



# CMA Statement on the Governance of Health Information

## *A patient-partnered health information governance framework*

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### WHAT IT IS

The purpose of this statement is to make the case for the development of a digital-era *patient-partnered health information governance framework* aimed at optimizing the benefits of health information in Canada for both individual care and Canada's broad ecosystem of health programs and services. The proposed framework would replace the current custodial standard of health information management with a patient-centric digital health information architecture that has clear alignment of public policy and oversight across all services and jurisdictions.

The framework would create the conditions for a team-based partnership between patients and trusted health system partners that promotes the dual role of health information:

1. *Primary use* by the patient and their circle of care (care team) to support quality health outcomes for the patient
2. *Secondary use* as population-based health data to support analyses under the auspices of trusted health information stewards for the purposes of public health, management, health policy, education, research and innovation

This would be supported by a newly defined and specialized role, the *health information steward*, that is accountable for overseeing the use of health information to promote quality health services and for population-based analyses.<sup>a</sup> To achieve this, in design terms, health information

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<sup>a</sup>Defining the specific authorities and accountabilities of the health information steward is beyond the scope of this document.

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must be supported by a governance framework that promotes an information architecture centred around the individual and promotes teamwork among patients, caregivers and health system partners. The rationale for this is clear: access to information is vital for a patient's circle of care to provide safe, quality care (primary use) and for generating high-quality data for enhanced population-based health data analyses to promote the public interest (secondary use).

Primary and secondary uses are not mutually exclusive in the proposed model. Their synergy is a key feature of the model. Health information generated in the context of individual care can be used for secondary purposes and secondary data use can generate insights that guide and improve individual patient care (e.g., supporting the clinical application of artificial intelligence and machine learning, and precision medicine).<sup>b,c</sup>

## WHY IT MATTERS

In the pre-digital era, analogue paper-based information technology required the maintenance of different versions of a patient's health record at each service location by service-based custodians, each with their own oversight structure. Legislation that enshrined the role of health information custodians became the standard for health information oversight in all jurisdictions in Canada.

This custodial paradigm:

- does not properly foster patients' rights of access to and control over their health information<sup>d</sup>;
- leads to the fragmentation of available health data sources and reinforces information silos and poor information exchange between members of a patient's circle of care; and
- does not promote access to and use of health information by trusted health system partners that would enhance population-based health data analyses, such as research and innovation, thus hindering the public interest purposes of secondary data use.

The advent of digital health technology creates the possibility for a health information architecture centred on an integrated virtual patient chart that is shared by all members of a patient's circle of care regardless of location and health service, thus eliminating the need for unique location-specific charts. However, there have not been comprehensive and systematic advances in health legislation, policy and workflow, which largely remain fixed in the traditional analogue custodial archetype and processes.

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<sup>b</sup>Determining the flow of information through artificial intelligence and machine learning is complex and requires a fulsome and nuanced approach beyond the scope of this document.

<sup>c</sup>The CMA's guidance for physicians on patient privacy is set out in the CMA's *Principles for the Protection of Patient Privacy*. Available from: <https://policybase.cma.ca/link/policy13833>

<sup>d</sup>See *McInerney v. MacDonald*, 1992 CanLII 57 (SCC), [1992] 2 SCR 138. Patient access, use and control are understood to apply to access, use and control by their proxies (caregivers, attorneys, etc.).

Reimagining health information governance for the digital age would bring many benefits. Both patients and health system partners would have more effective access to health information to strengthen the overarching aims of quality care and improved health outcomes for patients and society. The patient would have complete access to and control over their own health information to support personal care, and health system partners would have access to secure, population-based health data overseen by health information stewards who would ensure the secure and appropriate secondary use of data to improve the collective health of all.

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## GUIDING PRINCIPLES

These guiding principles and the overarching aim of quality care lay the conceptual foundation for the patient-partnered health information governance framework.

### 1. Person-centric

The principle of person-centrism can be understood to include three characteristics<sup>1</sup>:

**Individual focus:** The design of the health information governance framework is centred on the needs and perspectives of individuals, not exclusively on the needs of health system services. Patients participate directly in all phases of system design from conception to implementation. Health system partners, including a patient's circle of care, use health information to deliver secure, efficient, effective and responsive care that is consistent with the patient's preferences and meets their needs.

**Patient engagement:** Patients are able to meaningfully interact digitally with their circle of care by sharing information that represents their preferences and needs. Health information is created and presented in a way that is clear and understandable to the patient and removes barriers to patient information exchange and understanding.

**Personal agency:** Patients have access to and control over all aspects of their health care, including health information, to empower them in shared decision-making and engagement with their circle of care. Patients have a sufficient level of digital health literacy to participate meaningfully in the development, evaluation and improvement of health information design. The dimensions required of digital health services include a high level of accessibility, usability, security and patient support, identified through the patient-partnered framework.

### 2. Safety

The principle of safety is an integral element of quality care that requires the design of health information solutions to prevent harm to the patient. Harm is defined as follows:

- a threat to the physical, mental, cultural or financial health and well-being of a patient
- a threat to the security and privacy of their health information
- compromise of the legal rights of patients as owners of their health information

Harm can result from inappropriate or absent use and exchange of health information for primary or secondary use. To prevent harm, regulatory standards for health information use are required to optimize outcomes for the individual, community and society.

### 3. Collaboration

The principle of collaboration requires the participation and involvement of patients, their caregivers, their circle of care and other health system partners in sharing information and making decisions that reflect individual and population preferences and needs. Enhanced cooperation and communication are made possible by a health information governance framework that promotes interdisciplinary teamwork and informational continuity.

### 4. Trust

The principle of trust in this context is understood as the shared commitment of patients, their caregivers, their circle of care and other health system partners to embrace agreed-upon standards of practice for the collection, sharing and use of health information that emphasize collaboration, transparency, accountability, security and quality of service. Trust, supported by information protection and security and through patient partnership, must underpin and support the use of data for primary and secondary purposes.

### 5. Equity

The principle of equity in this context requires that we strive to eliminate avoidable and unfair barriers to patient access, use and control of their health information through intentional digital health literacy programming to ensure that everyone can fully participate and to support patient and health workforce excellence in health information use. Equity considerations are embedded in digital health service provision, design and oversight.

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## RECOMMENDATIONS

### 1. Engage patients as meaningful partners:

- Ensure ongoing patient engagement and communication (including all equity-relevant patient groups).
- Develop standards for patient, caregiver and provider education and supports in digital and data literacy.

### 2. Develop and implement a framework for data quality:

- A principles-based approach and a focus on the provision of quality care must inform the design of health information solutions to improve health outcomes for patients and the public.
- There must be clear, consistent and understandable standards and regulations aligned across all jurisdictions and for all data users and stewards.

- There must be data integrity, information sharing, privacy and information security standards and safeguards that enhance accountability and protect against misuse by public and private entities while encouraging the secure integration and flow of information.
- The requirement that health information is being systematically used and continuously improved for beneficial outcomes (for individuals, communities and society) through high-quality data generation must be met.

### 3. Establish the role of health information stewards and stewardship that informs:

- the mechanics of the regulation of health information management, storage and use;
- the scope and nature of patients' health information control;
- with whom and in what context and form health information can be shared;
- the relationship of health information and private health information technology vendors;
- the relationship between the new framework (which focuses on primary use and secondary use in the public interest) and the increasing use of health information for commercial purposes;<sup>e</sup> and
- the ability of health system partners to continue to meet their legal and regulatory obligations.

### 4. Implement strategic elements:

- Establish a process for the federal, provincial, territorial, First Nations, Métis and Inuit governments to achieve these recommendations.
- Prioritize barrier-free information collection, access and sharing, including data portability and enhanced data linkages for (1) patient care, (2) patient use and (3) permitted secondary uses.
- Respect and incorporate First Nations, Inuit and Métis health data governance sovereignty.<sup>f</sup>
- Collaborate with stakeholders (e.g., patients, health system partners, professionals and regulators).
- Identify and support useability and accessibility requirements for all users.
- Provide funding and supports to transition to the new model.
- Provide access to the tools and technology required to support the new model.

Approved by the CMA Board of Directors June 2022

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<sup>e</sup>Exploring the issues surrounding commercial uses of health information is complex and requires a fulsome and nuanced approach beyond the scope of this document.

<sup>f</sup>This includes the First Nations Principles of [OCAP](#)<sup>®</sup>, the Manitoba Métis principles of [OCAS](#) and the guidance of the Inuit Qaujimajatuqangit (IQ).

## References

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<sup>1</sup>Wilson EV, Wang W, Sheetz SD. Underpinning a guiding theory of patient-centered e-health. *Commun Assoc Inf Syst.* 2014;34:337-50. Available: <https://doi.org/10.17705/1CAIS.03416>