

Defining the content of shared electronic medical records (eMR)

An pragmatic and cost-saving initiative of the College of Family Physicians of Canada

With over a 100 million consultations last year, the Family Physician (FP) is most definitely the hub of healthcare provision in Canada; it is the point of first contact for most in our health system and the main resource for coordination of care. In addition, Canadian FPs have led the clinical community in use of computers and electronic communication. High on government agendas all around the world, the next logical step is to share electronic medical records (eMR) and the Family Physicians community is best placed to lead the definition of the clinical content that will be the foundation for Canada's shared electronic health records.

The College of Family Physicians (CFPC)) focuses on safety and quality standards for Canadian Family Physicians. Since its inception the CFPC has developed health record standards and supported family Physicians to meet these standards. With the advent of eMRs, the College will continue this professional leadership and is in the prime position to coordinate the specification of clinical information with the other professional clinical colleges, licensing bodies, quality-focused organisations and consumer representatives.

In the new and rapidly evolving eHealth environment 'meaningful use' is the mantra; ensuring that shared information benefits patient care and can be exchanged securely.

The current eHealth environment consists of health information stored in different formats designed by literally thousands of different companies, organisations and jurisdictions in Canada and around the world. This fragmented approach has each stakeholder repeat the same clinical content design process, resulting in largely overlapping, yet ultimately, unique solutions. To permit any sharing, integration and exchange of data created using these unique data definitions, mapping and repeated transformation of data is required; each process leading to increasing risk of error, ambiguity and loss of data.

High profile Canadian agencies currently involved in the definition of clinical content

- Canadian Institute for Health Information (CIHI)
- Canada Health Infoway (CHI) or (Infoway)
- Clinical system developers;
- Pathology and Radiology system developers;
- Professional medical teaching accreditation bodies
- Provincial medical licensing organisations

The missing element of current eHealth strategies – the ‘elephant in the room’ – is the need to determine and define the detailed content that is required by the clinicians to support safe clinical care in their eMRs. It is from this solid foundation that all other efforts should follow – exchange of health information; best-Physicians user interface design (especially alerts and warnings); integration of data from multiple sources for research, registries and reporting; care planning and coordination; implementation of standardised clinical decision support and Physicians audit tools.

A clinician-led approach to a ‘universal eMR’ – a long-term, data-driven eMR, based on high quality, standardised and non-proprietary clinical content specifications – can help to avoid these pitfalls. This approach has been gathering momentum with uptake and interest by the national programs of Sweden, United Kingdom, Denmark, Chile, Brazil, Kazakhstan and Singapore and the American College of Rheumatologists is the first clinician-led group to embrace this methodology. It involves collaborative development of shared clinical content definitions known as archetypes, which effectively places clinicians ‘in the driving seat’ – determining the content that they want and need in eMRs to support their care of patients.

Archetypes are computable definitions for a single discrete clinical concept – a maximal (rather than minimum) data set designed for all use-cases and all clinical users. For example, one archetype can describe all data, methods and situations required to capture a blood sugar measurement from a glucometer at home, during a clinical consultation, or when having a glucose tolerance test or challenge at the laboratory. Other archetypes enable us to record the details about a diagnosis or to order a medication. Each archetype is built to a ‘design once, re-use over and over again’ principle and, most important, the archetype outputs are structured and fully computable representations of the clinical knowledge. They can be linked to clinical terminologies such as SNOMED-CT, allowing clinicians to record the health information they need to provide direct patient care.

A template is used to aggregate all the archetypes that are required for a particular clinical scenario. These can also be shared, preventing more ‘wheel re-invention’. Individual content elements of each maximal archetype can be ‘disabled’ in the template so that the only data elements presented to the clinician are those that conform to Australian or local requirements and are relevant and appropriate for that clinical scenario. For example, a typical Discharge Summary may commonly comprise 10 common archetypes; templates allow the orthopaedic surgeon to express a slightly different ‘flavour’ of the Discharge Summary based on which elements of each archetype being either active or disabled, compared to that required by a Obstetrician who needs to share information about both mother and newborn. One size, or document, does not fit all, and templates enable use of standardised archetype building blocks while at the same time supporting requirements for clinical flexibility and appropriateness – allowing data structure governance at the same time as ensuring ‘fitness for purpose’ per clinician, per patient, and per clinical scenario.

The Clinical Knowledge Manager (CKM) is an online clinical knowledge management tool which provides a repository for archetypes and other clinical knowledge artefacts, such as terminology subsets and document templates. Based on a high quality asset management

platform it provides a clinical knowledge ecosystem supporting the publication lifecycle and governance of the archetypes. Within CKM, a community of grassroots clinicians and health informaticians can collaborate in online reviews of each archetype until consensus is reached and the agreed archetype content is published. Clinicians need no technical knowledge to engage with archetypes - the technical aspects of archetypes are kept hidden ‘under the bonnet’ - and they use their domain knowledge to ensure that the clinical content within each archetype is correct and appropriate. Each clinical content review is conducted online at a time of convenience to the clinician and usually only takes five to ten minutes for each participant. Thus the clinical community itself, as the domain experts, drive the eMR content definitions. The CFPC's CKM repository will become the leading peer-reviewed clinical knowledge resource for all parties seeking shared, standardised models for representing health information in Canada.

How achievable is this? Only ten archetypes are needed to share core clinical information that could save a life in an emergency or provide the majority of content for a discharge summary or a referral. If each archetype takes an average of six review rounds to reach clinician consensus and each review round is open for 2 weeks, it is possible to obtain consensus within an average of three months per archetype – some complex or abstract ones may be longer; other simpler, concrete archetypes will be shorter. Many archetypes are already well developed in the international arena. As archetype reviews can be run in parallel, a willing community of clinicians could achieve consensus for core clinical eMR content within three to six months.

It is estimated that as few as fifty archetypes will comprise the core clinical content for a primary care eMR, and maybe only up to two thousand archetypes for a hospital eMR system including many clinical specialties. The initial core clinical content will be common to all clinical disciplines and can be re-used by other specialist colleges and interested groups. More specialised archetypes will gradually and progressively be added to enhance the core archetype pool over time.

What are the benefits of a CFPC-led drive for national consensus on clinical content using archetypes and a national Clinical Knowledge Manager?

A collaborative and clinician-led approach to our health records will provide:

Benefits for CFPC and other professional colleges

- Fulfils CFPC’s professional responsibility to advocate for safety and quality in electronic health records.
- Development of a coherent national set of clinical content specifications to support quality provision of healthcare in Family Physician and specialist clinical software applications – shared core clinical content plus specialised domain-specific content.

- Online collaboration maximises the potential for a breadth of grassroots clinician engagement in ensuring correctness of the clinical content definitions.

Benefits for clinicians

- Common data definitions will facilitate exchange and re-use of data between systems and providers:
 - Improved data quality – clinical content specifications will be agreed and ratified by the clinician community; clinical data created will need to conform to the agreed archetype specifications.
 - Improved data ‘liquidity’ – so that data can flow between healthcare providers and systems to where the clinician needs it;
 - Improved data longevity – no loss of data from transformations or system migration will support the accumulation of comprehensive lifelong health records;
 - Improved data availability – integration of data based on the same archetypes from multiple information sources;
 - Re-use, integrate and aggregate data for supporting quality processes such as clinical audit, reporting and research; and
 - Break down the existing ‘silos’ of health information based on proprietary and varied clinical content definitions.
- Active participation by clinicians to shape and influence their eMRs, ensuring that eMR content is ‘fit for clinical purpose’.
- Every clinician, as a clinical domain knowledge expert, can have the opportunity to contribute to the developing and agreeing the archetype content. No technical understanding is required.
- Online participation in clinical content review will be of short duration and at times of convenience to the clinician, avoiding the significant time and opportunity cost of attendance at face-to-face meetings.

Benefits for patients

- Data created and stored in a shared, standardised and non-proprietary representation supports the potential for application-independent data records that can persist for the life of the patient.
- Improved data ‘liquidity’ – so that data can flow between healthcare providers and systems to where the patient needs it.

Benefits for CHI, CIHI and Provincial jurisdictions

- Development of a coherent national set of clinical content specifications to support the Computable eMR, health information exchange and secondary use.
- Enables national governance of foundation clinical content while at the same time facilitates flexible expression of local clinical requirements
- Efficient use of sparse clinical, informatics and stakeholder resources:
 - Design & create an archetype once; re-use many times;
 - Leveraging existing clinical specification work done internationally to improve local Canadian pool of archetypes;
 - Online collaboration maximise the potential for stakeholder engagement at the same time as minimising the requirement for expensive face-to-face meetings; and
 - Review and publication of agreed clinical specification definitions within weeks to months;
 - Review and standardisation of clinical documents containing agreed archetypes will be relatively short.
- Clinical knowledge management ecosystem:
 - Single national repository of clinical knowledge artefacts, including archetypes and terminology subsets.
 - Focussed and coordinated knowledge management environment where all stakeholders can observe, participate and benefit; the opposite of the current fragmented, isolated and proprietary approach to defining clinical content.
 - Digital knowledge asset management:
 - Manages authoring, reviewing, publication and update lifecycle of all knowledge assets;
 - Provenance and asset audit trails;
 - Ensures asset compliance to quality criteria;
 - Ensures technical validation of assets; and
 - Development of coherent release sets for implementers;
 - Governance of knowledge assets.
 - Distribution of knowledge assets via coherent release sets.

- Removes the need for per message or per document negotiation between vendors, organisations and jurisdictions each time information needs to be integrated or exchanged by use of the standardised content within more generic message wrappers or document structures.
- Transparency of editorial and publishing processes; accountability to the clinical community itself.
- Precludes the need for ratification of clinical documents through a traditional standards process when they consist of subsets of the nationally agreed archetypes.

Benefits for software developers

- Download coherent sets of clinical content definitions from a published and agreed national repository.
- Software development remains focused within the expert technical domain – user interface; workflow processes; security, data capture, storage, retrieval and querying; etc.
- Removes the need for per message or per document negotiation between vendors, organisations and jurisdictions each time information needs to be integrated or exchanged by use of the standardised content within more generic message wrappers or document structures.

Benefits for secondary users of data

- Existing data can be mapped to archetypes once only, and transformed into a validated and consistent format; new data can be captured and aggregated according to the same national archetype definitions.
- Data stored in a common representation can be more easily aggregated and integrated.
- Access to valuable data that would otherwise be unavailable.

Agreed and shared representations of the health information, embracing existing stakeholder requirements and developed rapidly by an active online community, will kick-start and accelerate many currently fragmented activities within the Canadian eHealth ecosystem. It will impact significantly on new and future activities by not having to create these clinical content definitions each time from scratch. Similarly, existing clinical systems will be able to leverage the agreed content definitions as a roadmap towards achieving full data conformance over time.

By driving and coordinating a formal archetype development, collaboration and publication effort, the CFPC will become the national leader in the push toward safety and quality in eMRs and CHI will harness the collective intelligence of the breadth of the Canadian clinical stakeholder community. As a result, Canada will hold a unique resource of nationally agreed, structured and computable health information definitions that will provide a robust and solid

foundation for all current and future eHealth activities. Sharing archetypes as the definition of our health information will not only provide a common basis for recording clinical information but also simplify the exchange of health information, aggregation of data for research and secondary uses such as public health reporting. Perhaps even more compelling, we are making certain that our domain experts, the clinicians themselves, warrant that the data within our eMRs, and flowing between healthcare providers, is safe and 'fit for purpose'.

Heather Leslie, Sam Heard, John Hughes
September 2010