Data formats

### Standard

* [ASC X12](https://en.wikipedia.org/wiki/ASC_X12) ([EDI](https://en.wikipedia.org/wiki/Electronic_Data_Interchange)) – transaction protocols used for transmitting patient data. Popular in the United States for transmission of [billing](https://en.wikipedia.org/wiki/Invoice) data.
* [DICOM](https://en.wikipedia.org/wiki/DICOM) – an international communications protocol standard for representing and transmitting radiology (and other) image-based data, sponsored by [NEMA](https://en.wikipedia.org/wiki/National_Electrical_Manufacturers_Association) (National Electrical Manufacturers Association)
* [HL7](https://en.wikipedia.org/wiki/Health_Level_7) – a standardized messaging and text communications protocol between hospital and [physician](https://en.wikipedia.org/wiki/Physician) record systems, and between [practice management systems](https://en.wikipedia.org/wiki/Medical_practice_management_software)
* [Fast Healthcare Interoperability Resources](https://en.wikipedia.org/wiki/Fast_Healthcare_Interoperability_Resources) (FHIR) – a modernized proposal from [HL7](https://en.wikipedia.org/wiki/HL7) designed to provide open, granular access to medical information
  + [Fast Healthcare Interoperability Resources](https://en.wikipedia.org/wiki/Fast_Healthcare_Interoperability_Resources) (FHIR) is a [Health Level 7](https://en.wikipedia.org/wiki/Health_Level_Seven_International) interoperability specification that defines [JSON](https://en.wikipedia.org/wiki/JSON) and [XML](https://en.wikipedia.org/wiki/XML) data formats and a [RESTful](https://en.wikipedia.org/wiki/Representational_state_transfer) [API](https://en.wikipedia.org/wiki/Application_programming_interface).[[63]](https://en.wikipedia.org/wiki/List_of_open-source_health_software" \l "cite_note-63)[[64]](https://en.wikipedia.org/wiki/List_of_open-source_health_software" \l "cite_note-64) It is available under the [CC0 license](https://en.wikipedia.org/wiki/Creative_Commons_license" \l "Zero_/_public_domain) [[https://en.wikipedia.org/wiki/List\_of\_open-source\_health\_software#Specifications](https://en.wikipedia.org/wiki/List_of_open-source_health_software" \l "Specifications)]

Open specifications

* [openEHR](https://en.wikipedia.org/wiki/OpenEHR): an open community developed specification for a shared health record with web-based content developed online by experts. Strong multilingual capability.
* [Virtual Medical Record](https://en.wikipedia.org/wiki/Virtual_Medical_Record): HL7's proposed model for interfacing with clinical decision support systems.
* SMART (Substitutable Medical Apps, reusable technologies): an open platform specification to provide a standard base for healthcare applications.

Open-source Healthcare Software

<https://en.wikipedia.org/wiki/List_of_open-source_health_software>

* OSCAR (Developed from McMaster University) [Krishna U will setup server running EHR]
  + Site: <http://oscarcanada.org/>
  + Software: <https://bitbucket.org/oscaremr/oscar/src/stable/>
  + User Manual: <http://oscarmanual.org/>
  + Server-side Manual: <https://oscaremr.atlassian.net/wiki/spaces/OS/overview>

Patient Information

<https://www.infoway-inforoute.ca/en/solutions/digital-health-foundation/understanding-ehrs-emrs-and-phrs>

# Understanding EHRs, EMRs and PHRs

Electronic health records (EHRs), electronic medical records (EMRs) and personal health records (PHRs) are similar terms but have different definitions and distinct purposes. At Canada Health Infoway, the terms are defined as follows:

* Electronic Health Record: An electronic health record (EHR) refers to the systems that make up the secure and private lifetime record of a person's health and health care history. These systems store and share such information as lab results, medication profiles, key clinical reports (e.g., hospital discharge summaries), diagnostic images (e.g., X-rays), and immunization history. The information is available electronically to authorized health care providers.
* Electronic Medical Record: An electronic medical record (EMR) is an office-based system that enables a health care professional, such as a family doctor, to record the information gathered during a patient's visit. This information might include a person's weight, blood pressure and clinical information, and would previously have been hand-written and stored in a file folder in a doctor's office. Eventually the EMR will also allow the doctor to access information about a patient's complete health record, including information from other health care providers that is stored in the EHR.
* Personal Health Record: A complete or partial health record under the custodianship of a person(s) (e.g. a patient or family member) that holds all or a portion of the relevant health information about that person over their lifetime. This is also a person-centric health record, but unlike the EHR, the patient has control or “custodianship” over the record, rather than the health care provider.

User data access requirements

[Personal Information Protection and Electronic Documents Act](https://en.wikipedia.org/wiki/Personal_Information_Protection_and_Electronic_Documents_Act) (PIPEDA) was given Royal Assent in Canada on 13 April 2000 to establish rules on the use, disclosure and collection of personal information. The personal information includes both non-digital and electronic form. In 2002, PIPEDA extended to the health sector in Stage 2 of the law's implementation.[[63]](https://en.wikipedia.org/wiki/Electronic_health_record" \l "cite_note-63) There are four provinces where this law does not apply because its privacy law was considered similar to PIPEDA: Alberta, British Columbia, Ontario and Quebec. (<https://en.wikipedia.org/wiki/Electronic_health_record>)

PIPEDA has following clauses (<https://en.wikipedia.org/wiki/Personal_Information_Protection_and_Electronic_Documents_Act>):

The *Act* gives individuals the right to

* know why an organization collects, uses or discloses their [personal information](https://en.wikipedia.org/wiki/Personal_data);
* expect an organization to collect, use or disclose their personal information reasonably and appropriately, and not use the information for any purpose other than that to which they have consented;
* know who in the organization is responsible for protecting their personal information;
* expect an organization to protect their personal information by taking appropriate security measures;
* expect the personal information an organization holds about them to be accurate, complete and up-to-date;
* obtain access to their personal information and ask for corrections if necessary; and
* complain about how an organization handles their personal information if they feel their privacy rights have not been respected.

The *Act* requires organizations to

* obtain consent when they collect, use or disclose their personal information;
* supply an individual with a product or a service even if they refuse consent for the collection, use or disclosure of your personal information unless that information is essential to the transaction;
* collect information by fair and lawful means; and
* have personal information policies that are clear, understandable and readily available.

[Although PIPEDA is federal, it has been "substantially similar" with each unique provincial acts]

The *Personal Health Information Protection Act*, known by its acronym **PHIPA** (typically pronounced 'pee-hip-ah'), established in 2004, outlines privacy regulations for health information custodians in [Ontario](https://en.wikipedia.org/wiki/Ontario), Canada. Breaches of PHIPA are directed to the Ontario Information and Privacy Commissioner.[[17]](https://en.wikipedia.org/wiki/Personal_Information_Protection_and_Electronic_Documents_Act" \l "cite_note-17)

The *Personal Health Information Protection Act* serves three important functions:

* To govern the collection, use and disclosure of personal health information by health information custodians.
* To provide patients with a right to request access to and correction of their records of personal health information held by health information custodians.
* To impose administrative requirements (regulations) on custodians with respect to records of personal health information.

Patient access to information

<https://www.infoway-inforoute.ca/en/what-we-do/blog/access-to-care/8495-patient-access-to-their-health-information-is-growing-but-there-is-still-work-to-be-done>

This analysis revealed that while eight in 10 Canadians wanted access to their personal health information, only four per cent had accessed it electronically.[[1]](https://www.infoway-inforoute.ca/en/what-we-do/blog/access-to-care/8495-patient-access-to-their-health-information-is-growing-but-there-is-still-work-to-be-done" \l "ftn1)

Provincial and regional portals are now available for all citizens in [Quebec](https://carnetsante.gouv.qc.ca/portail), [Alberta](https://myhealth.alberta.ca/myhealthrecords) and [Saskatchewan](https://www.ehealthsask.ca/MySaskHealthRecord/MySaskHealthRecord) as well as many in British Columbia and Ontario. Many Canadians in British Columbia and Ontario have also been accessing their lab results through lab service providers. At the more local level, a growing number of hospitals and primary care practices also offer patient access to personal health information through tethered portals. Finally, provincial immunization records are available to citizens in Ontario.

<https://www.infoway-inforoute.ca/en/what-we-do/blog/digital-health-records/8724-supporting-patients-digital-health-literacy>

Let’s think about a hypothetical patient and the ways in which they may now be engaging with the health care system. Perhaps, like many Canadians, they use their smartphones in many aspects of their lives – but now, it’s much easier to schedule a virtual visit with their primary care provider, using an app for a secure video call. If a medication is prescribed, their provider might send the prescription digitally to the patient’s pharmacy of choice through an e-prescribing service like [PrescribeIT®](https://prescribeit.ca/).

Or perhaps our hypothetical patient has a chronic condition tracked at home through a Remote Patient Monitoring (RPM) device. Imagine that they also view their lab results through a patient portal and communicate with their circle of care through a secure messaging system. As our patient accesses this combination of modern tools and modes of communication, a new way of providing care emerges, in which clinicians work with patients to keep them safe at home during challenging times.

[https://www.infoway-inforoute.ca/en/what-we-do/progress-in-canada#](https://www.infoway-inforoute.ca/en/what-we-do/progress-in-canada)

* EMR use results in health system level benefits, such as reduced numbers of duplicate tests and adverse drug events.
* Advanced use of EMRs can improve health outcomes and patient safety through preventive care and chronic disease management.
* 93 per cent of physicians who use an electronic medical record said EMRs allow them to provide improved patient care.
* 63 per cent of patients who have used digital consumer health solutions said they avoided an in-person visit because they could request a prescription electronically.
* 100 per cent of Canadians have at least one hospital clinical report, or their immunization record, available in electronic form, and their authorized clinicians can access this information outside of a hospital.
* 100 per cent of diagnostic images taken in Canadian hospitals are filmless, and stored in a repository for access by authorized clinicians.
* Drug dispensing profiles for 72 per cent of Canadians are now available for access by authorized clinicians.
* 85 per cent of Canadian primary care doctors and 79 per cent of community specialists are using electronic medical records to record patient encounters.
* Laboratory test results for 97 per cent of Canadians are available electronically for access by authorized clinicians.
* 36% of patients with online access to their health information avoided an in-person visit.
* 67% of patients with access to their health information felt better able to manage their health.
* 81% of Canadians who use virtual care services are satisfied.
* Canadians had more than 1 million telehealth consultations in 2018, an increase of more than 500% since 2010.
* Canadians avoided more than $420 million in expenses and saved more than 280 million kilometers in travel by using telehealth to access specialized care.
* 92% of primary care physicians who use a broader suite of functions in their EMR report they are more efficient.
* 82% of primary care physicians (and 77% of specialists) say they provide more efficient care with electronic records.

Other sources:

* Communication Systems in Healthcare [<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1579411/>]
* Electronic medical records and communication with patients and other clinicians: are we talking less? [[https://pubmed.ncbi.nlm.nih.gov/20499485/#:~:text=EMRs%20assist%20real%2Dtime%20communication,pose%20a%20distraction%20during%20visits.](https://pubmed.ncbi.nlm.nih.gov/20499485/" \l ":~:text=EMRs assist real-time communication,pose a distraction during visits.)]
* Helping clinicians and patients navigate electronic patient portals: ethical and legal principles [<https://www.cmaj.ca/content/cmaj/191/40/E1100.full.pdf>]
* SMART on FHIR: a standards-based, interoperable apps platform for electronic health records [<https://academic.oup.com/jamia/article/23/5/899/2379865>]