

Pan-Canadian Approaches to Data Sharing & Access

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1. GOAL

One of the most significant challenges in healthcare and research in Canada is siloed and fragmented data.¹ This project aims to help ensure equitable and efficient pathways for data sharing and access across Canadian jurisdictions and institutions for childhood cancer research, patients and their families.



2. OBJECTIVES

1. Examine barriers, bottlenecks, and facilitators in data sharing in childhood cancer research in Canada, within and between institutions.
2. Better understand the needs and experiences of people with lived experience (PWLE) to help improve access to and communication of healthcare and research data.
3. Conduct a horizon-scan review of the legal and policy context applicable to PWLE access to healthcare (research/clinical) data.
4. Develop practical, stakeholder-informed tools to facilitate data sharing processes for ACCESS researchers and to support PWLE in requesting, interpreting, and using their data.

3. TIMELINE



REFERENCES

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4. METHODS

Design: The project includes two integrated activities, centered on stakeholder engagement via mixed methods national surveys,² and supported by legal and policy horizon-scanning.



ACTIVITY 1: Facilitating Data Governance and Sharing Across ACCESS Members

Participants: Researchers, legal representatives, and contracts staff across ACCESS partner institutions (target n = 25-30).

Focus: The survey examines professional perspectives on data sharing, including its role, definitional clarity, ethical principles, compliance measures, and the use of multi-institutional and external data sharing agreements. It also explores challenges and barriers in data sharing, their impacts on research, and potential solutions.

ACTIVITY 2: Fostering Communication of Patient Data and Access to Results

Participants: Adult survivors of childhood cancer and parents/guardians (target n=30-40).

Focus: The survey examines needs, experiences, perspectives, and barriers related to access to medical records and research data. It also explores experiences with return of results, interest in and accessibility of research information, and supports towards meaningful data access.

PWLE engagement: Across survey design, deliverables, and dissemination.

6. IMPACT / OUTCOMES

Findings will be mobilized through:

- Two peer-reviewed journal publications regarding key survey findings and insights.
- A methods book chapter on sensitive trauma-informed survey research with PWLE.
- Researcher and public-facing presentations (n=3).
- Practical resources for stakeholders (templates for data access/sharing and a guidance document for PWLE).

By bridging institutional and lived-experience perspectives, this project will deepen understanding and generate empirical evidence to help reduce data silos, enhance transparency, empower patients and families, and accelerate childhood cancer research and knowledge mobilization nationwide.

5. RESULTS

ACTIVITY 1: Preliminary Survey Results

Perceived Importance and Scope of Data Sharing

Data sharing was consistently framed as foundational to childhood cancer research. Respondents emphasized the system-wide nature of data sharing impacts, spanning scientific progress, ethics, and public trust.

Ethical Principles

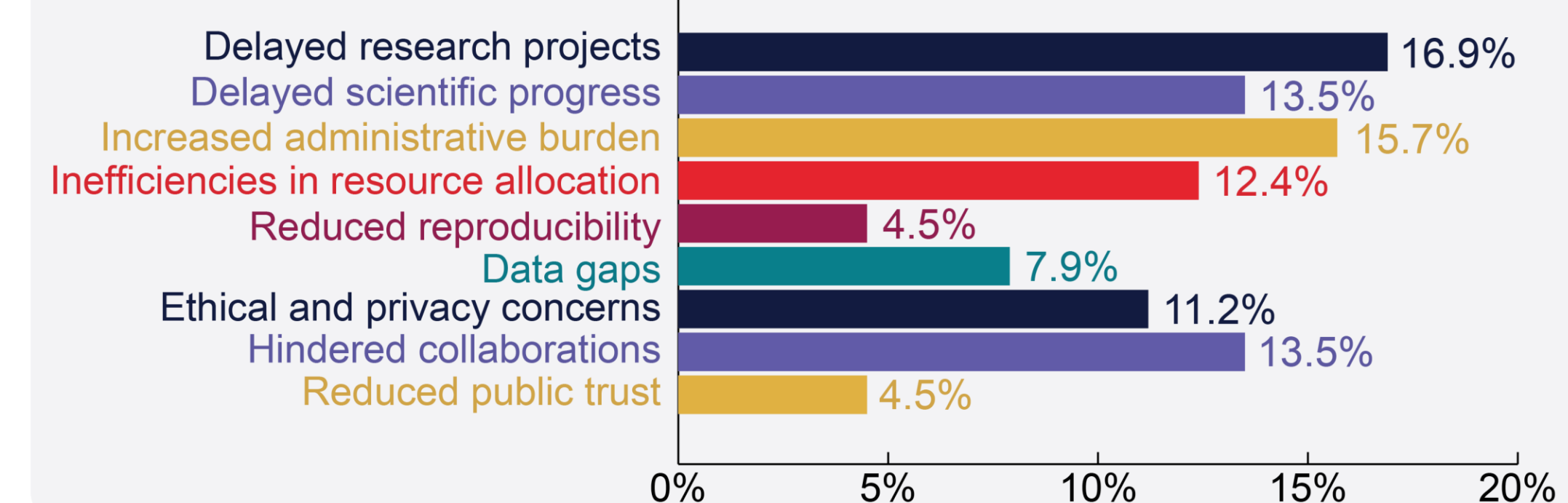
Open-text responses emphasized the need to operationalize ethical principles through streamlined processes, reduced bureaucracy, trusted coordinating bodies, and alignment with patient and family expectations for socially beneficial data sharing.

Lack of Shared Understanding

While all sites reported use of data sharing agreements (DSAs), conceptual misalignment persists. Only 26.7% of respondents believed stakeholders share a clear, common definition of a "data sharing agreement".



What is the impact of issues with data sharing processes on research?



Key Resource Constraints

The most significant resource constraints were funding and training/expertise. Similarly, limited technical expertise and administrative burden were rated as the concerns that most impact the uptake of data sharing.

ACTIVITY 2: Horizon-Scan Findings

Right of access established, but variably implemented:

Patients have a recognized legal right to access medical records across Canada; however, procedural requirements and thresholds for refusal vary by jurisdiction and institution.³

Research data present additional barriers:

Unlike clinical records, research data often lack standardized access routes. Return of individual results is not guaranteed and may depend on clinical relevance, institutional policy, privacy legislation, or "actionability" thresholds.⁴

Persistent gap between formal rights and lived experience:

Survivors and families report fragmented systems, administrative burden, dispersed records, and psychosocial barriers (e.g., trauma, research fatigue, survivorship transitions), contributing to unmet information needs.⁵

Interested in participating in one of our surveys?

Contact terese.knoppers@mcgill.ca or man.zawati@mcgill.ca

