

# Developing a voluntary emergency health record for children in Ontario: a significant step towards a lifetime health record

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**Abstract:** The province of Ontario in Canada is planning to create a longitudinal electronic health record (EHR is a lifetime record of an individual's key health history and care within the health system) for each of its 12 million inhabitants. The province has funded the development of the electronic Child Health Network (eCHN), an advanced example of an integrated and shared EHR from multiple systems at multiple sites for the benefit of patients and clinicians. eCHN offers the province the foundation of a voluntary emergency health record for children.

**Keywords:** longitudinal, paediatric, child, EHR, privacy,

## 1. Background

The purpose of this paper is to examine the possible steps that can be taken in the Canadian province of Ontario towards the development of an emergency health record for children and adults by building on the early success of a partial shared and integrated health record for children. This paper will first outline the history of the current record and then propose a possible approach to using that record as a platform for a province-wide emergency health record.

The current record is only a partial but a useful one. It provides four of the key data domains that health care providers consider to be amongst the most essential: first, admission, discharge and transfer data; second, transcribed reports, such as clinic notes, operative notes and discharge summaries; third, laboratory reports; and, fourth, radiology reports and images. These records originate in various health information systems that are located at various hospitals throughout the province and are sent, in real time, to a central repository, from which they can be viewed by authorised health care providers.

The stated aim of the provincial government is to build an emergency health record for children and adults. This record, eventually, should be available to any physician or other health care provider who may be called upon to look after a patient whose health record is not immediately available at that location. It is believed that often the history of the patient is crucial for the provision of proper care and the avoidance of errors that could hurt, rather than help, the patient. Building such a record is expected to be a lengthy and costly enterprise.

So far, the government has funded the establishment of a network that is providing a partial record and is moving in the direction of the province-wide, comprehensive record. The network is called the electronic Child Health Network (eCHN). It links 10 health care provider centres (six hospitals on eight sites, including a tertiary acute care hospital, a tertiary chronic and rehabilitation hospital, four community hospitals that serve as regional paediatric centres, a children's treatment centre, and a home nursing agency). It is currently funded to add at least 16 more hospitals and several other health care provider organisations in the coming year.

The Province of Ontario is often called Canada's engine of growth. It is by far the largest of the country's 10 provinces, with a population of about 12 million people. It is estimated that about 25 per cent of the total population or about 3 million people are under 19 years of age and are, therefore, considered, by definition, to be paediatric patients or "children." (Few of those between the ages of 14 and 18 would consider themselves to be "children" but, as far as the healthcare system is concerned, they are.)

Health care in Ontario is universally available to all residents at no cost to the individual. The Ontario Health Insurance Plan (OHIP) covers the full cost of all necessary diagnostic and treatment medical services for all citizens and most permanent residents in Ontario.

This coverage includes physician examinations, medical testing, emergency care, hospital care, optometry services, and emergency dental care. The hospital system is currently organised into 96 hospital corporations (with about 150 sites) across the province, ranging from community emergency facilities to speciality and research hospitals. The Ontario Ministry of Health and Long-Term Care is responsible for regulating and administering healthcare to all Ontarians.

## **2. Sick Kids**

Probably the best known of the speciality hospitals outside of Canada is The Hospital for Sick Children in Toronto, the provincial capital city. Popularly known as "Sick Kids" to nearly everyone in Canada, it is Canada's leading children's hospital. Its 127-year history is a one of innovation and excellent patient care. One of its great strengths is its role in the evolution of child health practices and knowledge. Through its role in direct patient care, the hospital refines and perfects new methods of treatment every day.

Through its role as a research institution, the hospital advances the world's understanding of the factors, which affect a child's health and aims to make discoveries, which can then be applied to improving that child's health. Research at the hospital began in 1918 with the development of the Nutritional Research Laboratory, where Pablum was developed in 1930. The HSC Research Institute was established in 1954. Today, the Research Institute houses a full spectrum of research, from bench to bedside. Sick Kids' scientists receive worldwide recognition for their discoveries and their contribution to global scientific knowledge. Some of their best-known discoveries include the identification of several disease-causing genes, such as those for Duchenne muscular dystrophy, cystic fibrosis, and Wilson disease. In 1969, Sick Kids' kidney transplant program began. In 1995, the 500th transplant was carried out. In 1972, Canada's first bone marrow transplant program began at Sick Kids. Today, Sick Kids has one of the two largest centres for bone marrow transplants in North America, with approximately 75 transplants performed each year.

In addition, Sick Kids has been leading the way in technological innovation, both in information and diagnostic services. For example, in 1979, Sick Kids pioneered a 24-hour-a-day, seven day-a-week paediatric telephone triage system that in the past year was subsumed by Ontario's new population-wide telephone triage program. Similarly, Sick Kids pioneered the Ontario Regional Poison Information Centre programs in Toronto. The Poison Centre has been serving the general public and healthcare professionals throughout Ontario since 1978. Its primary role is to provide telephone information and advice about exposures to poisonous substances 24 hours a day, seven days a week. Sick Kids' introduction of Canada's first functioning integrated and shared electronic health record was very much in keeping with this history of innovation.

In 1994, Sick Kids developed for itself a new "vision" that saw its future as "a children's hospital without walls." It recognised that the hospital's most important strength was the knowledge that resided within the institution, rather than the direct provision of expert care to individual children. (The hospital is affiliated with the University of Toronto and many of its professional staff members are cross-appointed to the University of Toronto.) And so, Sick Kids proposed a plan for a Child Health Network for the Greater Toronto Area. The purpose of this network was to be the sharing of the knowledge that resides in Sick Kids and to recognise patient care in a more efficient way through the creation of regional paediatric centres. The idea was to create smaller regional centres of excellence, so that fewer children would need to be diagnosed or treated at Sick Kids, but the same level of care could be made available to them at the other centres. Sick Kids would remain involved as the centre of this system, but would actually need to admit or treat only the most complex or difficult tertiary or quaternary cases. But Sick Kids' knowledge and expertise would remain, continue to grow and would be shared with the rest of the region, province and country.

In 1996, the Metropolitan Toronto and District Health Council endorsed the Sick Kids vision and in its hospital restructuring report recommended the establishment of a Child Health Network for the Greater Toronto Area. The provincial government quickly accepted the recommendation and in 1997, through its Health Services Restructuring Commission, directed the establishment of such a network as well as four other regional child health networks in the province. Officials and clinicians from Sick Kids and all the other hospitals in the Toronto region began planning to set up the new network. They soon realised that an electronic enabler was required to share the data, information and knowledge that were to be the lifeblood of the new network.

Sick Kids began to research possible software products with which it could build a shared and integrated health record. It was looking for a software application that eventually might be able to serve not only the hospital's own paediatric population, but the entire province's paediatric population, and eventually be scalable and extensible to serve the entire 12 million population of children and adults. An important pre-condition was to find a solution that did not require hospitals to replace any of the systems they had already purchased and were already using for their own purposes. Moreover, it was not considered desirable to require any hospitals to limit their future choices in purchasing any health information system from any vendor that they felt was most advantageous for their own needs. In other words, maximum autonomy and maximum flexibility for the future were the absolute prerequisites for whatever system was to be chosen. After considerable 'due diligence,' Sick Kids concluded that there was only one application on the market that could meet its needs. It was an IBM application called Health Data Network (HDN). (Since then, IBM changed the name to Health Network Services or HNS).

### **3. Proof of Concept**

With the help of IBM and funding from the provincial government, the hospital began to build the Proof of Concept for the electronic network. It took a couple of years to get the network to the point where it was possible to start aggregating the data from more than a dozen different vendor systems at five different locations within about a 100-mile radius. The network actually went live a year or so later. It has been functioning for about three years. Since then two more hospitals have been integrated and about 75 physicians' offices have been added. The physicians cannot contribute any additional data, but they are able to access the aggregated data from the various hospitals' databases. Thus, they are able to follow the progress of their patients as the patients are referred to community hospitals, tertiary care hospitals or home nursing care.

The provincial government decided to fund the network, because it saw the project as an early pilot towards the provincial vision for e-health. In 1997, there were no examples of electronic health records that the province could emulate. However, with the reputation of Sick Kids and IBM, the government felt that it was a risk worth taking. The provincial government hedged its bets by funding various pilot projects and planning exercises. It turned out that eCHN was the only successful implementation of an actual functioning shared and integrated health record.

An important factor in the planning of the electronic network was that it was always intended to be flexible and scalable. This was important to the government, which had a vision for creating a population wide and province-wide longitudinal health record. The architecture for the electronic Child Health Network was such that it could serve as the start of a comprehensive, shared electronic health record system. It was designed so that it could work with any existing system and other networks. It was to become a secure, electronic centralised database of Ontario children's health records, accessible only to authorised, participating health care professionals.

One of the reasons for the enthusiasm with which this shared and integrated electronic health record was greeted was the perceived limitation of the existing paper-based health record system. Partial records were often located at multiple sites, but no one had a consolidated or integrated record. Even within a single site, there was only one copy of the record available. This meant that charts were sometimes not available when they were required for clinical decision making. Moreover, for some reports, such as laboratory results, multiple versions of clinical information were issued, as further tests were completed, but there was a lack of clarity as to which report was the most recent. Community physicians, whose patients were being cared for at the hospitals, did not have convenient access to institutional records when they needed them. Whether the physician was located 10 miles or 100 miles or 1,000 miles from the hospital, she could not follow her patient's progress from the charts without going to the hospital.

### **4. How it works**

(A brief explanation of how the electronic network functions is in order here. Each hospital has a number of electronic information systems for various purposes. These include admission, discharge and transfer data, transcribed reports of clinic notes, operative notes, and discharge summaries, laboratory reports, and radiology reports. Typically each of those four systems is sold by a different vendor and cannot exchange or transfer information to another system at the same hospital. Nor can these systems exchange or transfer data or information to systems at other hospitals. The electronic

Child Health Network enables each of those 22 systems to transfer data and information to a central repository, from which each authorised user can view an aggregated and integrated version of all the partial records that normally live in each of the information systems at each of the hospitals. Typically, the users are physicians and nurses, although a few therapists also have been given access. The participating hospitals control access to the records, as they would to their paper records.

(The security of the records is ensured not only in a similar fashion to the physical security of paper charts, but also in several other ways. While the paper records can be accessed from a secure area of the hospital, normally the health records department, the electronic records can be accessed only from a secure area of the hospital or the physician's office. The individual hospital must assign a "User Name" and a "Password" to each user for that person to be able to view the charts. The data itself is transmitted through a Private Network, rather than through the Internet or a shared network. The system is set up in such a way that it locks away the chart after a timed interval and automatically logs off the user. An audit trail is kept of all the users who have viewed a chart. That audit trail is available to administrators for spot check purposes, with sanctions provided for unauthorised or inappropriate viewing of any charts. The stated policy of the network is that users have a professional responsibility to protect the privacy and confidentiality of the records. Anyone who breaches that professional trust is subject to disciplinary action.

(The record contains only consented data. The consent administration relies on individual patients (or their parents) giving informed consent to the hospital to permit their records (or their children's records) to be shared with other members of the network. Before being admitted to one of the eCHN member hospitals, a family receives written information that explains what the network is, why it exists and what it does. When the family arrives at the hospital, it is asked to sign a consent form. Only if the form is signed, does a flag go on to the child's record, signifying that consent has been given and the data in the file may be transferred into the shared and integrated database. If consent is withheld, or if the registration clerk forgets to ask for the consent, the patient's data is not transmitted to the shared database and is not available for viewing at other hospitals or at the family paediatrician's office.

(The Medical Entities Dictionary (MED) is a unique tool that the network uses for harmonising the data that originates from the diverse information systems at the various hospitals. The MED contains a list of the original test codes and descriptions of the laboratory (and diagnostic imaging) procedures from each of the hospitals, cross-coded according to the Laboratory Observation Identifier Names and Codes (LOINC) system. For laboratory procedures, this cross coding permits the conversion of results to a common enterprise unit of measurement, facilitates the aggregation of results from different institutions, and supports the development of an enterprise-wide reference range. The Regenstreif Institute at Indiana University and Purdue University, in Indianapolis, USA, owns the copyright for LOINC and maintains the system. There is no charge or licence fee for using the LOINC codes.)

The network is serving health care providers with faster and more accurate information that is readily available when and where it is needed for immediate care. Its benefits can be shown to advantage patients, clinicians, institutions and the provincial system as a whole. For patients, it helps to reduce the number of unnecessary repeat tests for children; it ensures that the chart is available when and where required; and, that accurate information is kept on file. Moreover, it helps to achieve improved outcomes for patients, including less inconvenience and fewer delays in treatment. For clinicians, the system ensures that the charts are legible and available when and where needed, so they can provide coordinated care to their patients, for better clinical decision-making. For the institutions, it reduces the costs for the distribution of reports, it improves service to referring physicians, it improves service to patients and families through a reduction in repeat questioning, more timely availability of results and contributing to a more complete personal health record. For the health care system, it helps to reduce costs and become more efficient by avoiding unnecessary duplicate testing, based on timesaving and less duplication of tests. It also provides a model for other populations, such as regions (north, southwest, east), age groups (such as geriatric care) or disease groups (such as cancer care or cardiac care). Increasingly, users, administrators and observers are looking at it as a model for a voluntary emergency health record for all the children and adults in the province.

## **5. Emergency record**

While this network was being developed, the provincial government was also planning an overarching infrastructure to serve the health sector. It had developed a vision for e-health in the province. To this end, it established a number of sub-sectoral e-health councils, including one for physicians,

one for community care organisations and one for hospitals. The mandate of these three councils was to advise the government on e-health priorities. The Ontario government also established Smart Systems for Health (now known as the Smart Systems for Health Agency—SSHA) to provide a secure, integrated province-wide information technology infrastructure to allow electronic communication among Ontario's health service providers. SSHA was intended to begin to transform the delivery of healthcare services in the province. SSHA was planning to build a common electronic information technology infrastructure for the province's health care system, including a secure network and a state-of-the-art data centre. It also embarked on a series of initiatives, which were designed to help to achieve the transformation of healthcare service delivery. The agency's mandate is to provide the secure, integrated, province-wide information technology infrastructure to allow electronic communication amongst Ontario's health service providers.

A key undertaking of SSHA is the development and implementation of a voluntary Emergency Health Record (EmHR). This is intended to be an electronic health record that contains the information most often required during the provision of emergency healthcare services. It will offer authorised healthcare providers secure access to shareable, clinically relevant information in a timely manner. This information is intended to aid clinicians in the decision-making process, improve patient care and outcomes, and enhance provider productivity and efficiency. Over time, this should evolve into a longitudinal EHR (a lifetime record of an individual's key health history and care within the health system). There are many possible ways to achieve that goal.

In any case, it will need to result in a secure, consent-based system, including a summary of essential demographic and clinical information (e.g., current and relevant past medical conditions, allergies and medications) that will inform healthcare providers and facilitate care in the absence of the patient's entire health record. This information will be similar to the contents of the Cumulative Patient Profile that primary care physicians are currently expected to create and place at the front of a patient's chart or maintain in electronic form. Information may be created and maintained by the patient's primary care physician, or others such as nurse practitioners and general specialists, when acting as the primary healthcare provider. Alternatively, clinical staff at hospitals could create it. In addition, the EmHR will include the past service encounter record of each patient. Such a record will detail a patient's interaction with the healthcare system where some service is provided, such as a consultation or surgical procedure. It is expected that the initial iteration of the EmHR will contain information about selected hospital service encounters, such as dictated reports (e.g., consult notes and discharge summaries), visit records (e.g., emergency room (ER) visits and outpatient clinic visits), and diagnostic test results.

One possible approach to achieving this EmHR, would be by building on the foundation of eCHN. The focus of eCHN has been on paediatric patients, primarily due to the fact that it was designed and built as the communication enabler for the Child Health Network for the Greater Toronto Area. An immediate and logical next step would be to expand the current network to cover the rest of the province. At the same time it would be possible to work on turning the current partial record into a full EmHR for the entire 3-million paediatric population of the province. If that were done, 25 percent of the population would have an Emergency Health Record. The eCHN chart already includes that part of the past service record that pertains to hospital visits and encounters (both in-patient and out-patient ones). As for the essential patient demographic and clinical information (variously called the Core Data Set, Cumulative Patient Profile or Pertinent Medical Data), the eCHN cumulative chart already contains such a section. A logical progression would be a geographical expansion of the children's network across the entire province, followed by a functional expansion to add more data that may be required by clinicians, before moving to other age groups or the entire adult population. Sometimes, it is more prudent to build systems in a modular fashion, rather than trying to do too many things all at the same time. While it is not yet known what approach the provincial government will follow for the creation of the EmHR, there is some evidence that it may take the slow, step-by-step, modular expansion route. Recently, it announced that it would fund the expansion of the electronic Child Health Network into Northern Ontario, a vast area of the province that is relatively sparsely populated but covers a geographic area that is larger than the United Kingdom and France put together.

## **6. Benefits**

This sample of the paediatric population has allowed eCHN to prove the technical infrastructure and application software. In the long run, the network does not have to be limited either to the Toronto

area or to paediatric patients. In fact, the current method for capturing paediatric patient records from the various information systems of the various hospitals involves screening out two large groups of all the patients seen at the member hospitals: those who are 19 years of age or older and those who have not consented to having their data shared with other health care providers are filtered out. The age filter could be removed in the future, if the provincial policy were to expand the record to patients who are 19 years of age or older. Through the paediatric focus, eCHN has demonstrated the software application, hardware infrastructure, and medical record (consent) process to be a robust vehicle for future expansion.

The benefits of this type of network are significant for a government looking to continue to enhance what is already a very good healthcare system. In this instance, the patients benefit, because charts are available when and where they are needed. There is a reduction in unnecessary duplicate interviewing and testing, and accurate information is kept on file. The clinicians benefit, because the charts are not only available, but are legible (something that cannot always be guaranteed with physicians' handwritten notes), and the charts are always at the correct location and always indicate the latest version of any report. The institutions benefit, because of the reduction in the cost for the distribution of reports, improved service to patients, reduction in questioning of patients, more timely availability of results, improved service to referring physicians, and contributing to a complete personal health record. The health system benefits from the cost savings achieved through a reduction in duplicate testing and interviewing as well as the greater likelihood that medical errors would be avoided as clinicians base their decisions on more complete and accurate data and information.

Despite these benefits, the public does not always see the advantage of electronic record keeping and sharing. There is a good deal of suspicion and concern about e-health initiatives, including EHRs. Until and unless people have some personal experience with such initiatives, they often remain sceptical. They are concerned about costs and confidentiality. The biggest boosters of the eCHN system are the parents of children with really complex cases, including cancer and chronic cardiac problems. They are the people who have testified to the benefits of this type of a service, based on their own experience with the health care system. They are the best people to put in perspective the issue of privacy and confidentiality. The province already has in place privacy and confidentiality laws. It is currently considering adding new levels of confidentiality restrictions, specifically for e-health transactions. ECHN meets and exceeds the existing legal privacy requirements. While it could be legitimately argued that children's medical charts would not be of much interest to anyone other than the children's family and clinicians, it is, nevertheless, important, on principle, to protect their privacy to the maximum level possible.

The story of Jason Pinney illustrates the value of this type of record. Jason Pinney is 16 years old and lives with his parents and sister in the West End of Toronto. He has had more than his fair share of health problems. At the age of 10, he was diagnosed with epilepsy, after suffering a seizure episode that lasted about 90 seconds. It turned out that he suffered hundreds of seizures a day. About six months later, he was diagnosed with a rare form of cancer that required an immediate operation at The Hospital for Sick Children.

Originally, Jason was a patient at Toronto's St. Joseph's Health Centre, where he was under the care of Dr. Mark Feldman, the hospital's Paediatrician-in-Chief. Dr. Feldman referred Jason to the specialists at The Hospital for Sick Children. At that time, Jason's mother, Chryse Gibson, had to go to St. Joseph's Health Centre, to pick up Jason's health records, including his diagnostic images and charts, and personally deliver them to Sick Kids.

A couple of years later, with the advent of eCHN, Ms. Gibson was one of the first parents to consent to having Jason's health records integrated and shared amongst all the doctors and other health care professionals at both facilities. Since then, Dr. Feldman and the other doctors, nurses and therapists at both hospitals have been able to view the latest notes about Jason from at least eight different information systems at the two hospitals. Dr. Feldman can also look at Jason's X-rays that are kept at Sick Kids from his office at St. Joseph's or even his community office at a different location. Here is how he explains how he uses the network.

"Jason is a kid whom I follow at SJHC with regard to epilepsy and school problems and was followed at HSC for cancer. Epilepsy drugs and cancer drugs may interact - I knew exactly what he was on. If

the parents had questions about his cancer treatments, I could answer some of them. If HSC had questions about his epilepsy treatment - they could get the info immediately. If he presented to either ER with symptoms related to his cancer or its treatment, his epilepsy or its treatment or unrelated problems requiring a treating MD to know his history in detail - eCHN made this possible.”

Jason’s mother, Ms. Gibson, explains that another reason she was happy to give consent to having Jason’s health records included in the network is for future reference. “If he is ever taken to an Emergency Room, whether he is conscious or unconscious, I want somebody there to know what that big scar (53 stitches) is all about. I want them to know that his epilepsy is gone. I want them to be able to get on with trying to figure out what may be wrong with him at that time, rather than trying to figure out what his history might be. That part is known and it’s all there for them to see. ”

The challenge is to take eCHN to the next level -- from an integrated and shared EHR for paediatricians to one that can also serve emergency and primary care physicians. This expanded EHR must offer authorised healthcare providers secure access to shareable, clinically relevant information in a timely manner. It should take into account the needs of the physicians and other healthcare providers and fit into the provincial government's plans for the medium and long term. It would appear that the proven success and future expansion of the electronic Child Health Network could represent a significant step towards the development of a more complete provincial voluntary Emergency Health Record.