Developing a Shared Electronic Health Record for Patients and Clinicians

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Abstract. Improving Shared Decision Making (SDM) and patient-provider communication, and providing all citizens with equal access to health information has become a high priority health policy goal. In this interdisciplinary, international research collaboration we develop and test CONNECT (Care Online: Novel Networks to Enhance Communication and Treatment), a patient portal that integrates a suite of context-sensitive patient communication and information tools into a patient-clinician shared electronic health record that patients can use seamlessly through heterogeneous networks from different locations (home, hospital, doctor’s office). In this paper we present methods used to develop CONNECT; how to safeguard data security and confidentiality and adapt user interfaces to different users, devices and contexts of use; as well as ensure safe and efficient data transfer through heterogeneous networks; and critical success factors and challenges.

Keywords: Electronic Health Record, Patient Portal, Mobile Solutions, Internet Support

Introduction

A rapidly growing amount of literature has addressed the importance of Information and Communication Technology (ICT) to improve SDM and communication between health care providers and patients. In many countries, empowering patients to take a more active role in their own health and provide all patients with equal access to health services and information have been declared high priority health policy goals[1;2] Web-based and other innovative ICTs have shown great potential to provide patients with information and communication specific to their needs. To utilize their full potential, such ICTs need to be integrated into the practice of regular health care. Personal and Shared Health Records have therefore, been declared an international research priority because of their potential to provide an environment in which health information about an individual can flow seamlessly among systems used by authorized health professionals, care givers and the patient[3]. In Norway, a number of public policy documents[1;2;4] outline strategies for extended use of the EHR.
To meet these goals, the Center for Shared Decision making and Nursing Research at Rikshospitalet Medical Center, with funding from the Norwegian Research Council, is currently developing CONNECT (Care Online: Novel Networks to Enhance Communication and Treatment). CONNECT is a patient portal that integrates a suite of context-sensitive, patient communication and information tools into a patient-clinician shared EHR to support shared decision making, patient-provider communication and patient-centered care. Developed for different environments (hospital, outpatient clinic and patients homes), these tools include (1) the Choice application used at the point of care, where patients on a tablet PC report and share data about their symptoms and illness experiences with their care providers to support shared care planning; (2) WebChoice an Internet-based support system that cancer patients can access from home through a secure patient portal. (3) In addition, we develop CONNECT mobile, a mobile client with device adaptation, providing mobile access to WebChoice information with seamless and secure network access.

The natural next step is to combine these tools into an integrated application within the context of a shared EHR. This can provide a seamless environment where patients can share their data, communicate with their care providers, and obtain support from where ever and whenever they need it, all within the same system. While the suite of Choice tools so far have been stand-alone systems primarily used by cancer patients, the underlying principles are generic and transferable to other patient groups. Therefore, we integrate these applications into regular health care which holds great promise to improve patient-provider relationships, patient self-management, effectiveness and continuity of care, and consequently patient safety for a wide range of health care users.

In this paper we present (1) methods for integrating the Choice/WebChoice applications into the EHR; and (2) CONNECT mobile, that provides a mobile solution of CONNECT in a manner that safeguard data security and confidentiality and adjust user interfaces to different users, devices and contexts of use.

1. Integrating Choice and WebChoice with the EHR

Currently WebChoice is a self-contained Web application that patients use from home through a standard Internet browser. It contains:

1. **Choice**, the comprehensive Assessment tool that allows patients to report and monitor symptoms, problems and priorities for care along physical, functional and psychosocial dimensions, currently and over time. Using branching logic, questions are personalized to previous responses so that only relevant questions are asked. It also includes ratings for “degree of bother” and “priorities for care” to assist provider and patient in rapidly determining which areas are most important to address. The system creates immediately a summary report that displays patients’ reported symptoms ranked by their priorities for care.

2. **Tailored Symptom Self-management Support.** At any time, the patient can obtain helpful advice from the Knowledge Base about how to self-manage their symptoms. Patients’ self-reported symptoms trigger the display of the appropriate subset of self-management activities. This information can be printed out for further reading or added to an individualized care plan. The Knowledge Base contains several hundred options for evidence-based self-
management strategies presented in patient-friendly lay language, obtained from scientific literature, validated by an expert panel and is regularly updated. Obviously, the knowledge base is not only helpful to patients, but also to care providers. In CONNECT it will be made accessible to them through the HER so that they can use it for evidence-based care planning with their patients.

3. In the Communication Component patients can communicate about anything they like. The application’s helpdesk system to handle messages from the patients.

- **Data Security.** Security and confidentiality are critically important due to the sensitive nature of health information, patient concerns, and institutional requirements. Strong security measures are therefore, implemented into CONNECT to protect this information. The current version of Choice and WebChoice has been approved by the Norwegian Data Inspectorate. In this solution patients are authenticated using a smart card based public key (PKI) solution from Bypass. Support for the BankID PKI solution is also implemented. The confidentiality of the information is protected with 128-bit Secure Sockets Layer (SSL) encryption. Other procedural and technical protections are ensured, such as storing data behind an Internet firewall, robust data integrity and auditing controls, and training of staff who are authorized to access patient data.

- **Support for multiple languages and diagnoses.** CONNECT will be implemented as a language independent system by separating the content from the system. Language is defined as an attribute of the user.

- **Interfacing WebChoice with the EHR.** For CONNECT we are building a generic integration logic that is built on a service oriented architecture (SOA). Thus CONNECT will not be tailored to a specific EHR vendor or just one technological platform. SOA describes how independent services with defined interfaces can be integrated without having previous knowledge of the services that actually perform the tasks. The format of the messages will be based on the EbXML framework as proposed by the Norwegian Centre for Informatics in Health and Social Care (KITH).

   Another important goal is that the integration of Choice/WebChoice with the EHR only requires minor, if any, changes to the existing EHR system. When a patient has completed a symptom assessment an assessment summary report is generated and a notification message is automatically sent to the EHR. The message contains a Uniform Resource Locator (URL) which is a link to the assessment summary report. The EHR will display this link to the clinicians together with information from other subsystems such as lab or radiology results. When clinicians click on the link they will automatically be redirected to CONNECT.

2. **CONNECT Mobile: Secure, mobile access to the shared EHR**

With mobile access to the EHR, we can reach the patient in other situations than only in the hospital and at home. Availability of powerful mobile terminals enable us to
extend access to the shared EHR through a mobile environment. Mobile access to sensitive information systems represents many challenges. To verify and solve critical technical issues, we have chosen a prototype implementation approach, where elements of the Choice and WebChoice applications are mobilized using standard mobile terminals enhanced with technologies for device-independent display, fonts and other user interface features, as well as mobility and security technologies. The mobile client can detect terminal capabilities and adapt the user interface. We use mobile IP, WLAN/Cellular network detection and Mobile IP for seamless selection of network access. For security, we use 128 bit SSL encryption. The mechanisms for practical authentication on a mobile terminal is still under study. The prototype implementation of CONNECT Mobile demonstrates how a context-sensitive, multi-modal patient communication and information tool can be implemented in legacy mobile terminals. A mobile phone, available to most patients, is enhanced using state of the art technologies to ensure adaptation, readability, mobility and security to ensure simple access to the EHR while moving seamlessly through heterogenous networks, and accessing and interacting with the EHR from different locations.

Figure 1: CONNECT component architecture

Key research issues in the project include verification of usability and readability that is needed on a mobile platform with limited display size and diverse user interfaces. We explore how we can create a WebChoice client that has the same user interface and ‘look & feel’ on different mobile phones with very diverse technical specifications, and how to create novel methods for secure authentication and encryption of sensitive information in highly mobile environment.

The CONNECT mobile client is an extension to the WebChoice system. Its lets the patient access some of the functionality in WebChoice away from home. The mobile client is programmed in Java MIPD 2.0, supported in all recent mobile terminals. The main functionality in the CONNECT mobile application includes registration of symptoms, access to database for evidence based information and forum resources. When using the Web-based WebChoice the patient needs a computer and must be online. When being away from home it can be difficult to access the system. Using a mobile device we solve the accessibility problem, but are facing other challenges on usability, connectivity, mobility and security challenges addressed in this project.

3. Discussion

While the CONNECT application holds great promise to improve patient-provider communication and help patients to better understand and manage their illness, critics may argue that it also could increase the digital divide. While providing all patients with equal access to health services and information are high priority health policy goals in most Western countries, not all patients will be able to benefit from the application. To use CONNECT, patients will need a computer, have access to the
Internet or own a cell phone, and are required to have a certain level of computer and health literacy. Thus people who are disadvantaged in the first place may also have the least to gain from the application. It could, however, be argued that helping 70% of the patients is better than helping none. As new technologies mature and more people gain access, these can be better adapted to the needs of people from varying socio-economic backgrounds.

On the clinician side, a number of challenges come into play when developing a new system such as CONNECT for routine clinical practice. Resource requirements, feasibility, acceptability and organizational issues need to be carefully addressed. The successful design, implementation and evaluation of clinical support systems depends on how useful clinicians and patients who are the potential main users perceive them. Among possible barriers to clinicians’ use of new information systems described in the literature are the organization’s attitudes towards innovations, the degree to which the system requires clinicians to modify established routines, and the lack of leadership support. Clinicians work under time pressure and competing obligations, and additional tasks are not likely to be carried out if not perceived helpful. Many information systems have failed because developers neglected users’ judgments about a systems’ feasibility, time requirements, and usefulness in clinical practice.

To safeguard against such problems, CONNECT is developed with extensive user-centred design methods. Patients and clinicians participate in all phases of the design process to help us understand their needs for shared decision making, documentation and information sharing; the context they work and live in, their underlying assumptions and expectations and how we best can address them.

On the technical side, a particular challenge is a trade-off between data security, and user friendliness. Because CONNECT is to be implemented as a plug-in into existing EHRs that require strict security measures behind safe firewalls, communication with the world outside rises security concerns and challenges related to how advanced authentication mechanisms such as PKI and Smartcards required for access to medical records can be combined with user friendly interfaces that even novel Internet users can master. For example the current WebChoice uses a PKI Infrastructure and “My page” technology. While this meets the highest security and privacy standards required by the Norwegian Data Security Act (Datatilsynet) the complexity and number the steps required to install the security measures on their computers have posed problems for a significant number of patients, and also hindered some to get online at all.

Another interface issue relates to compatibility of user interfaces. Every EHR has its own design. Plugging-in CONNECT may require different navigation routines and learning needs and not give the user the same touch and feel as the rest of the EHR.

To address these and other challenges the development process of CONNECT goes hand in hand with research that includes several doctoral students, to understanding and address these issues and find solutions for how they could potentially be solved.

The clinical systems environment at Rikshospitalet offers a state-of-the-art preview of what many other organizations and systems will offer in the future. By conducting research in this testbed, we can learn both how new interventions are useful, and just as importantly, how to operationalize the interventions. Technology adoption in the area of patient-provider information sharing and collaboration is never automatic. The use of such systems by patients and the willingness by practices to promote their use requires that systems are time neutral or save time and offer conveniences to users. Learning how to bridge the continuum between these approaches is an important area
of learning because of the high potential for benefits to all parties who participate in the care process. The project addresses key technological challenges of information and network security in a mobile environment. Issues like authentication, seamless handover between networks, adaptation to different terminals and secure access to the information stored in the EHR are requirements that must be solved as a part of the project to enable research in a “live” testbed, providing feedback to the interventions and how they can be successfully implemented.

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