify data access for research while continuing to afford appropriate data protections.

Measuring the Impact of Data Governance and Advanced Analytics

One of the other strategies under IHSPR's "digital modernization" priority is to "design innovative digital health research funding programs that support advanced analytics and the implementation and evaluation of digital health approaches ..." (CIHR IHSPR 2021: 16).

Funding program reviews by governments often rely on a calculation of "return on investment" (ROI). Many advanced analytics programs are challenged to generate quantifiable ROI based on the unknown future value of advanced analytics – either through value creation or through cost avoidance.

Furthermore, there have been prior investments in advanced analytics programs that have not achieved their value by being impaired in their ability to spread and scale across platforms, domains or jurisdictions. That failure to spread and scale is often a result of inconsistent data policies, standards and/or architecture. In other words, the lack of data governance has a direct impact on the challenges of realizing value from advanced analytic programs.

In an equitable learning health system, the algorithms (generated by research) that allow individuals to achieve their health objectives should be available to *all* residents of Canada. Many current funding models are antithetical to that outcome as their focus is often short term and based on locally available and unstandardized data.

To overcome these challenges, IHSPR's innovative funding programs should value and prioritize investment and experimentation that produces generalizable and shareable knowledge. This includes documentation of practices and other innovations like healthcare system–oriented training that would increase replicability from one setting to another. This work would leverage insights from international and jurisdictional partners, identify the essential elements that support scalability and drive spread and scale of innovation across Canada.

Harmonized Policy, Interoperability and Architecture

IHSPR can at minimum contribute, and at maximum drive, strengthening the foundation

of health data policies and interoperability. IHSPR's *Strategic Plan 2021–2026* includes "work with partners to continue *to improve access, linkage, and interoperability of data and data systems*…" (CIHR IHSPR 2021: 16).

No jurisdiction in Canada is incented to drive necessary harmonization and standardization across Canada. Groups that are pan-Canadian, such as IHSPR, can foster consistency through their requirements and funding arrangements. IHSPR also can help highlight the impact of the lack of consistency on research in time, quality and cost. That would serve to catalyze action to harmonize policies and processes and adopt data standards in the areas where it is of the greatest benefit while respecting the autonomy of local health systems. This will simplify the exchange of data across borders and facilitate IHSPR's mission.

This work should also tie into funding programs to minimize avoidable administrative work of data collection and normalization that benefits all jurisdictions to generate timely, impactful insights.

To that end, IHSPR should support research engagement and involvement with provinces and territories and other relevant organizations to develop harmonized data policies, including data access, data de-identification, protection and sharing of intellectual property and simplifying processes for cross-border research. IHSPR can engage with the regular reviews of the Tri-Council Policy Statement on the Ethical Conduct for Research Involving Humans (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council 2018) to ensure that the requirements for research ethics involving health data remain relevant and current.

Furthermore, as interoperability standards are developed, IHSPR should support this work by including requirements in their funding arrangements to reuse data standards, architecture and existing data assets, including master data for linking data sets. Where new standards/assets are required, IHSPR should require that these be shared for others to reuse later.

Building Capacity and Meaningful Engagement

Achieving the objectives in IHSPR's strategy will require improved understanding of digital health and data management among all stakeholders – leaders, health workforces, researchers and the public. That improved understanding will serve two distinct purposes – improving trust between stakeholders for the timely collection, sharing and use of health data and growing the capacity of people who perform essential functions in the generation of insights along the health data supply chain.

Trust must be built through meaningful engagement with stakeholders – most notably the public. Research into public perceptions of digital health data use, the acceptability (or not) of advanced analytics and the factors that influence those perceptions would reveal some important considerations for policy and codes of conduct.

Building capacity would ensure the pipeline of resources to perform critical data functions. This would include capacity at every step of the data supply chain from collection, sharing and use, as well as the data stewardship resources to coordinate all activities and ensure timely access to trusted data for research. Anecdotally, prior investments in advanced analytics that have failed to invest in upstream data functions have consistently failed to achieve their value proposition.

As such, IHSPR should encourage research to collect and understand baseline trust for digital health data use and opportunities to build trustworthiness through specific policies and/or codes of conduct.

Furthermore, IHSPR should explore methods to simplify the ability for individual research projects to incorporate stakeholder perspectives (notably among the public and Indigenous populations) in decisions about specific research/advanced analytics initiatives.

Finally, IHSPR should discover methods to contribute to a program with PTs and Health Canada that improves the health data literacy of leaders with a focus on the value of harmonized health data policy and consistent data standards. That program would improve the practices of data management and data science and build the pipeline of future leaders.

Conclusion

In advancing a world-class digital health data system, IHSPR has the ability to drive many areas that will be essential for long-term sustained success. IHSPR's *Strategic Plan 2021–2026* provides many essential planks of a world-class health data system (CIHR IHSPR 2021). Our advice is for IHSPR to take action that addresses the root cause of why prior similar attempts have been unsuccessful – primarily by influencing the strengthening of the health data foundation for Canada.

IHSPR's role as a strategic pillar of the Canadian Institutes for Health Research has the ability and credibility to champion a culture of collaboration and to drive change through its funding, training and leadership. Success will require partnership across the health sector and beyond. While it will be essential to involve many of the incumbent leaders in health data and digital health across Canada, a crucial success factor will be to involve the public in this work. Similarly, it is essential that First Nations, Inuit and Métis communities are engaged to lead their health data governance efforts to support better outcomes for their communities while contributing to better outcomes for Canada.

While this commentary was focused on the IHSPR's second strategic priority, the recommendations mentioned earlier will benefit IHSPR's other strategic priorities taken collectively as they all require timely access to data in a culture of improved literacy and trust, powered by innovative health data policies.

Articulating the value of consistent application of the Quintuple Aim (as the Quadruple Aim plus equity) will measure what matters most to Canadians. Driving coherence of governance, policy and standards will improve adoption and simplify data collection, sharing and use. That coherence requires trust and collaboration and will support scaling and spreading of excellence all across Canada.

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