Informed Decision Making and Interoperability in Medicine: the Doc@Hand Experience

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Abstract— New technologies have improved the ability of electronically storing, transferring and sharing medical data; they also create serious questions about who has access to this cross-media content and how it is protected and distributed. Doc@Hand provides a consistent level of information security for protecting electronic information from accidental or malicious codification, destruction, or disclosure by applying strict requirements for data security and privacy whilst complying with ethical standards. In addition, Doc@Hand handles the distribution of computer-based patient records, natural language queries and domain specific knowledge in a secure way.

In a scenario where the healthcare industry tends towards rapid decentralization, with multiple actors involved in the care delivery processes, the importance for professionals to collaborate, access and share data and knowledge becomes more and more relevant for improving patient management and providing better efficiency.

Doc@Hand aims to support healthcare professionals in this evolving environment by providing tools that allow access to geographically dispersed heterogeneous information sources via multiple network interfaces (Bluetooth, WLAN, cellular). Synchronised access is maintained regardless of location such that decision making for complex problem solving is supported.

I. Introduction

THE Doc@Hand project is funded by the European Community (IST-1-508015) and it aims to bridge the gap between patient-related data and unstructured information and knowledge, so as to dramatically enhance the ability of doctors to exploit this integrated information for more effective and cost-effective decision-making.

While in the past, the family doctor was the single actor in healthcare provision, at present, collaboration among different providers is seen as a key point for proper disease management. This collaboration is not limited to health care institutions but also encompasses social workers, private companies, insurance enterprises, and so on. The final result is a network of different actors/organizations with different roles and responsibilities who share the common goal of the patient's well-being.

Effective communication among the different actors within the network is still a pending issue. The *communication barrier* problem [1] actually hampers effective deployment of services through health care networks and significantly reduces their benefits. The example of the difficulties of moving a patient across the network, repeating exams and tests already performed, with poor information transmission amongst professionals is, unfortunately, commonplace.

The Doc@Hand project is developing a system, based on server and client –side software, which is the main tool for Healthcare professionals every time they need to perform tasks such as prescribing the best treatment option for their patients, or to access information and knowledge that are located in different repositories.

The Doc@Hand server is the central node of a network of cooperating organizations, sharing their repositories (or parts of them) according to a defined set of rules and policies that they have agreed upon.

The client-side software can be run on either a desktop PC or, more appropriately, a mobile unit such as a tablet PC. This perfectly fits the increasing mobility needs of healthcare work with professionals working in a variety of different environments. Thus, they can exercise their competencies inside the walls of hospital wards, visit patients at home during rehabilitation, have their own private offices where they receive patients and they perform domiciliary visits. The Doc@Hand mobile client operates as an anytime, anywhere assistant of the Healthcare professional in all of the activities they are involved in, acting as an intelligent

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portal to all the information and knowledge they might need at any given time.

The project has been developed with a two-step approach, each leading to the development and test of a prototype installed in the two participating Hospitals (the Barcelona Hospital Clinic and the Guy's and St. Thomas Hospital National Health Service Trust in London). Feedback from the users has been used to refine and improve the prototype, and the relevant findings and documents have been also submitted to a panel of independent experts (medical doctors, and medical IT experts) to evaluate their relevance and reliability.

In the following sections, we describe the system structure, the need for an information security structure, and the main innovations introduced during the project development.

II. System Specification

The Doc@Hand framework is multi-platform based and uses a distributed architecture mainly established on freeware and open source tools.

The framework is developed using Java and Microsoft .NET technologies; it is composed of several modules and these modules interact using Web Services. XML is used for all information and data exchange; clinical records (EHR) have a common XML schema for the end users. The Doc@Hand framework shows all the retrieved data as Really Simple Syndication (RSS) feeds compatible with the main news aggregators to exploit an interface familiar to the doctor.

The framework can exchange data in a secure and flexible way with heterogeneous external data sources and repositories [2]. It implements a seamless data sharing policy through a SOAP/UDDI/XML service framework for accessing patient records from clinical legacy systems, and to integrate unstructured document information hosted in medical repositories over the Internet.

The Doc@Hand system is composed of the following subsystems (Fig.1): the infrastructure subsystem, the semantic subsystem, the user agent subsystem, the user interfaces subsystem, and the service and collaboration subsystem.

The *infrastructure subsystem* has been implemented as a set of web services to interoperate in an integrated environment between Doc@Hand and legacy applications used in healthcare organizations, along with trusted web sources of clinical literature and HL7 message exchange engines which all co-operate to enable sharing of information among the different actors of the system.

Acting as a "mediator" between Doc@Hand and any external clinical application, the *infrastructure subsystem* provides an external interface to allow patient information stored into electronic health records to come into the Doc@Hand application and at the same time it creates an internal interface to communicate incoming data to other modules of the system. This external interface has been implemented as a generic server-side layer that is able to receive, to process and to redirect messages compliant with HL7 version 2.x and 3.0 clinical standards.

The *infrastructure* also provides an interface between Doc@Hand and trusted web sources of clinical information. It exposes a set of services that access external web sites and broadly-used search engines in order to retrieve and fetch into the system any relevant documentation.

The *semantic subsystem* (Fig.2) is composed of several different components to provide a smart search engine where ontology driven information retrieval and natural language processing for the English and Spanish languages are key features [3]. Search engines also provide the indexing of corpus documents. Knowledge parsing and extraction are provided by a semantic parser supported by multiple ontologies (Top, Middle and Domain levels). An Ontology server manages such ontologies and also provides an inference capability; knowledge representation is frame based (RDF standard), while an XML standard RSS is adopted for query results representation. The Semantic subsystem communicates with several Framework components, such as the infrastructure, the user agent (for push/pull queries and user profiled data), the user interface (for query results presentation, and patient list suggestions for clinical trials) and the administration management (ontology browsing) subsystems.

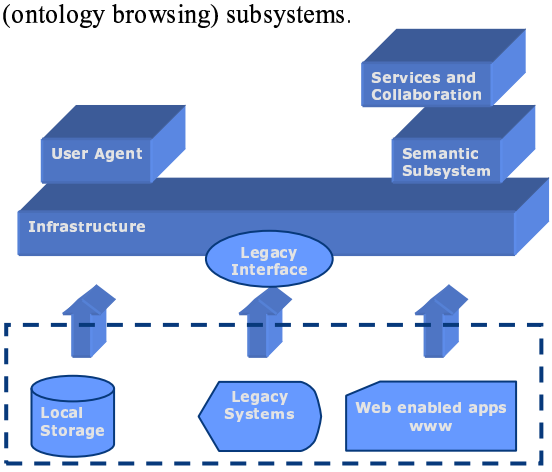

Figure 1: Doc@Hand Layered Architecture.

The *user agent subsystem* consists of two main modules. A *push/pull system* that manages data flow to a user, either data they have explicitly request (pull) or data they are interested in and is timely (push). The second module is a *user profiling system* that tracks user activity based according to their explicit and implicit interests and filters data accordingly. The user agent subsystem is central to almost all Doc@Hand activity and architecturally sits in the middle of other modules and manages the majority of data flow between them. It is tightly linked to the user interface subsystem.

The *service and collaboration module* is composed of two sub-modules: the collaboration module and the administration and user management module. The first is responsible for the communication between healthcare professionals, general practitioners and clinical specialists

that are authorized actors of the Doc@Hand system. It provides synchronous and asynchronous collaboration options, including standards-compliant chat and forum environments integrated under a Single Sign-On in the Doc@Hand system. The *administration and user management module* acts as the administration site of the Doc@Hand platform. It allows system administrators to manage user accounts and control user access rights to the system services. This interface also allows system administrators to manage which information sources must be active and accessible by users. End users are only allowed to access the Doc@Hand services whereas the system administrators can also browse and edit the ontologies and manage the corpus of documents.

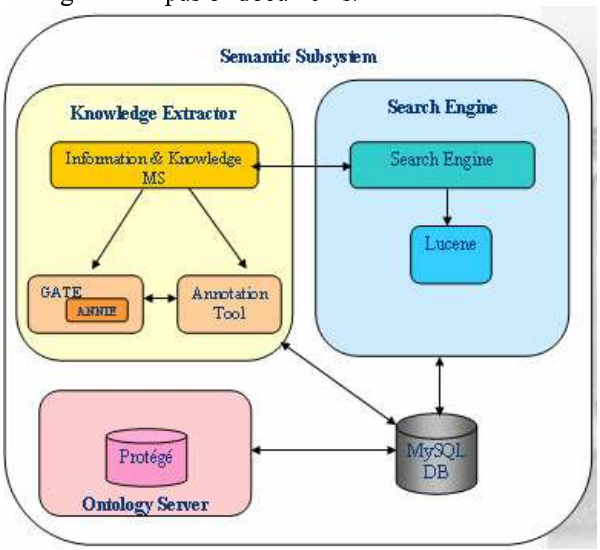

Figure 2: Semantic SubSystem.

The user accesses the Doc@Hand system by using a web browser: it is up to the *user interaction* module to create pages and send them to the browser. Technically speaking, there is no specific Doc@Hand software running on the client device (Doc@Hand is completely a web based application). A page displayed on the user's screen is composed by a set of panels arranged in a layout. Panels are the fundamental bricks that allow the users to build a customized user interface. There are two fundamental types of panel, that we define as templates: *toolbars*, that include items that launch tools and applications, and *windows*, that contain specific types of data or the output of external applications (each window can be associated to a particular service or functionality offered by the Doc@Hand system). Panels are capable of exchanging information among them to integrate and enrich the content provided by the system. Panels are web pages dynamically generated on the server by a corresponding piece of software. The server is also responsible for building the patchwork of the panels and sending a complete page to the browser.

A. The Need for an Information Security Structure

Information security affects all users in all businesses every single day, and a significant number of information security incidents occur by accident. Knowledge of the dangers and threats can be an effective safeguard; as such knowledge can often prevent a potential problem from escalating into a major incident.

An information security structure consists of a series of inter-related building blocks which together comprise an effective safeguard against external attacks and internal accidents and misdemeanors.

Information security should be a structured and managed process where information security policies, procedures and guidelines must be in place and properly implemented and monitored. Information security policy is intended to support the protection, control and management of the organization's information assets. These policies are required to cover all information within the organization which could include data and information. They need to cover the full range of risks associated with creating, amending or storing information.

III. DOC@HAND MAIN INNOVATION

A. Data Pushing Strategy

Information has to be ready in advance and if appropriate copied locally to the user device for immediate use (i.e. 'pushed'). On demand (i.e. 'pulled') searches are also supported. Pushed data aims to be context aware and "understand" a users likely needs.If explicit querying was the only way for the professional to get the information he needs, the burden could be unaffordable. Push technology is a way to automate the search and retrieval functions, and it has been already adopted in several information services (e.g. PointCast[1]); the innovation here is its introduction in the Healthcare field, which is intrinsically "knowledge intensive". Push allows searching, filtering and delivering relevant information right to the user based on his profile.

B. Ontology Based Searches

The amount of information to be considered by an intelligent healthcare application can be huge: clinical records, guidelines, pharmaceutical information, scientific literature, reference material, etc. It is evident that if this mass of data is not adequately filtered and organized it could become useless or too time consuming/frustrating to handle.

Knowledge representation via ontologies is the approach used by Doc@Hand to face these issues and will be used to both pre-process users queries (in natural language and in a structured form) to feed one (internal) or more (external) search engines, and to post-process the obtained results by performing an enriched content query that tries to identify the really relevant concepts in the query and thereby add additional related information to the results.

Briefly, accordingly to Tom Gruber [4], an ontology is a specification of a conceptualization. Doc@Hand uses three medical ontologies: a Middle level ontology that comes from NCI (National Cancer Institute) which provides more than 20000 generic oncologic concepts, and two distinct Domain Ontologies (one for Colon cancer domain, one for Multiple myeloma domain) providing more than 200 concepts

[1] See at http://en.wikipedia.org/wiki/PointCast

developed ad hoc by technical engineers and domain specialists. These ontolgies are used by Doc@Hand to automatically determine the similarity of documents, records and queries so that users are guided in their decision making by having exposure to all relevant information. At our end user sites this takes place in the context of the early referral of colon cancer and with regard to patient recruitment for clinical trials.

C. *Integration of Decision Support Systems*

Decision support systems (DSS) are already used in clinical practice to a certain extent, though they are often independent applications and not very well integrated into a single tool for the Healthcare professional. The value added by Doc@Hand is to include them seamlessly in a patient and task oriented perspective so the professional will have their results available within the same framework.

D. *Privacy vs. Interoperability*

In the medical field nowadays there is an increasing need and opportunity of integration and communication of large amounts of data referring to patients and diseases: that presents a potentially incommensurable phenomenon of data sharing among multiple actors and multiple organizations.

This situation requires suitable software, hardware and networking support to enable data transference, coupled with suitable tools for privacy protection. There is a real risk of exposure of patient's personal data and also for that of staff know-how and for scientific intellectual property. Protection of privacy depends mainly in having a secure system. Security first of all requires that persons accessing the system are properly identified, and authenticated. Once they are authenticated, they can be authorized to read or manipulate specific information. It is also crucial to properly define the boundary of protection.

Our proposed system can manage a large amount of sensible data in a secure way whilst respecting privacy and security. We can say that privacy is the goal and security is the tool and it is useful to consider both of these definitions when thinking of the ethical framework in which Doc@Hand operates.

A patients private personal information (EHR, Electronic Health Record) is treated by respecting privacy policies; no data are stored locally, all EHR content is managed entirely on memory as received from external heterogeneous data sources (typically, the healthcare institutions information system).

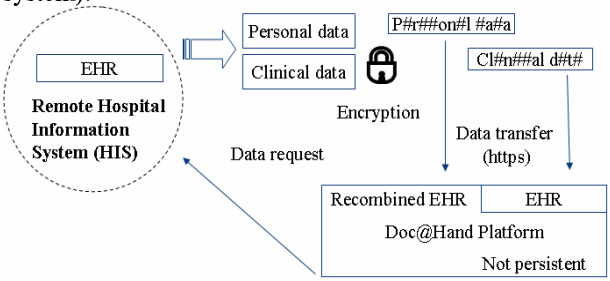

Figure 3 -*Interoperability*

An EHR is composed mainly of two distinct sections, personal data and clinical data; such EHR are stored locally on medical IT infrastructures, protected by firewalls and other security policies. On the other hand, such data need to be collected by request, retrieved by the Doc@Hand infrastructure layer in a transparent manner and then submitted to system processing. Thus, it is clear that transmission from local IT infrastructures to Doc@Hand could be unsafe; our solution is to use the secure HTTP protocol to scramble information before transmission and to maintain the personal/clinical data separation during any communication. In this way, the EHR becomes completely anonymous; it is recomposed once received thanks to the packageID previously assigned to it.

E. *ASP: a new deployment paradigm for healthcare services*

Healthcare services are traditionally deployed within the intranet of an institution, protected and isolated from other networks or the internet. This discipline is imposed by security and privacy concerns that are of paramount importance in the management of sensitive clinical data. On the other hand, the desire for decentralized delivery of healthcare services and the interconnection of heterogeneous systems, contradicts the above restrictions. Moreover, several institutions are reluctant to invest resources in IT for various reasons, the most prominent being high up-front expenditures and maintenance costs.

Doc@Hand aims at lowering the entry barrier for healthcare institutions by providing key services in an ASP (Application Service Provider) modality; a service provider hosts Doc@Hand, which is offered on a subscription basis to healthcare institutions. The benefits for healthcare institutions are obvious, as the Total Cost of Ownership is substantially lower in a hosted Doc@Hand deployment, taking into account the high initial investment and maintenance costs associated with setting up IT infrastructure in healthcare institutions. Furthermore, ASP deployment allows ubiquitous access to Doc@Hand services for its users with minimal requirements; just a web browser is sufficient to access all Doc@Hand services from any PC connected to the Internet.

Delivery of Doc@Hand services over the Internet raises concerns over the privacy of sensitive data. A survey for the assessment of current legal and ethical constraints, associated with the transmission of sensitive data over the Internet using the latest technologies for secure, private networks, is being conducted; through the results of this study, Doc@Hand will determine the services which will be available in ASP mode, aiming at becoming the integrated, one-stop shop for medical knowledge.

IV. DOC@HAND EXPERIMENTATION

The Doc@Hand project has developed an integrated prototype in a real environment working with the referral of *colon cancer* patients.

Colorectal cancer is the second most common cause of cancer. It is accepted that primary care plays a crucial role in the early detection of lesions. However, in spite of its importance, this process does not always happen in a timely and adequate manner thus jeopardising the proper management of the disease. By making available the necessary information to the clinicians and drawing their attention to specific points, the possibilities to reverse this state of affairs increase.

Doc@Hand is developing a specific solution supporting colon cancer referral from Primary Care to tertiary level. The following process steps are being supported:

1) Effective screening at Primary Care. This is founded in the existing clinical protocols implemented either in textual documents or through DSS modules.
2) Prompt referral from Primary Care to Specialised Care.
3) Follow-up (at risk group) at Primary Care. These are the individuals with no cancer declared yet but with an increased risk of developing the condition. They are kept under the responsibility of a general practitioner but an increased frequency of monitoring is required.
4) Early diagnosis & treatment at the specialised care centre. Once the patient is referred, put them on the protocol track for reaching the diagnosis.
5) Consulting, guidance, support.

The pilot is currently under execution and it intends to cover both the clinical and the managerial domain. Regarding the former, indicators focus on establishing the contribution of Doc@Hand to detect more suspicious cases at earlier stages, increase accessibility to diagnostic procedures at tertiary level and diminish the length of time to establish the confirmed diagnosis. With respect to the latter, the importance is set on the overall consumption of resources incurred to handle the patient through the different levels of care and how professional practices to retrieve data about a particular case from different sources can be more efficiently undertaken.

A second pilot covers the problem of automatic suggestion of suitable patients for recruitment into clinical trials. A trial matching algorithm is able to compare any patient record with clinical trial eligibility criteria (via document analysis), thereby providing a patient suitability ranking that is very useful for the specialist as a first pre-screening activity.

V. CONCLUSIONS

Nowadays, healthcare professional are involved in a huge amount of various activities and so the need to concentrate their resources and save time is paramount. Very often they have to deal with a number of different systems where information is dispersed.

The result of this situation is often that most of the huge quantity of available knowledge is simply ignored because it would take too long to dig into the different repositories, and the search is limited to the minimum set of documents that are vital to the task being undertaken. The types of available data and knowledge are numerous, ranging from the clinical records of patients and collections of cases from different healthcare service providers, to online libraries of academic institutions, professional associations and specialized publishers. In all cases the access to information is regulated, either for privacy and confidentiality reasons, when a patient's sensitive data is involved, or just because the information, as in the case of clinical literature, is provided as part of a paid service. Even when the formal accomplishments are fulfilled, inter-organization agreements signed or the service fees are paid, the practical problem of easily searching for data, filtering, merging and ranking the results still exists.

If this is, from one side, a waste of productivity, it also impacts on the quality of work of the doctors, as they are forced to make decisions having only a partial view of the situation. And, of course, it reflects on the quality of the service perceived by patients.

Our approach puts healthcare professionals and the problems they have to deal "at the center of the world" thanks to an intelligent system able to support them in their day-by-day activities. Doc@Hand aims to support healthcare professionals in this evolving environment by providing tools that allow access to geographically dispersed heterogeneous information sources via multiple network interfaces (Bluetooth, WLAN, cellular). Synchronised access is maintained regardless of location such that decision making for complex problem solving is supported. Our server and client software combine to be sensitive to a users schedule and will push profiled data *to hand* to allow better time management and quality of service.

All this is possible under an accurate and effective IT system designed at the outset in order to protect sensitive data and to assure it's privacy during the access, management and transference of it.

VI. REFERENCES

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