Case Study: Scotland's Emergency Care Summary Is a First Step Toward a National Health Information Exchange

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This report discusses the creation and implementation by the government of Scotland of a summary patient record covering Scotland's 5 million citizens. Organizations that are planning regional or national clinical information-sharing initiatives can use this report to guide their efforts.

Key Findings

- Emergency Care Summary (ECS) is a success because it met a specific business need.

- The Scottish Executive Health Department (SEHD) achieved clinician buy-in by closely involving clinicians in two key activities: selecting the data for ECS and designing the security and access protocol for ECS.

- The security and access protocol follows a two-step model: 1) information is uploaded on an opt-out basis (patients are assumed to have consented unless they opt out); 2) all accesses to patient information require explicit consent from the patient.

- A critical factor in the success of ECS was training out-of-hours staff to use ECS appropriately.

Recommendations

- Information governance is a central problem in clinical information exchange. It is essential to get agreement among clinicians on who is responsible for maintaining a patient's data, the consent model to be used and what control patients should have over who accesses their data.

- Before implementing a clinical information exchange project, ensure you conduct a baseline measurement. Otherwise there will be difficulty in demonstrating the value of the project.

- Ideally, a clinical information exchange project should be led by clinicians, as long as those clinicians are representative of the clinicians who will be using the clinical information exchange.

In previous reports, we have examined the efforts by governments to form health information exchanges (HIEs), also known as electronic health record (EHR) programs (see Note 1). Such initiatives are intended to improve the quality of care by providing clinicians with better access to appropriate and concisely expressed patient data. A central goal of many HIE initiatives is to create a "patient summary" — a set of basic data intended to help clinicians care for a patient about whom they do not have any information. SEHD designed a patient summary application — the ECS — to provide data to clinicians out of regular working hours. The need for ECS arose because most Scottish general practitioners (GPs) opted out of providing out-of-hours (OOH) care. By closely involving clinicians in the design of the system and by starting with a limited data set, SEHD has been able to gain the approval and participation of most Scottish GPs. To gain more value from ECS, SEHD plans to carefully broaden the scope of the data collected and expand access to the data.

CASE STUDY

Introduction

The four "home countries" of the U.K. (England, Scotland, Wales and Northern Ireland) have each administered their healthcare systems independently since 1999. The branch of the Scottish government that is responsible for healthcare is the SEHD. The principal healthcare delivery organization in Scotland is the National Health Service of Scotland (NHS Scotland).

The Challenge

Scotland's healthcare system suffers from the same inefficiencies in information exchange as most other healthcare systems. The impetus to create ECS came not from a conscious, strategic effort to overcome these inefficiencies. Rather, it was an opportunistic response to a change in the provision of OOH primary care in Scotland. The Scottish NHS is organized into 14 regional health boards, which own and manage hospitals and which procure primary care from GPs, who are independent contractors. Each health board operates an OOH service, staffed by nurses and GPs, that provides nonemergency primary care when GP offices are closed. Each OOH service has a central hub and between two and nine satellite centers. Prior to 2003, Scottish GPs were required by their contract with SEHD to provide OOH care. In 2003, SEHD and Scottish GPs signed a new contract, which allowed GPs to opt out of providing OOH care. Most GPs chose to opt out. GPs and SEHD agreed that, to provide adequate quality patient care, the OOH clinicians needed access to a subset of patient data from GP electronic medical record (EMR) applications (almost all GP practices in Scotland already had EMRs). ECS was designed to meet this need.

Approach

Clinician Engagement

The development of ECS took three years and closely involved clinicians. Discussions between SEHD and clinicians began in 2003. Because ECS contains data from GP applications only, the clinician organizations most closely involved were those representing GPs. These included the Royal College of General Practitioners, the Scottish GP Committee of the British Medical Association, and Scottish Clinical Information Management in Practice (SCIMP), the main GP clinical informatics group in Scotland (the ECS project board has been chaired by the head of SCIMP). Now that ECS has been implemented, the project board is being dissolved. Because the discussions were limited to GPs, SEHD did not have to negotiate the more complex field of

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hospital informatics, where there are substantial differences between the needs of doctors and nurses, academic and community hospitals, and different specialist departments.

In 2004, the GPs agreed on the minimum dataset for ECS (see Note 2), and the security and access protocol was developed by SEHD in cooperation with the clinician organizations. Agreement on the security and access protocol by GPs, and its subsequent approval by the General Medical Council and the Information Commissioner of Scotland, were critically important in clinician acceptance of ECS.

All GPs in Scotland were already connected to SEHD through NHSnet, the national network that covers the NHS in Scotland and England, and that has recently been upgraded under the English NHS's National Programme for IT. However, they were not sending any of the data included in ECS prior to the introduction of ECS.

Rollout

In 2004, pilot versions of the ECS software and database were developed, and a first set of pilot tests was completed and evaluated. In 2005, a second set of pilot tests was completed. An upload of 3.5 million records occurred in early 2006, following a public information campaign. The remaining 1.5 million records were uploaded in late 2006, and early 2007. Because each citizen has a unique healthcare ID number and is registered with a single GP practice, SEHD can ensure that each citizen has a unique ECS record.

The uploads of GP records to ECS were done on an opt-out basis after a public information campaign; patients were assumed to have agreed to having their records uploaded to ECS unless they opted out. However, to view an ECS record, clinicians must obtain explicit consent from the patient. If the patient withholds consent, the clinician cannot refuse to treat the patient despite only having limited information.

When relevant data in a patient's EMR record is changed, the EMR system generates an update for ECS. Updates are automatically pulled from the EMR systems twice daily. ECS data is stored in ECS Store, a national database. SEHD has required that all GP vendors in Scotland modify their applications to communicate with ECS Store, and this has now occurred. The General Practice Administration System for Scotland (GPASS), which was developed by NHS Scotland and is used by 85% of GP practices in Scotland, was the first application to become compliant. GPASS accounted for the 3.5 million records uploaded in early 2006. ECS did not require any changes in data terminology and coding, because ECS data is presented in read-only format and is not exchanged with other databases.

The ECS application cost approximately £500,000 to set up, and the interface work for connecting ECS to NHS 24 and the OOH applications cost approximately £2 million.

Access by OOH Clinicians

ECS was created to provide OOH clinicians with access to essential patient data. Most patients who come to OOH centers are referred by NHS 24, Scotland's national nurse call center. NHS 24 staff send electronic referrals to ECS Store that incorporate the patient's national healthcare ID number. After obtaining patient consent, OOH clinicians open the referrals from within their OOH patient management applications and pull up patient ECS records from ECS Store. Some OOH patients are walk-ins. For those patients, the OOH clinician enters as much demographic data as the patient can provide (most patients do not know their national healthcare ID number), sends a query to the ECS Store, is presented with minimal data on one or more patients who possibly match, and selects the correct patient record. ECS also has a "record reject" facility. If the OOH clinician believes the ECS record is incorrect, he or she can send a "reject" message to the ECS Store, accompanied by an explanation for the rejection. An important gap in ECS is the fact that

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OOH clinicians cannot themselves contribute data to ECS. For example, if an OOH clinician prescribes a medication to a patient, that data is not recorded on ECS, nor is it sent to the EMR system of the patient's GP. SEHD is discussing with clinicians how to overcome this gap.

Discussions About Broadening Access to ECS and Content of ECS

Since the launch of ECS, many hospital clinicians, as well as pharmacists and dentists, have been requesting access to it to provide them with summary data on their patients. SEHD ran a pilot project to provide staff at hospital accident and emergency (A&E) departments with access to ECS via a Web browser over a secure network. Anecdotal reports indicate that access to ECS data by A&E staff helped save lives, and therefore the access will be widened to A&E departments at other hospitals. SEHD and clinicians are also planning to allow patients to access their ECS data. SEHD faces the challenge of having to negotiate each expansion of access with GPs. Under the U.K.'s data protection laws, GPs are the "data controllers" of the medical records of patients registered with their practices. The data controller role requires that, before GPs allow other clinicians to access the records of their registered patients, they find out the purpose for which the data will be used.

SEHD and clinicians are discussing whether to expand the ECS dataset to include major medical events and diagnoses. It is unlikely that this will happen in the near future. The problems include the lack of a controlled medical vocabulary to normalize definitions, and the resulting variations in data quality. Many GPs fear that they will be held liable if OOH clinicians make mistakes in patient care due to misinterpretation of patient data in EMR applications.

Security and Auditing

The ECS security protocol, designed by SEHD and clinicians, states that clinicians will access only the ECS data that their user role permits them to access to care for a patient. However, SEHD has no way to ensure that security breaches do not occur. Data access requires a user name and password, and data extraction is encrypted. SEHD has chosen not to follow the example of England's NHS Connecting for Health agency and create a complex framework for Role-Based Access Control, believing that such a framework would be impossible to apply in practice in a hospital, especially in the context of emergency care. Instead, SEHD is relying on auditing. The ECS Store keeps an audit trail of all successful and attempted accesses to ECS records. GPs can access ECS Store and review the audit trail for the records of patients registered with their practice; however, up to now, few GPs have used the audit facility. Auditing is also conducted by health boards.

The Future

ECS is in transition from being a project to becoming a component of an emerging Scottish national e-health strategy. Each of the 14 health boards will have an electronic patient record comprising detailed local hospital data in local clinical databases. An extract will be kept in a national database — SCI Store (ECS Store is a national instance of SCI Store, and both ECS Store and SCI Store are managed by Atos Origin through a long-standing contract with SEHD). SCI Store would hold ECS data, laboratory results, and immunization and screening records, all of which would be accessible through a single interface. This vision is many years from reality. In the meantime, ECS is a good first step toward a national health information exchange that is intended to emerge gradually and in close cooperation with clinicians.

Results

ECS Store now contains more than 5 million patient records, accounting for almost the entire population of Scotland. Approximately 650 citizens and approximately five GP practices out of

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960 have opted out. As of June 2007, ECS was receiving approximately 41,000 accesses per week. Half were for demographic data only, and the other half for the complete ECS record including clinical data. Approximately 5,000 accesses per week come from clinicians at A&E departments.

The development of ECS has created a dialogue among SEHD, GPs and hospital clinicians about patient data. GPs in Scotland have traditionally been reluctant to share data. SEHD is advocating the view that patient data belongs to the patient, and that any clinician who needs to access the data should be able to view and modify it. Anecdotal reports indicate that ECS appears to have increased the confidence of GPs in the value of clinical information sharing, given that it was created relatively quickly, helps improve patient care and has experienced no serious problems since its launch.

Critical Success Factors

- ECS had a specific purpose and was made a clear priority by SEHD.

- Clinicians were closely involved in the concept and design of ECS. GPs decided on the dataset. The ECS project board also included clinicians from NHS 24, the OOH services and the emergency services.

- A wide variety of clinicians and medical associations was involved in developing the security and access protocol, as well as the consent model. Agreement on these documents was instrumental in securing the agreement of GPs to share their data through ECS.

- SEHD provided each health board with a project manager and funds for training and software rollout at OOH centers. The main task was training OOH clinicians on how to use ECS effectively.

- Gaining the trust of GPs was a critical prerequisite for gaining the trust of citizens and the media.

- SEHD has successfully positioned itself as the honest broker between GPs (who are reluctant to expand access to ECS because they view themselves as the guardians of their patients' records) and other clinicians (who want access to records). ECS has, therefore, helped to spark discussion among clinicians about the value and mechanics of clinical information sharing.

Lessons Learned

ECS has a few ongoing challenges:

- SEHD did not conduct a baseline evaluation of the state of OOH care before the project began. Although there was a consensus on the value and purpose of ECS, SEHD did not set up a way to measure the specific benefits it provided. As a result, SEHD cannot conclusively demonstrate the value of ECS.

- SEHD did not initially appreciate the complexity of the information governance issues raised by ECS. Under the Scottish Data Protection Act, it is unclear whether legal responsibility for patient data rests with the patient's GP, the health board or the SEHD.

- SEHD has no "watertight" solution to the problem of data security. However SEHD appears to have obtained an adequate level of trust and security to satisfy the concerns of most clinicians.

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- There are some gaps in information coverage, such as the inability of ECS to accept data from OOH clinicians, that are being gradually addressed.

RECOMMENDED READING

"Critical Success Factors for Electronic Health Record Programs (Business Strategy, Governance and Project Planning)"

"Critical Success Factors for Electronic Health Record Programs (Stakeholder and Vendor Relationship Management)"

"Electronic Health Records: Essential Functions and Supporting Infrastructure"

"Electronic Health Records: Optional Extra IT Functions"

Note 1
Digital Record Systems Acronym Confusion

In April 2004, a speechwriter for President Bush saved a few words by combining the terms "electronic medical record" (EMR) and "personal health record" (PHR) to create "electronic health record" (EHR). Subsequent U.S. government documents and the U.S. media have adopted EHR as the term describing systems that contain individualized medical information. The term EHR, however, is used in a different sense globally, where it usually refers to a nationally or regionally sponsored repository of electronic health information. Gartner uses EHR when describing the federal initiatives. In our other research, however, we use the more-precise terms — CPR, EMR and PHR (see "A Clear Definition of the Electronic Health Record").

Note 2
Data Items in the ECS Record

- Patient's demographic details: name, address, telephone number, gender

- Name of the GP practice the patient is registered with, plus GP contact

- Allergies to substances and medications

- Acute medications prescribed by a GP during the past 30 days

- All repeat medications for chronic conditions

- Technical data (such as consent status, registration status)

- Date and time of last update

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