Forging the Path

Toward a Shared Standard for EMR Data

Highlights and Recommendations From CIHI’s Primary Care Forum
# Table of contents

Executive summary ............................................................ 4
Forum overview ............................................................... 5
Key themes ................................................................. 6
Implementation ideas ...................................................... 9
Post-forum considerations ................................................ 10
Recommendations for forging the path forward ......................... 11
Conclusion ..................................................................... 13
Appendix A: Participant list ................................................ 14
Appendix B: Agenda ......................................................... 17
Executive summary

In November 2018, the Canadian Institute for Health Information (CIHI) hosted Forging the Path: Toward a Shared Standard for EMR Data, an invitational forum to bring together thought-leaders for a dialogue on standardizing primary care electronic medical record (EMR) data in Canada. The objectives were to

- Understand the current state of EMR content standards for capturing diagnosis/health concern and treatment information in Canada;
- Share examples of successful EMR content standards implementation; and
- Obtain agreement on a common direction for standardized EMR data to capture diagnosis/health concern and treatment information in community-based primary care in Canada.

The longer-term goal is, of course, to increase availability of standardized data to support both clinical and secondary needs.

The following themes emerged:

1. There is agreement on the need for a national approach to standardize EMR diagnosis and treatment data across Canada in a clinician-friendly manner.
2. A forward-looking, outcomes orientation is needed to generate comparable EMR data that is fit for purpose.
3. Value proposition scenarios will help to promote the benefits of comparable data.
4. The experiences of clinicians with data collection and use should be considered when designing a solution.
5. It is necessary to address EMR data and information governance issues, such as defining data flows and resolving data privacy and security concerns.
6. Canadian public-sector stakeholders face primary care EMR data access issues. A collective strategy is needed to discuss these considerations with EMR vendors in a way that is mutually beneficial.
7. Both EMR data standards and artificial intelligence (AI) approaches could be used to produce a comparable minimum EMR data set for health system use.
8. Canada should build on lessons from the journey of the United Kingdom’s National Health Service (NHS) Digital to standardize EMR data, such as building on policy drivers and taking a phased implementation approach.
Participants also proposed that an effective path forward requires strong partnerships and collaboration to address the identified issues and to advance participants’ ideas. In this context, this report makes the following post-forum recommendations to drive change:

1. Develop a national strategy for a comparable minimum set of primary care EMR data to support health system use, as well as an action plan to drive change.
2. Establish an advisory group to develop and implement the strategy.
3. Initiate a collective approach to vendor engagement as soon as possible.

In the coming months, CIHI looks forward to initiating collective work to advance these recommendations.

**Forum overview**

Forging the Path: Toward a Shared Standard for EMR Data was a primary care forum hosted by CIHI on November 29, 2018, in Toronto. Thought-leaders from across Canada were invited to participate in a dialogue on standardizing certain primary care EMR data elements for health system use (see Appendix A). The forum’s objectives were to understand the current capability of EMR content standards to capture diagnosis/health concern and treatment information in Canada and to share examples of successful EMR implementations. Common agreement on a direction to support further EMR standardization in community-based primary care in Canada was sought. The longer-term goal is to increase availability of a minimum set of standardized EMR data to support both clinical and health system needs going forward.

In addition to engaging with a Canadian panel and a keynote speaker from the United Kingdom’s National Health Service (NHS) — Jon Calpin of NHS Digital — participants were asked to share their experiences and thoughts about the need to standardize a minimum set of primary care EMR data for health system use (see Appendix B). They were also asked to identify actions or questions to be answered that could set the stage for the way forward.

Key themes emerged during the forum dialogue, which are captured in the summary below.
Key themes

1. **There is agreement on the need for a national approach to standardize EMR diagnosis and treatment data across Canada in a clinician-friendly manner.**

   Participants agreed that a pan-Canadian clinician-friendly standards-based solution to support the generation of comparable primary care EMR diagnosis/health concern and treatment data (hereafter referred to as diagnosis and treatment data) would be valuable to their collective efforts across the country. There was also a thorough discussion about whether a single standard should be pursued compared with a coordinated hybrid of existing standards. The group considered how each standard (i.e., classifications or terminologies) has a different focus. For example, the International Classification of Diseases, Ninth Revision (ICD-9) is predominantly used for billing purposes whereas terminologies such as the Systematized Nomenclature of Medicine–Clinical Terms (SNOMED CT) are focused on clinical use. Some participants described their local efforts to map SNOMED CT diagnosis codes to ICD-9 codes as potentially helpful to meeting clinicians’ clinical and billing needs at the same time. It was also noted that a pan-Canadian standard minimum data set for health system use must be available in English and French.

2. **A forward-looking, outcomes orientation is needed to generate comparable EMR data that is fit for purpose.**

   Participants noted that it was time to begin moving toward EMR systems that can produce comparable data to support outcome evaluation at all levels of the primary care sector and the health systems. In order to support the evaluation of outcomes, attendees reaffirmed that collecting fit-for-purpose data will in turn drive data standardization.

3. **Value proposition scenarios will help to promote the benefits of comparable data.**

   The purpose of the scenarios is to make the case for the value of a standardized EMR minimum data set and to solicit stakeholder involvement in collecting, generating or using comparable data. Attendees shared some great examples.

   - **For physicians:** Standardized data allows for comparable quality improvement for chronic disease prevention and management. It also allows clinicians and teams to make better decisions at the point of care.

   - **For policy-makers and researchers:** Standardized data can be used for comparable analysis of impact and improvements in health outcomes. It also supports the sharing of data with other sectors (e.g., acute care, home care) and leads to better care transitions.
• **For patients**: A minimum set of standardized data from across the continuum will provide comparable information to help patients manage their own care, with the aid of their families and caregivers and in consultation with clinicians. Attendees thought that patients’ interest in their data could be a key lever for change.

• **Allied health professionals and vendors** were other audiences identified.

Participants also noted that patients and clinicians should have timely access to selected standardized patient data across the continuum because information continuity is important to improving care.

4. **The experiences of clinicians with data collection and use should be considered when designing a solution.**

Forum attendees said that standards implementation for a minimum EMR data set needs to be grounded in the workflow of front-line primary care practitioners. They agreed that the collection of standardized EMR data should have little impact on the delivery of patient care and that technology should be leveraged to enable the task. The group acknowledged that there is a human change management component to standards design and implementation. As well, they proposed that education would be required to make any solution sustainable.

5. **It is necessary to address EMR data and information governance issues, such as defining data flows and resolving data privacy and security concerns.**

A participant captured this theme best by saying, “Strong and effective data governance structures are important to achieve EMR data standardization.” Considerations identified over the course of the day included the following:

• **Clarifying EMR data and information flows**: Attendees thought that primary care EMR data flows, including flows of selected standardized data, should be well understood to inform governance requirements. The data flow examples identified were
  – Primary care clinics to primary care clinics;
  – Primary care clinics to hospitals; and
  – Primary care clinics to data-sharing platforms for patient portals, electronic health records and/or research.

• **Resolving data privacy and security concerns**: Participants agreed that certain privacy and security issues need to be addressed to mitigate stakeholder concerns. These include
  – Potential privacy gaps when primary care patient information is shared with caregivers;
  – Possible physician liability issues if sensitive patient information is inadvertently exposed; and
  – Potential patient worries that their data is not secure.
6. **Canadian public-sector stakeholders face primary care EMR data access issues.**
   A collective strategy is needed to discuss these considerations with EMR vendors in a way that is mutually beneficial.

Forum attendees proposed that there are substantive EMR data access issues for public-sector stakeholders (including approved third parties) who seek EMR data for primary care planning, analysis and research or for practice-level quality improvement. Participants voiced their concerns that vendors are currently controlling access to the data in primary care office–based EMR systems and are charging excessive fees for the extraction of patient data. Attendees voiced an urgency to address this issue and the importance of making Canada’s governments aware of it.

Participants proposed that a collective approach to vendor engagement and negotiation would create an opportunity to improve data access for public-sector stakeholders and to enable selected data standardization across Canada. In the longer term, this may also allow vendors to realize greater value from EMR data. It was proposed that provincial and federal legislation might be used to govern the use of EMR data, particularly to ensure that policy analysis, research and quality improvement is supported.

7. **Both EMR data standards and AI approaches could be used to produce a comparable minimum EMR data set for health system use.**

Participants discussed how best to use AI approaches, such as natural language processing and machine learning, to produce a comparable minimum EMR data set. Some participants felt that using AI techniques is the best way forward to structure selected EMR data for some physicians. However, many other participants thought that both standards and AI are needed.

8. **Canada should build on lessons from the journey of the U.K.’s NHS Digital to standardize EMR data, such as building on policy drivers and taking a phased implementation approach.**

The keynote speaker, Jon Calpin, identified lessons learned by NHS Digital’s journey to standardize primary care data using SNOMED CT. They included the following:

- Policy, legislative and contractual strategies were successful change drivers.
- Physicians were brought on board as partners.
- Vendor relationship management included early engagement as well as central management of EMR system requirements and certification.
- The benefits of a minimum set of standardized EMR data were promoted to various audiences.
- Implementers took a staged approach, including a discovery phase, and did not expect immediate results.

Some forum participants were interested in exploring a national legislative framework in Canada, similar to the NHS approach, to drive standardization. However, others wondered whether such an approach was transferable to Canada.
Implementation ideas

Throughout the day, participants were encouraged to propose specific implementation actions. There were a range of ideas proposed, some of which are listed below and grouped by topic.

Compile information on the current state in primary care and keep it updated:
- Understand the extent of standardization of a minimum EMR data set in Canada.
- Assess EMR data flows, starting in primary care clinics.
- Gather information about the current vendor landscape from a pan-Canadian view.

Refine and supplement requirements used to shape the current CIHI content standards. This could include the following:
- Establish business requirements to create comparable EMR data in selected areas.
- Determine the top 5 most compelling information priorities to drive change.

Design a solution specific to diagnosis/health concern and treatment:
- Analyze the benefits and risks of possible classifications and terminologies before selecting the most appropriate standard for use across Canada.
- Consider a parallel role for AI to make a minimum data set comparable.
- Co-design a solution(s) with primary care clinicians for relevance.

In addition, the group proposed some key activities to move forward:
- Develop a national strategy and action plan to drive change.
- Use a steering group to inform and implement the strategy.
- Develop a stakeholder engagement plan and a collective approach to vendor engagement as soon as possible.
- Inform decision-makers about the forum themes and proposed next steps.
Post-forum considerations

Forum participants agreed about the need for a national approach to standardize EMR diagnosis and treatment data in a clinician-friendly manner. Beyond the discussion on the day of the forum, there are several contextual factors at play.

In the near term, additional work is required to understand the current capabilities of EMR systems to generate standardized diagnosis/health concern and treatment information in Canada. This could extend to the entire minimum data set found in the Pan-Canadian Primary Health Care Electronic Medical Record Content Standard, Version 3.0 — Business View designed for data comparability, interoperability and health system use in priority areas. Refer to the side bar for an overview.

Another important consideration is the need to make EMR data accessible and affordable for public-sector stakeholders, including approved third parties, for the purposes of quality improvement and research. The advent of a national framework for data and information governance will greatly protect primary care EMR data as a public good. CIHI is currently undertaking work on the Health Data and Information Capability Framework that will be released in the coming months.

There is a need to begin a pan-Canadian vendor dialogue and it has been proposed that:

- There is an opportunity to learn more from primary care EMR system vendors about the current capabilities and future possibilities to standardize a minimum set of EMR data; and
- It is important to explore data accessibility and affordability with EMR vendors.

The Primary Health Care Electronic Medical Record Content Standard (PHC EMR CS) is a minimum EMR data set for health system use of primary care information. It identifies 45 EMR data elements (such as diagnosis and treatment) and associated value sets (such as ICD-9 and SNOMED CT) to support the generation of comparable EMR data in priority areas. Once the minimum standardized data has been extracted and aggregated from point-of-care systems, its health system use can range from generating client summaries for electronic health records, to measuring performance using a chronic disease EMR data repository, to conducting primary care research. The PHC EMR CS was developed by CIHI, along with Canada Health Infoway, at the request of policy and clinical stakeholders from across Canada’s provinces and territories. See CIHI’s Primary Health Care web page for more information.
For forging the path forward

CIHI is an independent, not-for-profit organization dedicated to providing essential health information to all Canadians.

CIHI works closely with federal, provincial and territorial partners and stakeholders throughout Canada to gather, package and disseminate information to inform policy, management, care and research, leading to better and more equitable health outcomes for all Canadians.

Given the information shared by forum participants, and the EMR system vendor considerations emphasized in the post-forum analysis, CIHI proposes that a national approach be undertaken to make EMR diagnosis and treatment data more comparable and available across Canada. This approach will address stakeholder needs for a minimum set of comparable EMR data:

- For clinicians — to manage patient care and for quality improvement activities;
- For patients and caregivers — to manage their health and the health care they receive;
- For policy-makers — to understand the contributions of primary care to health system and patient health outcomes; and
- For researchers — to support their investigations into primary care at the practice and system levels.

However, CIHI does not make progress alone. It seeks partners and their active involvement. Building both on the ideas raised by forum participants and on post-forum considerations, CIHI proposes the following actions and leadership roles to initiate the way forward:

1. **Develop a national strategy for a comparable minimum set of primary care EMR data to support health system use, as well as an action plan to drive change.**

   CIHI offers to lead the development of a strategy paper to initiate change. The strategy paper will incorporate ideas and proposed actions raised by forum participants and will be informed by future consultation with the stakeholder groups identified in this report. A key focus of the paper will be to answer the following question: What are the essential components of a primary care EMR information system that supports health system use in Canada?

   The strategy document will include the following:

   - A current state description and identification of key issues to be addressed;
   - A future state description, capturing a pan-Canadian vision to drive local efforts;
   - Business requirements to drive change;
• Common stakeholder priorities (e.g., 3 priority chronic diseases) to guide testing and initial use of a minimum set of comparable EMR data across multiple jurisdictions;
• A plan for a standards solution to make EMR diagnosis and treatment data comparable, as well as a parallel role for AI;
• A framework addressing primary care data governance needs that aligns to a larger health data and information governance capabilities framework in Canada; and
• A stakeholder engagement plan that includes jurisdictions, clinician groups, EMR system vendors and others.

Once the strategy document is finalized, it is proposed that an action (implementation) plan be developed by pan-Canadian stakeholders as part of the advisory group described below. One of the priority actions will be to raise awareness of current EMR data issues with health system decision-makers across Canada, specifically by briefing the Conference of Federal–Provincial–Territorial Deputy Ministers of Health.

2. Establish an advisory group to develop and implement the strategy.

Forum attendees had various ideas about the nature of the advisory group's governance structure (e.g., should it consist of partnerships, a consortium or an alliance?) and membership (e.g., should constituents be decision-makers or subject matter experts?). CIHI will work with stakeholders to determine which governance model makes the most sense and will invite identified stakeholders to form such a group. CIHI will also provide secretariat support for the advisory group meetings.

3. Initiate a collective approach to vendor engagement as soon as possible.

Forum participants emphasized the importance of taking a collective approach to advancing their relationships with EMR system vendors. CIHI is willing to initiate the engagement process by gathering contextual information from vendors who sell their products in multiple Canadian jurisdictions. Thereafter, it was proposed that the steering group would determine how best to engage the vendor community in the longer term.
Conclusion

CIHI has developed this report to provide highlights of the November 2018 forum Forging the Path: Toward a Shared Standard for EMR Data as well as to give some post-forum analysis.

CIHI was pleased to host this forum to determine how best to increase the availability of a minimum set of standardized primary care data across the country. By the end of the day, forum participants had affirmed their commitment to meaningful change. They agreed that an effective path forward requires strong partnerships and collaboration.

Participants also identified some detailed ideas for moving the work forward and some key activities to initiate change.

CIHI will continue to engage stakeholders and monitor activities across Canada on the important topic of addressing gaps in comparable EMR data related to diagnosis and treatment. In the coming months, CIHI looks forward to forging the path together.
## Appendix A: Participant list

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
<th>Organization</th>
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<tbody>
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Appendix B: Agenda

8:30–9:30 a.m. | Breakfast and registration

9:30–9:40 a.m. | Welcome from forum host

CIHI
Brent Diverty
Vice President, Programs, CIHI

Kathleen Morris
Vice President, Research and Analysis, CIHI

9:40–9:55 a.m. | Opening remarks

Objectives for the forum
Michael Hunt
Director, Spending, Primary Care and Strategic Initiatives, CIHI

Dr. Keith Denny
Director, Clinical Data Standards and Quality, CIHI

9:55–10 a.m. | Forum overview

Walk-through with facilitator
Michael Schlesinger
Consultant, Lough Barnes Consulting Group

10–11 a.m. | Forum panel: Canadian experiences

Senior leaders from across the country will provide their perspectives on the journey to make EMR data useful through standardizing primary care data. Context-setting introductory remarks by each panellist will be followed by a moderated discussion.

Moderated by Michael Schlesinger

Jeff Aitken
Executive Director, Information Technology Services Branch, British Columbia Ministry of Health

Kim Wieringa
Assistant Deputy Minister and Chief Information Officer, Health Information Systems, Alberta Health

Rod Burns
Chief Information Officer and Chief Privacy Officer, Alliance for Healthier Communities

Dr. Mohamed Alarakhia
Family Physician, Centre for Family Medicine Family Health Team; and Managing Director, eHealth Centre of Excellence

Dr. Don MacDonald
Vice President, Health Analytics and Evaluation Services, Newfoundland and Labrador Centre for Health Information
11–11:15 a.m. | Networking break

11:15 a.m.–12:15 p.m. | Participant roundtable

Building on the Canadian panel discussion, participants will have an opportunity to share local snapshots of recent successes and challenges related to EMR progress in their organization or jurisdiction.

Moderated by Michael Schlesinger

12:15–1 p.m. | Networking lunch

1–2 p.m. | Forum keynote

International experience

NHS Digital will share insights and learnings from the U.K.’s creation of a primary care framework as it moves forward with a standardized data solution.

Jon Calpin
Programme Manager, NHS Digital

2–2:15 p.m. | Networking break

2:15–4:15 p.m. | Forging the path — Toward agreement

Through a moderated discussion, participants will work toward agreement on a common direction for standardized EMR data to capture encounter information related to diagnosis/health concern and treatment in community-based primary care in Canada.

Moderated by Michael Schlesinger

4:15–4:25 p.m. | Forum summary

Key learnings and next steps

Michael Schlesinger

4:25–4:30 p.m. | Closing remarks

Michael Hunt, Dr. Keith Denny, CIHI