Design of a Patient-Centered, Multi-Institutional Healthcare Information Network Using Peer-to-peer Communication in a Highly Distributed Architecture

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Abstract

Objective: to design a community healthcare information network for all 450'000 citizen in the State of Geneva, Switzerland, connecting public and private healthcare professionals. Requirements include the decentralized storage of information at the source of its production, the creation of a virtual patient record at the time of the consultation, the control by the patient of the access rights to the information, and the interoperability with other similar networks at the national and european level. Methods: a participative approach and real-world pilot projects are used to design, test and validate key components of the network, including its technical architecture and the strategy for the management of access rights by the patients.
Results: a distributed architecture using peer-to-peer communication of information mediators can implement the various requirements while limiting to an absolute minimum the amount of centralized information. Access control can be managed by the patient with the help of a medical information mediator, the physician of trust.

Keywords:

Community Healthcare Information Network, Peer-to-peer communication. Distributed architecture. Virtual Patient Record.

Introduction

A better communication of all stakeholders of a healthcare system is one of the ways to reduce the existing information gaps. These gaps contribute significantly to the public health problem of epidemic proportion that results from medical errors [1]. The improvement of the continuity of care in modern, complex and fragmented healthcare systems has the potential to increase their quality, their efficiency and the satisfaction of their patients [2-4].

In order to address these issues at the regional level, the government of the State of Geneva [5] has launched the "e-toile" project that aims at connecting all the stakeholders of the healthcare system, private and public, via a community healthcare information network. It has been decided, at the political level, and in order to address worries resulting from prior unsuccessful attempts, that the network will implement three major require-

ments: a) the medical information is kept at the source of its production i.e., as close as possible to the 3'000+ professional stakeholders of the network: there is no central repository; b) on the basis of the simultaneous presence of the patient's and the professional's access card establishing a therapeutic relationship, the relevant information is aggregated into a virtual patient record, which exists only for the duration of the consultation, and c) the patient keeps control of which information can and cannot be accessed by the various stakeholders involved in his/her care.

Existing projects

Healthcare information networks and health cards have been developed and deployed for more than a decade. Although none of them implement all the requirements of the e-toile project, they provide useful experiences and lessons. In the Rimouski project [6], launched in 1995, all medical information is stored on a chip card: the limited storage space limited the amount of information available, excluding radiographs and large documents. This project demonstrated the difficulty of maintaining up-to-date information on such media. The Laval project which followed in 1999, implemented a central repository of medical information, using the health card for administrative purposes and for the access to the repository. This project exposed the issues related to the security, confidentiality and the difficulty of maintaining a centralized copy of information originating from numerous stakeholders.

In Europe, large scale projects in France [7] and Slovenia [8], amongst others, are used successfully to streamline the administrative authorization and reimbursement processes and the dematerialization of drug prescription. This is also the case in many North-American integrated delivery networks, where the consolidated nature of a single institution facilitates the design and implementation of the network. In Europe, most multi-institutional networks typically focus on a specific population of patients and providers (e.g., hemophilia, diabetes).

Local determinants

Switzerland is characterized by its high level of federalism, illustrated by the co-existence of 26 different health systems – one for each state – and the very limited coordination role of the federal government in health matters. The State of Geneva has the

highest concentration of health professionals in the country, with more than 1'400 private practitioners who operate mostly in solo practices, 1'200 physicians in public hospitals, for a population of 450'000 (Table 1). There is no gate keeping mechanism and patients consult specialists directly. Unsurprisingly, the demand for care being proportional to the offer, health costs are also the highest in the country.

In the early 1990's, a first attempt to connect healthcare stakeholders via a centralized database was unsuccessful, mostly due to the "Big Brother" perception by citizen and care professionals of the centralized approach, and the overall low level of computerization of physicians' practices.

The situation has evolved, with an explosion of healthcare costs mandating the improvement of the efficiency of care processes, and with a better understanding of the problem of medical errors and the impact of miscommunication. In the meantime, most professionals are now using computers in their daily practice, and express the need for a better communication and the access to added value services.

Several studies have outlined the needs and expectations of healthcare professionals regarding their usage of information and communication technology. For example, the FORRMEL study [9] showed that private practitioners expect, in decreasing order of importance, the following added value services: access to the medical record of the patient, decision-support for drug prescription, electronic mail, access to reference databases, and medico-economical optimization tools.

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citizens in Geneva: 450'000
private physicians: 1'400
physicians in public hospitals: 1'200 (2'2    00 beds,
                                   8'000 collaborators)
pharmacies: 180
long -term care facilities: 3'500 beds
private clinics: 10
laboratories: 10
home care services: 1'200 collaborators
other care providers: physical therapists...
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Table 1: Stakeholders of the e-toile network

Methods

Organizational aspects

Taking into account the "scars" from the previous attempts at building a healthcare information network, a participative approach has been taken from the start of the project. An independent structure, the IRIS Foundation, has been mandated by the State of Geneva to design, implement and exploit the network. Representatives from all stakeholders are members of the Foundation Council, including, consumers and patients, private and public care providers, pharmacists, medico-social facilities, insurance companies. Besides technical workgroups, two commissions have been active from the start, dealing respectively with the ethical aspects and the information protection aspects.

Requirements

The architectural and technical design of the e-toile network is based on the following requirements:

- Patient-centered: the patient owns the information and can decide who has access to which information.
- Access card: patients and providers are identified by a chip card which is the access key to the network. The card does not contain any medical data.
- Secure access to data: security features include the decentralization of the virtual patient record, encryption, access logs, and the absence of a centralized list of patients.
- Interoperability: the e-toile network must be able to communicate with other healthcare networks, at the Swiss and European levels.
- High availability: the access to the virtual patient network must be possible 24 hours a day, 7 days a week.
- Ethics: the e-toile network must comply with the legal requirements of data protection and the rules of medical ethics.
- Patient-provider relationship: the e-toile network should support and reinforce the relationship between the patient and his/her "physician of trust". The "physician of trust", or medical information mediator, plays a key role in assisting the patient for the access and parameterization of the virtual patient record.
- Respect of practices: the use of e-toile must be compatible with existing practices and should not increase the professionals' workload.
- No automated decisions: e-toile's role is limited to providing the appropriate information at the right time, including alerts and notifications. The providers remain in charge and responsible for their decisions.
- Integration: e-toile must be able to integrate with existing systems. It should also foster the development of third-party added value services and be open enough to integrate these.

There are four types of services provided by e-toile:

- Access to the virtual patient record in order to bring to care providers the patient's information useful for an optimal decision.
- Specialized tools for communication, including secure e-mail and teleconsultation tools.
- Decision-support tools such as knowledge bases to support medication prescription, alerts, reminders, and reference databases.
- Logistical support tools in order to share information related to resources that can be used to optimize and coordinate the longitudinal care of the patient and improve its continuity. These tools include appointment systems, databases about the availability of long-term care facilities.

The "physician of trust"

In order to assist the patient in the management of his/her healthcare related information, in a setting where there is no systematic primary care provider who could play this role, there is a need

for a medical information mediator, the "physician of trust". Identified by the patient, and not necessarily directly involved in the care process, the "physician of trust" has, along with the patient, access to all the information available on the network. His/her role is to explain the contents of the patient's record and to guide the patient in using it appropriately, in particular when it comes to limiting access to an important information, or to revealing information that could go against the interests of the patient. The "physician of trust" is not a gatekeeper and has no formal role in controlling access to care.

Pilot projects

To explore the feasibility of the e-toile network and to demonstrate the key concepts while allowing a wide participation of the stakeholders, several pilot projects have been carried out.

The first prototype aims at getting a working model of the access rights to the virtual patients record, taking into account the needs of the average citizen as well as the more granular control of the access to various parts of the patient record in more complex situations.

The second pilot project demonstrates the successful adaptation of a computerized physician order entry and clinical decision-support system from a public university hospital to a private group practice where it was integrated in the local electronic health record. This is also the first step towards dematerialized prescription communication to pharmacies. It finally illustrates how knowledge relevant to the ambulatory setting is complementary to the one used in the hospital, and opens interesting perspective for the collaborative maintenance of prescription knowledge bases.

The third pilot project demonstrates how documents produced within the hospital can be made accessible to other care providers, with the patient's approval, over a secure internet connection.

Results

The multidisciplinary composition of the Foundation Council and the participative design of the pilot projects have enabled to gather the feedback and validation of a wide audience, representative of the expected stakeholders of the e-toile network. The main concepts of the design have been further validated by international experts in the field of medical informatics, telemedicine and security. The legal basis of the project also requires the modification of local laws dealing with the maintenance and communication of medical information, but this topic is outside the scope of this article.

Overall technical architecture

The distributed nature of the information sources and the absence of centralized repositories can be implemented within a peer-to-peer architecture. As illustrated in Figure 1, only two databases are centralized: the list of healthcare professionals and their access rights, and the list of all "mediators" on the network. The access for healthcare professionals is managed centrally, along with the "license to practice" or the "license to exploit" a healthcare-related business that are handled by the State of Geneva. The list of all "mediators" is necessary in order to mon-

itor the system and detect situations where all possible information might not be available due to the failure of one or more of the nodes.

The core of the network is made of peers, the "mediators" which connect the various access points and information sources. Each mediator manages the documents published by the information sources it represents on the network. The mediators also handle requests for information by the other mediators. Key functions of the mediator include: authorization of the users, normalization of the documents to be made available on the network, management of the access rights to these documents, logging of all requests and accesses to these documents, and communication of requests emanating from local access points to the other mediators.

Access points to the network handle the identification and authentification of stakeholders using chip cards and PIN codes. The simultaneous presence of the patient's card, the patient's PIN and the professional's card establishes the existence of a therapeutic relationship, and grants access to the virtual patient record, within the limits set by the patient and the general access rules.

Interconnection with other networks are established by additional mediators which handle the translation and forwarding of requests.

Access rights

The control of access to the patient's healthcare information is schematically organized in concentric circles of increasing security:

- Administrative information is available to all professionals of the network and include demographic information and health insurance coverage.

- Utilitarian information is available to all care providers and its access does not require the patient's PIN code. This information is exported specifically by the patient, and would normally include allergies, major risks, organ donor status, and any information that the patient want to make available to all care providers.

- Medical information is available to care providers only when the patient's PIN code is entered, thus establishing the therapeutic relationship. This category contains most of the medical information. Access to this level of information can be requested by physicians without the use of the patient's PIN code, using an "emergency broken glass" procedure which will lead to a posteriori justification of the access.

  Very sensitive information, identified as such by the patient, either retrospectively or proactively, will only be available to specifically designated care providers, and to the physician of trust. One of the important roles of the physician of trust is to make sure that the patient understands the implications of "hiding" some of his/her medical history.

- Secret information, whose need to be available on the network at all is still debated, would only be accessible by the care provider who originated it and by the patient.
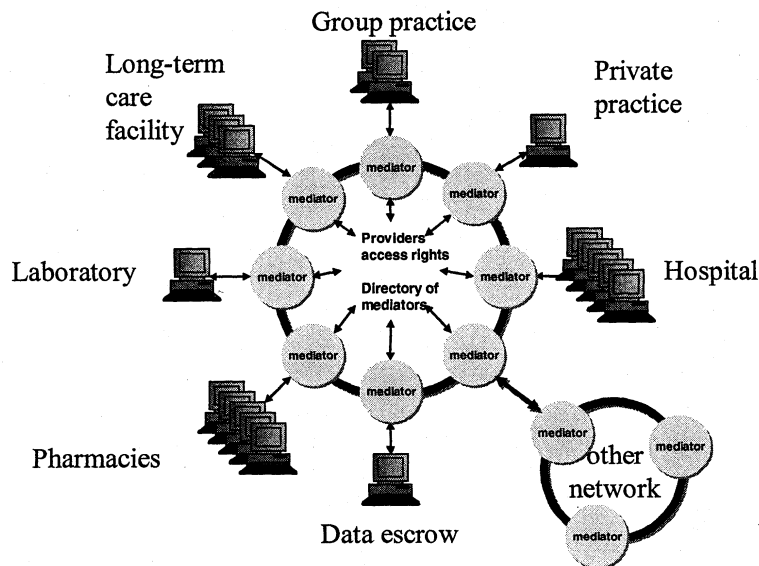
Figure 1 - Schematic architcture of the e-toile network: stakeholders are linked by a peer-to-peer network of mediators that handle the implementation of security policies, the broadcasting of the requests emanating from its stakeholders, and the responses to incoming requests from other stakeholders. Other networks can be connected via similar mediators. As the identification of citizen/patients is implemented by a hardware token, there is no need for a central repository of their identities. Providers credits are attributed by a central authority and are centralized. The list of the existing nodes in the network is also centralized, as it is necessary to monitor the overall availability of the system.

In parallel, a matrix describes the general rules associating each type of accessible documents with each professional role. The combination of the patient-specific access rights and the general rules is used by the mediator to decide if the access to a specific document can be granted.

Discussion

The distribution mechanism based on a network of peer mediators is conceptually scaleable to accommodate the estimated 3'000+ contributors to the virtual patient records. However, the currently available infrastructure and technology does not permit to implement highly secure, reliable and available mediators in each provider's office. A concept of "staged decentralization" recognizes the fact that large organizations will be able to handle their presence on the network, whereas small practices will delegate this task to "data escrows". It is estimated that about 30 mediators will form the initial network and their number should increase to several hundreds within five years.

Interoperability with existing and planned networks requires a technical harmonization. The Netlink project [10] has developed a standard that underlies several European projects of health cards, should soon be adopted as a European standard, and offers an practical choice. The situation is somewhat more confused at the messaging and conversational levels, where various standards compete, including the HL7 version 3 [11], and the CEN ENV 13606 [12].

Beyond technical aspects, several cultural obstacles are foreseen. The widespread adoption of such a network will accelerate the patient empowerment and responsibility, and will increase transparency on the behaviour of both patients and providers. Even though these changes are inevitable and already under way, their acceleration can be perceived negatively and will lead to resistance. Communication, participation, and an emphasis on the potential of such information networks to improve the quality and efficiency of care is critical.

Conclusion

The design of a patient-centered, multi-institutional healthcare information network, aimed at connecting all citizen and all healthcare providers in the State of Geneva, is described. It uses a distributed network of mediators, communicating via a peer-to-peer mechanism, in order to keep medical information as close as possible to its source, without centralized patient information, while enabling scaleability and interoperability with other networks. The patient controls the access of the information in his/her virtual record, and is assisted by a health information mediator, the physician of trust.

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