

Governance for Electronic Medical Record Data Used for Secondary Purposes

Last updated: March 2020

Doctors of BC Position

- With increasing demand for access to data in physician electronic medical records (EMRs) and the associated risks and benefits of use of that data, Doctors of BC calls for the establishment of appropriate and collaborative governance to ensure oversight, monitoring, and accountability, as it relates to the use of EMR data by external organizations for secondary purposes.
- Such governance must reflect meaningful consideration of issues related to:
 - the intended patient, health care provider, and health system benefit;
 - appropriateness and transparency of the access and use;
 - respect for patient and health care provider privacy and cultural safety; and,
 - health care provider perspectives, gained through ongoing provider engagement and participation.
- Each of these considerations, or key principles, is elaborated on in this policy statement.

Background

The range and volume of personal health data collected and accessible through a variety of sources including EMRs, administrative claims, mobile devices, and social media, are rapidly growing.[1] While physicians have historically collected health data for the primary purpose of providing care to patients, there is widespread agreement that EMR data are valuable for purposes beyond direct patient care and treatment.[2] These purposes, known as “secondary purposes,” include health system management, such as advancing patient safety, resource planning, system evaluation, and quality improvement.

As demand for access to physician EMR data increases, there is a need to consider broader issues related to data stewardship and governance. As custodians of patient information stored in EMRs, physicians have obligations to protect, maintain, and control access to this data by others, in accordance with privacy laws, professional standards and ethics.[3]

Physicians recognize the benefits related to using EMR data for secondary purposes, where such use can enhance the provision of patient care, improve the effectiveness and efficiency of our health care system, advance clinical research, and support population and public health goals. However, providing access to EMR data for these purposes poses complex legal, ethical, technical, and economic challenges.[4, 5]

To mitigate risks and ensure public interests are protected, Doctors of BC calls for the establishment of appropriate and collaborative governance, as it relates to the use of EMR data by external organizations for secondary purposes.

Appropriate and collaborative governance is crucial to ensuring there is oversight, monitoring, and accountability. Key considerations to guide data governance are outlined below.

Analysis

Intended patient, health care provider, and health system benefit

Using EMR data for secondary purposes should generally be for the direct benefit of patients or an indirect benefit to the public through improvement of the health care system.[6] The intended benefits should be clearly defined and communicated prior to the disclosure and use of EMR data for any secondary purpose.

Appropriate and collaborative governance can ensure there is careful consideration of the risks and benefits of the defined secondary purpose on patients and health care providers. The collection of EMR data for secondary purposes should not jeopardize the provision of patient care. Additionally, while collection and use of these data may be intended to benefit patients or improve an aspect of the health system, the impact on health care providers should also be considered to avoid unintended consequences, such as unnecessary administrative burden.

Costs associated with the collection and maintenance of EMR data should also be considered by external organizations seeking to use these data for secondary purposes. This includes consideration of the time and efforts involved in structuring EMR data so that the data are accurate, useful, and meaningful. This also includes the time it takes for physicians to enter into data sharing agreements.

Physicians play a key role in the creation of high quality data. Doctors of BC believes the time necessary to create and share good data is valuable. Appropriate resources and supports should be made available to health care providers to ensure continued collection and appropriate stewardship of health information. Benefits from using EMR data for secondary purposes can be achieved when health care providers are supported to leverage these data to

improve knowledge and the effectiveness of the health care system. Health data are often used for quality improvement initiatives with the intention of improving the health system and patient experiences. However, data related to how health care providers practice, including data on patient outcomes, only reveal part of the story. Assessment of the health system as a whole requires examination of health care providers, in addition to systems administrators and the programs and policies they oversee. To support health care providers to engage in sharing EMR data for secondary purposes, there is a need to ensure evaluation practices are fair, equitable, and meaningful.

Appropriateness and transparency

Clinical and administrative EMR data are becoming increasingly sought after by researchers, governments, health authorities, and commercial entities for analysis.[2] However, issues surrounding the appropriateness and transparency related to the use of these data, including the development of large data repositories and the commercialization of data, need to be considered.

Governance structures should be created, with meaningful health care provider involvement, when it comes to the use of EMR data for secondary purposes. Governance structures should develop use, disclosure, and data retention policies prior to creating data repositories. These policies should outline how data will be used, collected, maintained, protected, and analysed.

Patients have the right to know what their data can be used for without their knowledge and/or consent.[5] Information related to the purpose, rationale for the use, and what safeguards are in place should be readily available. Additionally, physicians have a right to know the intended use of their patient data and clinical practice information when sharing these data with external organizations.

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Trust is key to maximizing the value of using EMR data for secondary purposes.[7] The establishment of appropriate and collaborative governance that supports transparency will increase public and health care provider confidence in the use of these data for purposes other than direct patient care.

Respect for patient and health care provider privacy and cultural safety

Patients share their personal information with their physician as part of the trust built through the patient-physician relationship. As custodians of this information, physicians have an obligation to manage the confidentiality of patient information, including managing disclosures.

Respect for patient and provider privacy can be achieved if there are guidelines to offset the inherent loss of personal privacy. To achieve the defined secondary purpose for using EMR data, there should be:

- Clear public and/or health care provider interest and material value.
- Adequate security and safeguards to protect patients and providers, including clear policies to address breaches.
- The most limited scope of data necessary, based on the principle that only data which is required should be gathered.
- The most limited personal identification necessary and appropriate for the defined secondary purpose.
- Appropriate consideration of the possible need for patient, community, and health care provider consent.
- Protection of communities and populations experiencing health inequities, including meaningful consultation and/or community consent when data are used to analyze care of identifiable populations.

Meaningful health care provider engagement and participation

Doctors of BC supports the use of EMR data for secondary purposes, including the enhancement of physicians' knowledge and competency, and for purposes that seek to improve the effectiveness and efficiency of clinical practice. To support physicians to share their EMR data for these purposes, meaningful physician engagement and participation is essential. In instances where EMR data are used for physician clinical quality improvement activities, governance should be led by physicians, who are the stewards of the data. This will help ensure there is representation and meaningful engagement from community-based physicians. This will promote a culture of continuous improvement and build trust in data sharing practices.

Conclusion

Doctors of BC calls for the establishment of appropriate and collaborative governance, as it relates to the use of EMR data by external organizations for secondary purposes. The foundational principles highlighted in this policy serve as a guidance for data governance. Upholding these principles will help to ensure public and health care provider confidence is established and support the sustainability of future use of EMR data for secondary purposes.

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History

March 2020.

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