



► **REPORT**
from England

The Electronic Health Record Journey Into Uncharted Territory: Early Messages From the English Scouts

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ABSTRACT

England's Electronic Record Development and Implementation Programme has the overall aim of piloting electronic health record systems and concepts. This involves exploring issues associated with developing and implementing an electronic health record and using information drawn from various electronic patient record systems. As England's South Staffordshire demonstrator site illustrates, determining content for an electronic health record is a very complex process. There are also issues of consent, access and completeness — to name a few — that also need to be addressed. The electronic health record is a long and arduous journey; this article examines the many challenges that England faces.

INTRODUCTION

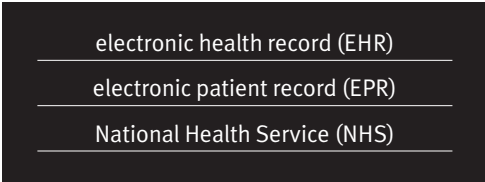
It was argued in the last edition of this journal, that England leads the way in terms of moving the health information agenda forward at a national level (Protti 2001). It was pointed out that the electronic record is central to the English National *Information for Health* strategy.

“The arguments for a move towards an electronic record are compelling. Such records are more likely to be legible, accurate, safe, secure, and available when required, and they can be more readily and rapidly retrieved and communicated. They better integrate the latest information about a patient's care, for example from different ‘departmental’ clinical systems in a hospital.” (Section 1.32)

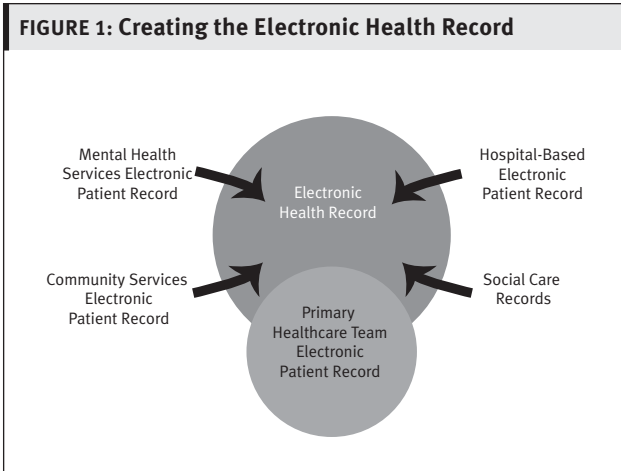
The Electronic Record Development and Implementation Programme is one of the many initiatives currently underway in England. It's the equivalent to the scouts who were sent out in advance of the early emigrant parties and pioneered the American west in the 1800s. The Electronic Record Development and Implementation Programme selection panel considered 19 pan-community (countywide) proposals and 94 focus group (individual sites), for example, hospital trust proposals, from which four and 13 sites were selected respec-

tively. One of the four pan-community sites chosen was South Staffordshire (South Staffordshire Health Community EHR Information Requirements and Data Capture Issues 2001).

The overall aim of Electronic Record Development and Implementation Programme is to scout out the issues associated with the development and implementation of a variety of electronic record systems in different contexts. The purpose of the Electronic Record Development and Implementation Programme demonstrators is to pilot electronic health record (EHR) systems and concepts. This involves exploring issues associated with the development and implementation of an EHR, using information drawn from various electronic patient record (EPR) systems in use by different clinical professionals. The pilots plan to supplement this clinical information with data entered by patients. A time scale of two years has been given to the EHR pilots. By the end of 2002, the 17 projects will have investigated, explored and implemented a variety of different approaches to a range of aspects of the electronic record agenda.



The English have a distinctly different view of the EHR and the EPR. They view the EPR as the record about the periodic care provided primarily by one institution. Typically it relates to the healthcare provided to a patient by an acute hospital but could include community and other types of facilities such as physician offices and mental health facilities. On the other hand, they view the EHR as a longitudinal record of a patient's health and healthcare — from cradle to grave. It combines the information about patient contacts with primary healthcare as well as subsets of information associated with the outcomes of periodic care held in the EPRs. Schematically, they picture the EHR as follows:



THE EHR JOURNEY IN SOUTH STAFFORDSHIRE

The EHR is a journey, not a destination (Protti 1998). The journey metaphor views the EHR as a process as opposed to a “thing” or “set of things” (such as computers, records, etc.) (Gallup 2000). A journey usually involves people traveling together. All these people have roles. Some may be guides or crew members that work together and are trained to deal with most contingencies as the ship proceeds on its journey. Others are the passengers, who trust the crew to get them to where they are going. But the experienced passenger knows that any journey can be buffeted by ill winds and that external forces can always upset the journey.

Any journey includes an element of chance or unpredictability that something unanticipated will occur on the trip. For some, this randomness provides a sense of excitement in dealing with the unknown or the unexpected. For others, it is a cause of stress and anxiety. Implementing an EPR — let alone an EHR — is very much like a major operation; the intensity of pain, time to recover, and successful outcome are dependent on the awareness, fitness, and effectiveness of the total process experience (Frohwerk, 1999). The 17 English Electronic Record Development and Implementation Programme “scouts” are out in front determining where best to ford the rivers and finding out where the hazards lay. They are an amalgam of different organizations with at least one thing in common — they are all attempting to integrate patient/client data

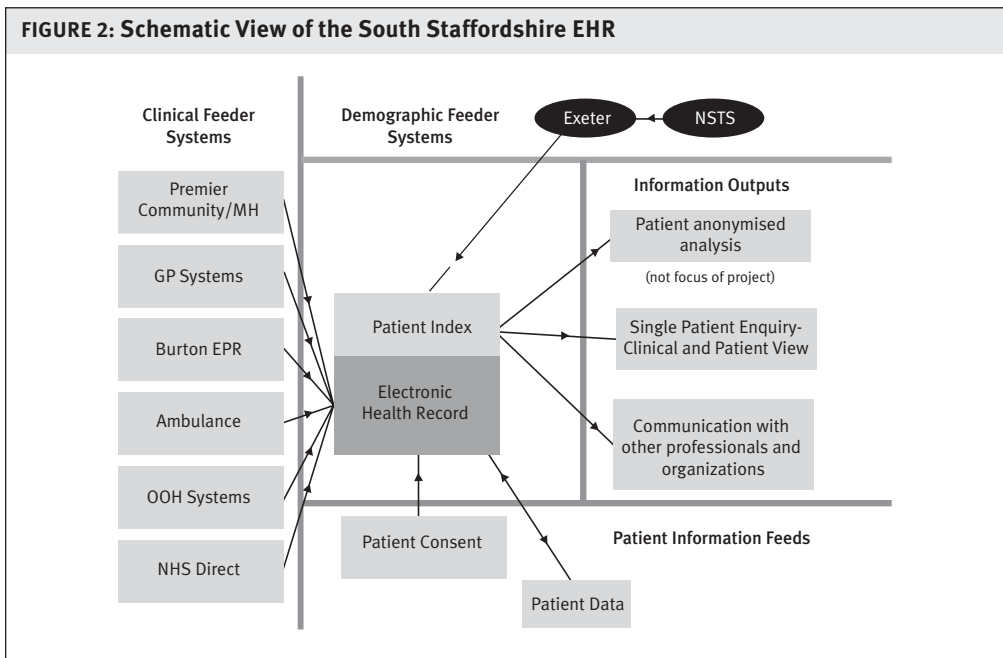
from a variety of organizations, which in the past were autonomous and independent of each other.

One of the more senior and experienced scouts is the South Staffordshire Health Community. It was successful in its proposal to be an EHR demonstrator site for several reasons:

- It recognized the successful EPR development at Queens Hospital in Burton.
- It has a strong history of pan-community development.
- Its geographical area is representative of the national NHS family.
- It has commitment from all participating organizations.
- It has demonstrated innovative and advanced thinking.
- There is a high level of clinician involvement.
- Strong technical support exists.
- It already covers a large portfolio of national targets.

South Staffordshire Health Community is made up of the South Staffordshire Health Authority and its six primary care groups, which cover the southern half of Staffordshire — a population of some 580,000 and an area of 750 square miles, with 92 GP practices. There are five trusts (hospitals) within its borders, two acute, one mental health, one community and one combined mental health, community and acute unit. It is served by an ambulance trust covering the whole county. The location and geography of South Staffordshire Health Authority is such that its population uses services from a high number of National Health Service (NHS) and other healthcare providers relative to other authorities, with nearly 40% of the acute provision being from trusts outside of South Staffordshire Health Authority’s borders. (<http://www.doh.gov.uk/nhsexipu/implement/flis/wmids/staffs.pdf>)

For purposes of clarification, following is a brief description of some of the elements in Figure 2.



NHS Strategic Tracing Service

NHS staff, subject to stringent security procedures, can use the NHS Strategic Tracing Service to obtain patient NHS numbers and a range of up-to-date administrative information. This includes name, address, date of birth, sex and, where appropriate, date of death, plus GP details for all GP-registered patients. The NHS Strategic Tracing Service database covers every patient in England and Wales.

Exeter

A system maintained by the NHS Information Authority provides core functionality for health authorities in areas such as paying GPs and managing screening activities. Each Exeter system holds a database of local patients, together with a range of supporting information (including some clinical data). The Open Exeter module gives health authorities the facility to grant online access to information held on their systems to authorized organizations.

Out of Office Hours

The system of providing primary care outside normal hours, whereby general practitioners in many parts of Britain have established coopera-

tives. They are non-commercial organizations, led and staffed by local principals in general practice, which enable doctors to spend less time on call by working within a large rota. In some cases, cooperatives have also opened primary care centres, to which patients can be invited instead of receiving a home visit. Cooperatives often have general practitioners available at the centre. These GPs give telephone advice to many patients who contact them.

NHS Direct

NHS Direct is the national, nurse-led telephone helpline (call centre), which was announced in December 1997. The purpose of the new service is to provide easier and faster advice and information about health, illness and the NHS so that people are better able to care for themselves and their families. The recently introduced Internet-based NHS Direct Online provides information on healthy living, self help, illnesses, conditions, treatments and outcomes, and nhs.uk will soon feature information on local care and services and how best to use them. NHS Direct Online is currently receiving up to 1 million hits a week from over 17,500 visitor sessions.

CONTENT OF THE SOUTH STAFFORDSHIRE EHR

As part of the Electronic Record Development and Implementation Programme process, a wide array of stakeholders were involved in defining the content of the EHR. The user groups were asked to make a list of the information about patients that they would like to have made available to support them in the delivery of healthcare. All the requests were accepted and a composite list created. This list was sent out to participants, who were asked to comment. To date, users have generally supported the collated requirements presented in this document. The requirements have been compared to those identified in the national Electronic Record Development and Implementation Programme EHR content questionnaire. The only significant differences identified to date are that South Staffordshire users additionally identified patient disabilities, aliases and preferred gender.

The composite list at present is a mixture of general and more specific data items. General requirements arise from the identification of a need for information from a source (e.g., Social Services), but an inability at this stage to identify the particular information required to be held in an EHR. The list is a wish list in that users were asked for the information that they thought could be useful in undertaking their healthcare delivery task or as a patient without any constraints being applied. Judgment has not been exercised at this stage on the feasibility of providing the relevant data, although data capture issues have been identified.

The list is summarized in Table 1. It is worth noting that, in addition to the items shown in the table, there is a need to:

- Identify the source/provenance of the data for all data items.
- Attribute to the originating healthcare professional any interpreted information or opinions, such as diagnosis or statement of symptoms.
- Access supporting information via the EHR—(for instance information about the healthcare provider or individual clinician providing the healthcare events in the EHR).

TABLE 1: Composite List of Information to Help Healthcare Delivery as Identified by Users

1	NHS Number
2	Date of birth
3	Death Details
4	Name
5	Address
6	Postcode
7	Telephone number
8	Sex/gender
9	Preferred gender
10	GP Details
11	Blood type
12	Next of kin
13	Organ donor (by organ)
14	Disability
15	Preferred language
16	Aliases (Other names is a kinder term.)
17	Religion
18	Health promotion data and chronic disease management data
19	Allergies
20	Alerts, warnings, and patient wishes
21	Ongoing medical problems
22	Past significant medical events
23	Treatments
24	Medications
25	Immunizations
26	Healthcare professional contacts
27	Conditions that may endanger patient or others
28	Alerts — non-clinical from other organizations (e.g., police, social services)
29	Flags for preventing all or parts of records being stored on EHR
30	Voluntary sector/career contacts
31	Social Services data
32	GP out of hours contact data
33	NHS Direct contact data
34	Ambulance Service contact data
35	Patient entered healthcare data/ wishes
36	Appointments booked

In the course of defining each of these data elements, a number of issues have already been identified, including data capture concerns. A few examples indicate the complexity of the process of determining the content of an EHR.

Allergies

Allergies range from reactions to drugs to reactions to particular foods or environmental conditions.

- Such information is deemed to be potentially important in emergency and immediate healthcare delivery.

- While the effects of some allergies are discernible, others may be interpretation [interpreted] by patients by cause and effect. Healthcare professionals may consider such allergies to be of dubious provenance.
- Such information can be provided to the EHR and, on the basis that data items will have their sources associated with them, healthcare professionals will be aware of the alleged allergy and will be able to pursue the veracity of the information as they see fit.
- Information about allergies is held in EPR systems but no consistent quality standards are applied.
- This is a repeating field in that there are multiple and possibly contrasting sources of this information.

Alerts/Warnings

Alerts/Warnings are considered to be factors about a patient's health that need to be drawn to the attention of another healthcare professional before or at the time of treatment.

- Alerts have particular importance within the immediate and emergency healthcare delivery.
- A consensus view on what constitutes an "alert" needs developing.
- Means of structuring or defining alerts for easier understanding are also required.

Patient Clinical Summaries

Patient Clinical Summaries are an understanding of the patient's medical history and are at the heart of providing informed and high quality clinical care that is responsive to a patient's needs.

- User requirements have been stated in terms of ongoing medical problems, significant medical events and treatments. Considerable further work on the definition and classification of these items is required, building on previous knowledge.
- The Burton Natural Community EHR Simulator developed the concept of "ongoing conditions or problems" and identified many problems in the terminology of clinical summaries. These problems remain and revolve around the separation of:
 - Ongoing clinical problems — problems or

conditions that are long term e.g., diabetes.

- Significant clinical events — these may be important for a period of time but then less so, e.g., a broken leg.
- Recent events — some trivial conditions may be important or relevant if they are very recent, e.g., sinusitis.
- In terms of summarization, a "recent event" may be also considered significant by the GP and so it could appear in "significant events" as well as in "recent events" in the EHR. Even further. If this recent event is the diagnosis or start of an ongoing clinical problem it could also be displayed in "ongoing problems" (i.e., it could be displayed in three sections, as it is an important problem that happens to be ongoing, significant and recent).

Patient Medications

For patient medications, the prescribing information was identified as a key requirement in immediate care settings.

- Different systems may currently use different drug dictionaries. The target standard — the clinical product reference source — is not yet available.
- Other issues relate to the currency of medication information and whether patients are actually or still taking the medication prescribed.
- Non-prescription medications may be recorded separately by patients as well as being sometime recorded in the GP records as over the counter medication.

Healthcare Professional Contacts

It is envisaged that every episode of care/health event is linked with the details of relevant healthcare professionals involved in the care of the patient.

- The purpose of this would be to provide the user of the EHR the opportunity for arranging appropriate follow up if necessary, as well as to readily see all of the healthcare professionals involved in patient care at any one time.
- It should also facilitate electronic communication (email) to these professionals
- Lists of healthcare professionals involved in a patient's care are not readily available.

- Within *Information for Health*, it is suggested that all healthcare professionals should be identifiable.

Conditions That May Endanger Patients Or Others

An “Alert” in the EHR would record when patients might be a danger to themselves or to their careers as a result of a medical condition.

- There are appropriateness and confidentiality issues raised by such data being available in the EHR.
- This information could be captured from EPRs, but it is not consistently recorded.
- This would be a repeating field, as there could be a multiple set of such alerts.

Flags for Preventing Records Being Stored on EHR

User groups identified that there would be a need for such functionality, reflecting statements in *Information for Health* and associated guidance. This was raised, not only for a patient to prevent information going onto the EHR, but also for the health professional to have similar control.

- The above information raises significant issues on why health professionals should need such control in general or whether this is in relation to a specific limited requirement.
- This functionality would also need to interact with EPRs.
- Patients may not object to storage of records within an organization’s EPR but could be concerned about storage within an EHR.
- The level of detail required is not yet clear, (e.g., should there just be a flag indicating that something undefined is missing, or should the flag highlight more specific areas such as organization/service/diagnosis?).

Patient Entered Data

Potential patient users have agreed that the possibility of accessing and recording information in the EHR is welcome. However, work on the content is required, even if that is to enable patients to record their comments in unstructured ways.

Issues that arise are associated with:

- Access to the EHR and the environment in which patients have access.
- What patients can see of their record.
- What can they do with their record?
- Guidelines on how to use the EHR, etc.

OTHER EHR ISSUES

In addition to content issues, there is an array of other issues, most of which are still outstanding. They provide further evidence that the EHR journey will not be without controversy, challenge and hard work. A sample of the issues identified by South Staffordshire include:

1. When Must/Should the EHR Be Used?

- Debate over whether it should be compulsory to view an EHR for each contact.
- Clinicians quite clearly believe that it should be up to them to decide when they need more information than is available from existing records or history. They regard the requirement to look at an EHR for every contact as a waste of time.
- This issue impacts most of the operational considerations relating to the use of the EHR and particularly its use as a communication vehicle.

2. Who Should Have Access to the EHR?

- Debate over the wider audience for an EHR outside immediate clinical or personal access.
- As an example, consider emergency contraception being given over the counter by pharmacists. Do they have a right/need to know if there are any contraindications?
- This raises a number of questions about whether pharmacists will need to have access.

3. Consent

- For the purposes of the initial pilot it is assumed that the patient can share all or nothing, but consideration needs to be given for the future when consent may be given to sharing different parts of the record in different situations.

4. Completeness

- How much credence can a clinician give to the completeness of the record?
- Patients can withhold consent for information

to be shared. Thus a clinician cannot be certain that a record is complete.

- This could give rise to problems where sensitive/critical information is withheld (e.g., substance abuse, termination, sexually transmitted diseases, etc).
- It is anticipated that local security policies will ensure that such sensitive information is not sent to the EHR.

5. Timeliness

- For an EHR to be of use in an emergency scenario, it must be as up-to-date as possible. Some way must be found to indicate to users how up-to-date the EHR is.
- It needs to be clear when information will be passed from an EHR (e.g., every time any entry is made, every time an episode is completed, or after a certain number of hours).
- This needs to be clearly understood to ensure that the technology can handle the potential volumes of individual data items flowing to the EHR.

6. Working Practice 1

- Feeder systems must be competent and able to pass information “instantly.”
- There is an assumption that all the existing feeder systems will be able to produce the required data in a suitable format in a timely manner.
- While this may be true for the initial pilot participants, it is not true for the NHS as a whole.

7. Working Practice 2

- If the source EPRs are not updated in a timely manner, the EHR may not serve such a useful purpose.
- Discharge summaries are not always produced electronically and thus they may not find their way onto an EHR.
- Discharge summaries that are produced electronically are not always produced at the time of discharge and thus the information does not reach the EHR in a timely fashion.
- For the majority of GP patients, having better, more timely, electronic information

from hospitals, etc. would provide more immediate benefits to provision of care than access to the EHR (seamless paperless links with hospitals, GPs, etc.).

8. Use of EHR as a Formal Communications

Medium

- There are arguments that state that the EHR should not be used as a primary communications device.
- It is argued that all clinical communications should emanate from a source EPR or from a clinician instigated action (e.g., sending a fax).
- If there are a set of actions that need to be triggered by data held only in the EHR, then a mechanism needs to be created to allow that information to be transferred directly to an organization-based system (EPR or similar).
- There is a medico legal implication. The person who sends the information is responsible for ensuring that the next professional gets it. Thus, using an EHR — which is not necessarily going to be seen by another clinician — to request information, to notify of a discharge or to cancel appointments is not valid, as there is no guarantee of it being seen by the next person.

9. Role of the EHR as a Primary vs. Secondary Record

- There is a stated assumption that the EHR is a secondary record. However, for some features, such as patient-entered information, it will be a primary record.
- There are also a number of suggested uses of the EHR where it is implied that clinicians would enter information directly onto the EHR, i.e., it could act as a primary record.
- It is thus unclear whether direct updating of the EHR is to be allowed and, if it is, there needs to be a two-way mechanism to allow EPRs to receive data from the EHR.
- The manner in which amendments to EHR data are recorded has still to be determined.
- If a patient provides more up-to-date information than is held on the EHR, then a mechanism must be in place to allow that change to be logged.

10. Simplicity of the EHR Screen

- There is a danger of having too much presented on the home page.
- The concept of traffic light warnings (e.g., a button turning red if alerts exist) will be seriously undermined if every button changes colour every time information is present.
- Warning and alert indicators should be the exception, not the rule.

11. Deletion of Data

- A general characteristic of the EHR is that it is a full birth to death record, deletions or overriding previous data items should not normally occur.
- But there is a future need to remove some information after a certain period to comply with the requirements of the Data Protection Act.
- This apparent contradiction needs to be resolved.

12. Clinical Coding in EPR and EHR System

- The viability of the use of look-up tables to translate the variety of local coding schemes into English terms in the EHR requires further research and support from the NHS Information Authority.

CONCLUSION

One of the messages coming back from the Electronic Record Development and Implementation Programme scouts is the reaffirmation that the EHR is a long and arduous journey. It is also being confirmed that there are a number of trails to follow. One of the trails is the central data repository approach where all of the patient/client data is put into one pot from which everyone shares. Another trail is the so-called “virtual” EHR, which is a collection of individual records that reside in a variety of information systems and locations and on multiple types of media. These records will collectively reflect the current health status and lifetime medical history of an individual. The EHR is “virtual” in the sense that the information will not physically reside in one place. When viewed on a computer worksta-

tion, the EHR will appear to be in one place. In reality, the individual records will be retrieved from many information systems, such as laboratory, radiology, document imaging, General Practice, community health, private care organizations, mental health services and others.

Given that there are many trails, the EHR journey involves a general direction but no specific destination point — it’s similar to the pioneers heading west and not knowing whether they were going to end up in Oregon, California or elsewhere. A number of unpredictable events have already occurred on the EHR journey — the emergence of the Internet-based personal health record being but one example. Projecting this one dynamic into the future, it is not difficult to foresee the time when patients/clients will expect their providers (physicians, hospitals, etc.) to automatically update their personal health record — the one that they control and will record their own experiences and events. The relationship or linkage between these emerging personal health records and the emerging EHR is an exciting part of the journey. It seems safe to predict that as healthcare organizations travel into the 21st century they will face many more such challenges (e.g., will the EHR/PHR be held on smart cards or other media?). As passengers and crew on this journey, how they react to these challenges will determine how smooth their trip will be and how long it will take.

Regardless of which trail is followed, what is becoming clearer is that the EHR will not be the electronic form of the old paper record; it will be something entirely different and surprisingly more intelligent than previously imagined. The EHR will be the convergence of the data that has been stored with the intelligence that has been codified and used to assist in the increasingly difficult task of diagnosing and prescribing for patients/clients who have complicated diseases or a constellation of diseases. **e**

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THE UNIVERSITY HEALTH NETWORK

The University Health Network (UHN) is one of Canada's largest acute-care teaching hospitals, comprised of four healthcare providers located in downtown Toronto: Toronto General Hospital, Toronto Western Hospital, Princess Margaret Hospital and Toronto Medical Laboratories. UHN has a long-standing tradition of patient care, education and research. In fact, it has provided care to the community for more than 200 years. UHN is also the primary teaching hospital for the University of Toronto. For additional information, please visit our website at www.uhn.ca

Shared Information Management Services (SIMS) is a department of UHN responsible for the complete spectrum of information management activities. Over the next 4 years, as part of UHN's Information Management Strategy, SIMS will be implementing an Electronic Patient Record (EPR) Strategy consisting of 5 major opportunities: migrating to an electronic patient chart (eChart Program), providing better support for clinical decision making (Clinical Decision Support Program), facilitating integration with external healthcare providers (Community Integration Program), supporting research strategies (Research Informatics Program), and implementing enterprise-wide resource management (Resource Management and Scheduling Program).

The eChart Program forms a critical component of the Information Management Strategy, focusing on automating the patient record, and eliminating the current paper record. The purpose of the eChart program is to implement a single, integrated, confidential and secure electronic record at UHN in the ambulatory and inpatient areas; to reduce UHN's dependence on the paper chart to achieve space reduction requirements; and to implement the systems which help lay the foundation for this Strategy.

Project Managers, Electronic Chart (eChart)

We currently have several openings for Project Managers, eChart. Successful candidates will demonstrate a high level of interpersonal skills and solution-oriented approaches in working with members of their team. These positions are key leadership roles within our organization. Successful candidates will gain a significant level of experience implementing complex IT solutions across multiple leading-edge platforms. Your projects will directly support patient care and high-tech healthcare equipment, and you will work on an entire range of projects, from small-scale deliverables to massive implementations. Some current projects include: implementation of an enterprise-wide ECG system, Pharmacy Order Entry, enterprise-wide deployment of a new standard clinical desktop, and implementation of a Pathology lab information system.

As an integral member of SIMS, Project Managers on the eChart team are responsible for all activities consistent with a technology implementation in a healthcare environment including:

- Leading a team in mapping business requirements to software availability by analyzing and assessing clinical and customer business information systems requirements
- Developing and monitoring of the project budget
- Project planning and control
- Implementing and supporting new systems/system solutions to meet customer requirements, technology and SIMS standards
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Required Experience and Skills:

- 2+ years of project management experience leading full project life cycle clinical systems implementations in a healthcare setting
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- Excellent verbal and written communication and presentation skills

Preferred Experience:

- A clinical background in Nursing, Cardiology, Radiology or other clinical area is highly desirable
- Knowledge of health information sciences
- Knowledge of client server environment and relational databases

Education:

- Undergraduate degree in Health Informatics, Technology Management, Computer Science, Allied Health required
- PMP designation preferred

SIMS offers a competitive compensation and benefits package. Please forward your resume in confidence, indicating position title in the subject line, to: E-mail: simsrecruit@uhn.on.ca Fax: 416 340-3818. The University Health Network thanks all applicants for their interest in these positions, however, only individuals selected for interviews will be contacted.

The Electronic Health Record
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