Research and Theory

Special issue: Infrastructures to support integrated care: connecting across institutional and professional boundaries -
Bridging the gap: a virtual health record for integrated home care

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Abstract

Introduction: The coexistence of different information systems that are unable to communicate is a persistent problem in healthcare and in integrated home care in particular.

Theory and methods: Physically federated integration is used for design of the underlying technical architecture to implement a mobile virtual health record for integrated home care. A user centered system development approach is followed during design and development of the system.

Results: A technical platform based on a service-oriented approach where database functionality and services are separated has been developed. This guarantees flexibility with regard to changed functional demands and allows third party systems to interact with the platform in a standardized way. A physically federated integration enables point-of-care documentation, integrated presentation of information from different feeder systems, and offline access to data on handheld devices. Feeder systems deliver information in XML-files that are mapped against an ideal XML schema, published as an interface for integration with the information broker, and inserted into the mediator database.

Conclusions: A seamless flow of information between both different care professionals involved in integrated home care and patients and relatives is provided through mobile information access and interaction with different feeder systems using the virtual health record.

Keywords

medical records systems, computerized, integrated advanced information management systems, information storage and retrieval, internet, home care services, nursing record

Introduction

Home care is becoming an increasingly important part of healthcare, and the trend towards trying to shorten the time a patient spends in hospital care is likely to further increase the amount of care provided in the patient's home. Studies described in [1] show that home care is a cost efficient alternative to residential care of elderly patients, and with current trends of increased numbers of elderly citizens in need of care, and shrinking resources within the healthcare sector, home care of elderly patients is bound to increase.

In many western countries, home care of elderly is shared between different care provider organizations [2], and several studies show that cooperation between different providers in home care needs to be improved [3–5]. In integrated care professionals from different organizations have to work together in a team-oriented way to provide high quality care for a

patient. This requires high quality of collaborative working relationships, clarity and commonality of objectives, frequent communication among team members, a clear understanding and respect of individual roles and skills within the team, and the general flexibility of practitioners [6].

In a hospital, or a clinic, coordination between health-care workers is facilitated by frequent formal or informal meetings, and by a large number of exchanged, and available, documents, such as electronic health records and laboratory results. In home care, however, the team consists of distributed healthcare professionals, who rarely meet, and therefore have trouble coordinating their work [4]. Despite the mobile nature of home care, mobile IT tools giving access to electronic health records are rarely available. Generally, documentation is performed on respective stationary system, or on paper, and the systems used in different organizations are autonomous and incompatible. In non-integrated organizational structures and information systems professionals risk spending time searching for misplaced information instead of taking care of patients [3]. Lack of adequate mobile information access and communication tools also hampers the professionals' work; sharing information and coordinating work within the care providing team in particular.

Today, patients themselves and their relatives, especially family carers, take a greater responsibility for the care. Over the last 15 years, there has been an increased reliance on the family to help sick aged relatives [7] and support of the family seems essential to maintain the informal care system [8]. Therefore, not only care providers need to increase safety and quality of care; patients and relatives also need access to supportive tools keeping them informed and facilitating cooperation with care professionals.

The electronic health record is one of the most important tools of healthcare professionals, both as a source of information regarding a patient's health, and as a documentation tool [9]. It contains clinical data and supports professionals with needed information for frequent decision-making as well as cooperation with colleagues [10]. It is, however, not likely that any single information system could ever cover all needs of the various care professionals [11]. An integrated version of different electronic health records from different care providers is needed to allow for adequate information access and documentation at the point of care.

The purpose of this paper is to present the architecture of a mobile virtual health record, used by both healthcare professionals and patients/relatives, developed

within the research project Old@Home [12]. Results from a qualitative evaluation of the system from the different users' perspectives are also presented.

Previous research/related work

Several important attempts have been made worldwide to solve the problems of accessing information from health information systems distributed to many locations. The technology of the Good European Health Record (GEHR) [13], and Synapses/Synex [14,15] projects (1992–1999) can be seen as a first mature approach to reach interoperability and integration of electronic health records. The openEHR foundation [16] is a non-profit open source organization bringing together an international community of people working towards realization of electronic health records to support seamless and high quality patient care.

Currently, much work is performed on a national level in e.g. UK where the National Health Service Care Records Service (NHS CRS) [17] aim to provide an integrated solution for sharing information between different care providers, starting with a Summary Care Record that will be made available in 2007. In Germany the bIT4health (better IT for better health) project [18] aims at establishing a health telematics platform supporting seamless care by combining card enabled communication mediated by the patient with network based interoperability between all actors involved. In Denmark, the G-EPJ project [19] provides a national framework for a common information structure for electronic health records. There is also an industry initiative called Integrating the Healthcare Enterprise (IHE) [20] promoting the coordinated use of standards such as HL7 [21] in order to improve the way computer systems in healthcare share information.

The work mentioned here are on a national or international level, but local efforts focusing on integration also exist. Many of these activities consist of theoretical models and most of them are restricted to healthcare and do not include social care which is an increasing part of home care. Considering the complexity of creating integrated solutions, and the limited number of systems actually in clinical use today, we believe that more practical cases such as the one presented in this paper are important to demonstrate the feasibility of a theoretical model. Moreover, we focus specifically on the ''gap'' between health and social care, presenting a solution for home care and mobile applications, considering the special requirements this poses on the integration architecture.

The virtual health record concept

Forslund et al. state that the virtual patient record is virtual in that "*it is a view of the data that might be configured differently at different locations, but that is mapped into a common format at the time the record is required*" [22]. They also stress that patient information must appear to the user as a unified set of data even though it may be spread all over the country. The user's view might access only a specially tailored subset of the record in order to handle issues of displaying the information in an intelligible manner. [22] van der Linden et al. define a virtual electronic health record as "*an EHR that contains all primarily medical, information on a patient, stored in a variety of systems in a variety of locations over a long period of time, secured against illegal access, provided with an audit trail, and presented to the reader as one dossier*" [23].

We have chosen to use the term virtual health record for our solution since it provides users with an integrated view of information stored in different health information systems, in different locations. The various professions require and consequently access different subsets of integrated information.

Materials and methods

The project was geographically located in Hudiksvall, a small, rural town in Sweden [24]. The region has an established fiber optical network infrastructure connecting all locations forming the study site: two of the Gavleborg County Council's primary care centres, the elderly patients' private homes and one Municipality nursing home for the elderly, from where home care of elderly patients living in their private homes is coordinated. At the nursing home and in some of the private homes, wireless network (WLAN) hotspots

have been installed. All wireless networks were configured for maximum security (Figure 1).

Integration method

There are several general approaches to integration;
- *Message based integration* is characterized by data communication between systems that rely on message communication protocols, with data structures and message contents following a standardized structure [25].
- *Virtually federated integration,* also referred to as indexing or pointing, implies that information remains within the data storage of feeder systems, and the role of the integration functionality is to keep track of where information is stored and how to access it. Each feeder system regularly sends updates of its index information, a set of structured pointers referencing location of the data, but the actual information is kept in its original storage.
- *Physically federated integration*, or publishing; implies separate data storage in the form of a mediator database, or publication database, to which feeder systems publish information agreed upon on a regular basis, triggered by a set time frame, or by user activated functions in the system [26].

A message based integration approach is mainly useful when the type of information to be communicated and shared is selected beforehand, as well as the destination, and is used for sharing segments of an electronic health record. However, it does not provide technical means for seamless creation and transparent access to shared information [27], and was therefore not considered for developing the virtual health record.

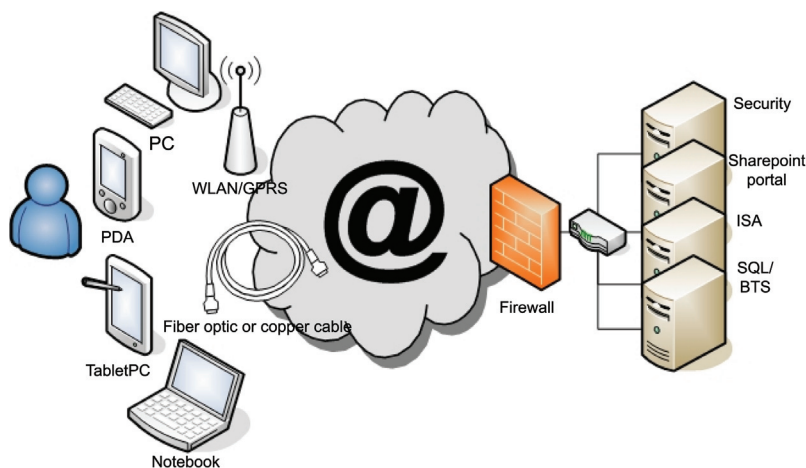Federated solutions to integration provide a uniform way to access patient data from different clinical

Figure 1. Hardware and technical infrastructure.

information systems, and provide an environment for integrated access to clinical information. Therefore these were considered when designing the technical platform.

Using a virtually federated integration ownership of information is straight forward, and information is stored in only one place. It is also relatively easy to add or remove feeder systems. All feeder systems must, however, be online when information is requested and virtually federated integration is most suitable for so called vertical integration, showing information from one feeder system at a time [26]. The method is mainly used for accessing information, and not for interacting with or updating it.

In a physically federated integration, issues of ownership and responsibility for information stored in separate data storage are more complicated to handle. It is also more difficult to add new feeder systems; a mapping process for each system is needed before information can be stored in the separate storage. The benefits are that feeder systems need not to be online for information access and it is easier to create a horizontal integration, showing information from several different feeder systems in one view [26]. Furthermore, interaction with feeder systems can be implemented; updated or added information can be published back to the respective feeder system. In addition, information which is not available in the feeder systems, such as multimedia or information used for communication between different care providers can be stored.

Since major requirements for the virtual health record have been documentation support at the point of care, integrated presentation of information from different feeder systems, and the possibility of offline access to data on handheld devices [28], publishing was chosen for the integration design.

Qualitative evaluation

The virtual health record was introduced at the test site and used by care professionals, patients and relatives for a period of 5 months. A questionnaire based user analysis was performed before initiating the deployment process, with questions relating to experience of, personal interest in, and general feelings towards information and communication technology. The users' expectations on the virtual health record, both positive and negative, were also discussed.

Evaluation consisted of qualitative interviews with users, both individual and in groups, primarily focused on experiences from using the virtual health record.

Fears and expectations expressed at the beginning of the deployment were revisited during and after the test period, comparing them to actual problems that occurred and the benefits that the virtual health record brought.

Test group
The virtual health record was used by patients and their relatives, as well as three main care professional groups regularly involved in the home care of elderly citizens: (1) general practitioners and (2) district nurses, both employed by the county council and (3) home help service personnel, mainly assistant nurses, employed by the local authority (municipality). Selection of the user group was made from a patient's point of view. Eighteen patients (out of approximately 40) living in the healthcare district forming the study site, their respective home care providers and 6 relatives took part in the study from the beginning. Some of the patients fell off and new ones were included during project time, resulting in 6 patients remaining the same during the entire project. Eight regular assistant nurses from the home help service and 6 substitutes, 3 general practitioners and 2 district nurses are regularly taking care of all patients in the district (fall 2005). They were all engaged in the project and did not change much during project time. Two district nurses from another district were also involved in the project as domain experts.

A method based on a general user centered system development approach [29] was followed during design and development of the virtual health record. Participatory Design [30,31] involve real users acting in real settings to improve development of information and communication systems. Accordingly, a subgroup of the health care professionals; 3 assistant nurses from home help service, 1 general practitioner and 2 district nurses, participated in the entire development process, whereas the whole group were active during test and evaluation phases, all actually using the virtual health record. Patients (n=2) and relatives (n=6) were actively involved in development and testing of the virtual health view aimed at the patients themselves and their relatives.

Results

The virtual health record architecture suggested here enables care professionals and patients/relatives to cooperate and communicate easier, thereby facilitating the provision of integrated care. A pragmatic approach was used in the design of the architecture, attempting to find a solution that takes today's situation with legacy systems and lacks of information
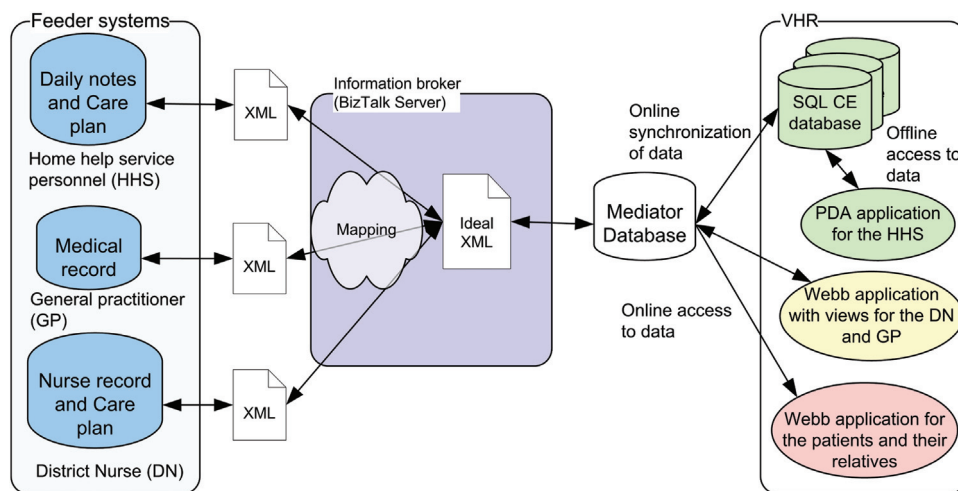
Figure 2. The integration architecture.

standards into account. End user applications that address specific issues of integrated care are crucial in order to realize the full benefits of the integration architecture, and therefore the different applications developed for different user groups are also presented as part of the results.

The virtual health record architecture

A service-oriented approach was used when designing the virtual health record architecture, where database functionality and services are separated. This guarantees flexibility with regard to changing functional demands and allows third party systems to interact with the platform in a standardized way.

The virtual health record implements a physically federated integration, and gathers information from three separate feeder systems, used by three different care provider categories. Each feeder system is accessed through a web service. Publishing of information from the feeder systems is triggered by an information broker requesting information about patients currently listed in the virtual health record, and the web services deliver information in an XML-file in a pre-defined format. Due to the lack of information standards in today's legacy systems, a variation in XML-file structures makes it necessary to map each XML-file towards an ideal XML-schema suitable for integrated home care. The information broker maps the XML-files from the feeder systems against the ideal schema developed within the project, and sends it as input to a web service which inserts it in the mediator database.

Once information is in the mediator database, users can access it through their virtual health record-applications. Each user category has a specific view,

giving access only to information they need and are allowed to read. Two types of applications have been developed; (1) online web applications used by general practitioners, district nurses and patients/relatives, and (2) an offline application for a handheld computer used by home help service personnel. Each handheld device has a local SQL CE 2.0 database to which data to and from the mediator database is synchronized using server based filters ensuring access rights configured according to different users' roles. The online web applications interact directly with the mediator database through a roaming session based virtual private network (Figure 2).

The information broker
The information broker's primary tasks are to coordinate information transfer between the virtual health record and the feeder systems, and to handle information mapping between the feeder systems and the Old@Home ideal schema.

Web service orchestrations [32] are set up in the information broker to coordinate and control the information transfer. The orchestrations handle the calls to different web services, receive and forward messages delivered by the web services, and make sure that the work flow is executed in the correct order. Figure 3 shows the design of the process of transferring added or changed information from the virtual health record back to the feeder systems.

The process of information transfer in the information broker can be triggered by different events. The current implementation uses time-scheduled triggering, where the mapping process is activated on regular intervals, but other events, such as a request from an end-user application are also possible.
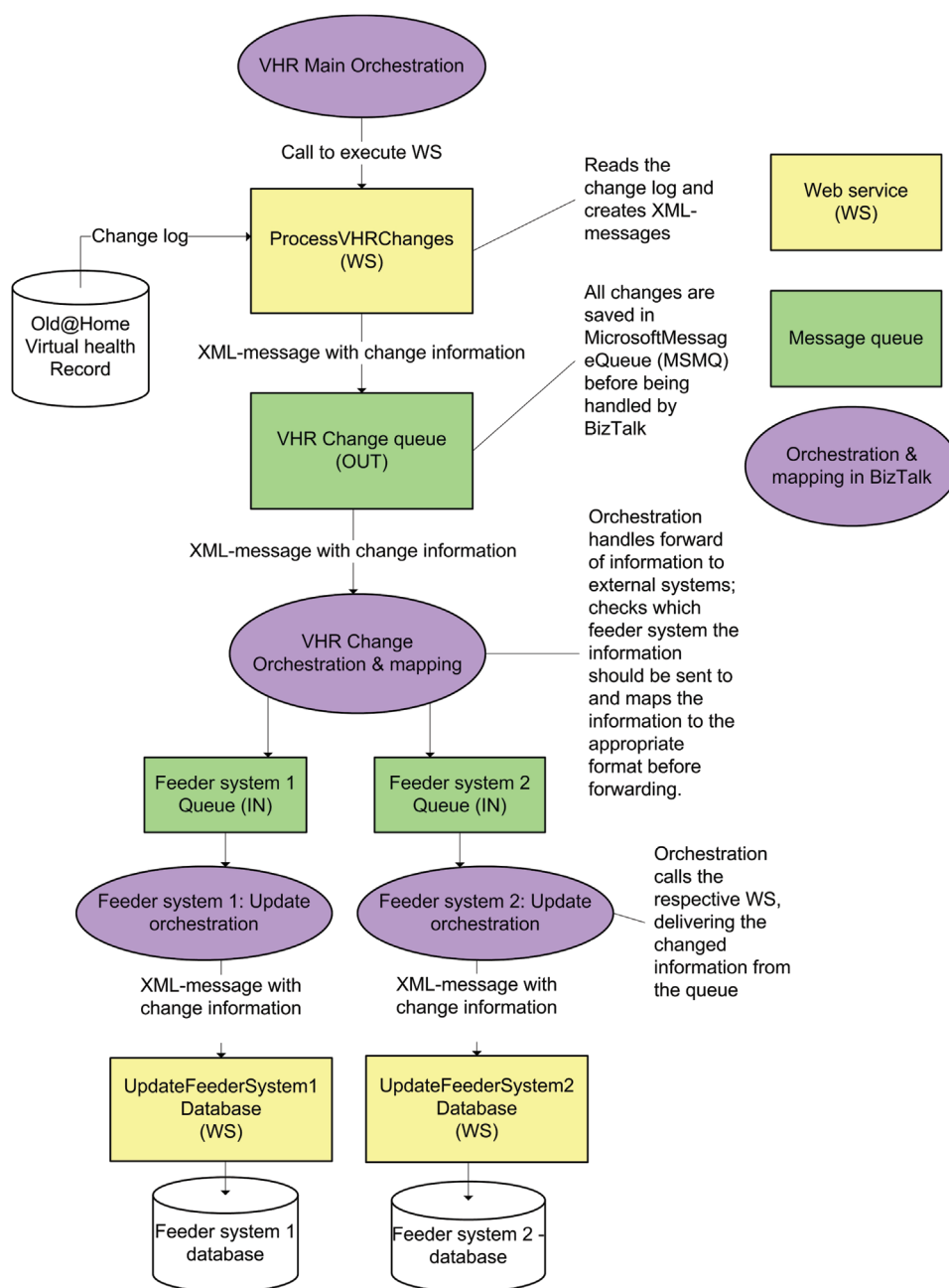
Figure 3. Process of transferring information from the virtual health record to the feeder systems.

In case of completely standardized feeder systems, the role of the information broker would simply be to organize the information transfer between the virtual health record and the feeder systems. Today, however, system providers that develop web services in order to communicate with this information broker have to adapt to the format of the ideal schema.

Naturally it is also desirable for the ideal schema to be compliant with a standard for information sharing, such as ENV 13606 [33] or HL7 [21]. In the Old@-Home project, we chose not to focus on any one standard, but to find the solution that best met the requirements of the mobile virtual health record, based on available standards. Work aiming at finding a national standard for information sharing in Sweden is also in progress, and the flexibility of our solution will make future adjustments of our ideal schema to a national standard feasible, when such is made available.

The mediator database

The physically federated integration method requires a mediator database to which information from feeder systems can be copied and where additional

information, which is not available in the feeder systems, such as certain multimedia information or information used for communication between different care providers, can be stored. This type of information is not published back to the feeder systems, but remains in the mediator database, connected to a specific patient. However, all information that is documented at the point of care is stored in the mediator database and subsequently published back to the appropriate feeder system, as is shown in Figure 3.

New or updated information in the virtual health record has to be published back to the right feeder system. Therefore a change log structure has been included in the mediator database; whenever information is added or changed a new post is created in the change log with information about when information was changed, which patient it belongs to and where, which table, in the mediator database it is stored.

Security and access rights
When sharing information between different care provider organizations, and making this information available to patients and relatives, reliable security mechanisms are vital. This is particularly important when separate data storage is used, and/or offline applications with local databases are available. To provide health care professionals, care provider organizations and patient with trustworthy and secure solutions, it is of essence to focus on authentication and security on different levels. On a high level, role based access rights enables each user group to only have access to information on patients they work with, and only to a limited amount of information on each patient. In order to ensure that the solution remains useful even though the amount of information is limited, it is important to determine what information different user groups need access to, and therefore a thorough analysis of information needs is required.

Patients are also able to control access rights, to deny certain user groups access to certain information, although so far no one has chosen this alternative. On a low level all methods in the application have an equivalent operation in AZMAN and each user has one or more roles, all stored in the directory. Every method itself checks if the user has the right to perform that method. Access rights are granted to authenticated users stored in the directory, roles are synchronized to the PDA/SQL CE after a full authentication to the server online. When granted access data leaving the server is in an encrypted secure channel and all data stored are encrypted and all security can be managed centrally.

Developed applications

Different prototype applications, or views, for different user groups have been developed with the main goal to give access to necessary information regardless of which feeder system it is originally stored in.

The professionals' views
The health care professionals can access current information about their patients through the virtual health record. If they are unfamiliar with some patients, their health history can be checked and practical information, such as address, maps and travel information, is available. As the information is gathered from several different feeder systems, the home help service personnel can see certain information from the district nurses electronic health record and vice versa. This enables the care providing team working in integrated home care to obtain a broader picture of the patients' health, and an overview of the entire care process.

An aggregated care plan containing information from both the home help service personnel's care plan and the district nurse's care plan is, for example, available in the virtual health record. This increases the cooperation between the two professions, as they become increasingly aware of the work performed by the other care providers, and how this affects the patient's health. All health care professionals are able to document the care they provide while at the patient's home, instead of having to wait until they return to their offices. This increases the quality of the documentation since information does not have to be remembered for long periods of time. Point of care documentation also enables information to be rapidly spread throughout the care providing team, supporting cooperation and communication.

In case of unexpected events important information such as the prescription list and the latest daily notes can be checked and contact information for other care professionals is available. In case of emergency, the health care professionals are able to immediately provide the ambulance with important information about the patient, such as risk factors.

To allow for a holistic overview of information available and ease of use of both the PDA and the web applications, special consideration has been given to the design of the graphical user interface. Important aspects have been to identify the origin of information, that is, from which feeder system it is gathered, to support the staff's work processes, and to reduce the number of clicks. For instance, identification of origin of information is done by color coding. All information

from the general practitioner's system is displayed in blue color, from the district nurse's system in yellow color and from the home help service personnel's system in green color. Thereby the health care professionals can instantly see from which profession the information is gathered, and interpret it accordingly. For more detailed descriptions of the visualization and interaction techniques used see [28] and [34].

The patients and relatives view

The view for patients and relatives is a mean to involve patients and relatives in the care process by providing important information without generating extra work load for the care professionals. This view contains certain information from different care professionals' documentation, such as; the aggregated care plan, the prescription list, and notes from the home help service personnel.

Patients can access the virtual health record themselves, and/or allow close relatives to have access to the information. Being able to read certain parts of the care professionals' documentation increases safety and trust for relatives living far away and allows patients and relatives to re-read information such as the care plan agreed upon. Relatives have access to certain parts of information available in different feeder systems and can see what type of care has been provided etc. For instance, if an elderly patient has been given new prescriptions by the general practitioner, relatives can see these changes in the prescription list containing instructions from the district nurse.

The patients and their relatives can also access the aggregated care plan agreed upon with the home help service personnel and the district nurse, and are thereby able to keep up to date with and feel more involved in the actual care provided. This also enables them to give more informed feedback on the care process, and discuss the care provided with different care providers.

Results from the qualitative evaluation

The degree of IT usage differs between the different groups of healthcare personnel. At project start, general practitioners and district nurses documented either digitally on their respective medical and nursing record systems when working at the office, or on paper. The home help service personnel used only paper-based documentation. None of the groups used digital, mobile documentation facilities or had access to any tools for information sharing. The user analysis indicated that few, other than the general practitioners, had experience of working with information and communication technology and the majority were not what

are normally referred to as early adopters of technology.

Expectations

The analysis of the professionals expectations prior to the introduction of the virtual health record revealed a number of fears; *lack of support;* from management and from IT-support, *technical problems*; disturbance of daily work, *time consuming*; take too long to perform everyday tasks, the personal interaction with the patient will suffer, *lacking usability and/or lack of belief in ones own capabilities*; too difficult to learn, too difficult to handle, *not useful;* the provided functionality will not be adapted to and useful in the work situations, *personal responsibilities;* fear of making mistakes when using the system, fear of loosing or damaging the hardware, and finally fears related to *team work*; if members of the group do not use the tools double work loads, misunderstandings and conflicts within the team can occur.

Positive expectations were also great, and mainly related to; *improved work situation;* less paper-work, safer documentation, more meaningful work, access to information, and *personal development;* interesting to learn something new, new experiences, improved competence.

Results

Most fears were not realized during deployment of the system. Technical problems and a perceived lack of support, however, remained issues throughout the test period. The technical problems were mainly related to the mobile technology; despite efforts to make the processes of synchronization and connection to the Internet as smooth and easy to use as possible, there were reoccurring problems where the health care professionals were unable to perform these tasks.

The synchronization was for example initially experienced as too time-consuming. The implemented filters required all information about patients the current user was granted access to, to be transferred, instead of only changes that occurred since the previous synchronization. This caused particularly long synchronization times when a new user logged on to the handheld device. In the project, this was solved by providing each user with a separate SIM-card on which their information was stored, so that when the users changed handheld device, they also changed SIM-cards. In the future, however, a less primitive solution to the problem would be required.

Despite the experienced problems, the health care professionals felt that the positive outcomes outweighed the problems and adopted the virtual health

record into their daily work. Personal development and improved work situations were confirmed results after the introduction of the virtual health record, as well as an increased insight into their work processes and improved cooperation within the team.

The view for patients and their relatives was tested by a group consisting of 2 patients and 6 relatives. All were convinced that the tool is very important and increases safety and trust. Elderly patients are often forgetful and their relatives, especially if living at a distance, have to contact the home help service personnel to keep informed. The participating relatives found the virtual health record very useful and usable. The application will however have to be better adapted to the specific requirements of the elderly patients [12].

Discussion

Needing offline access to the virtual health record in mobile work situations poses certain problems with respect to e.g. keeping the information updated and security aspects, and a proposed solution to these is the two-level synchronization described above, between local SQL CE databases and the mediator database, and between the mediator database and feeder systems.

When giving health care professionals access to information gathered from several different feeder systems, one has to take the problem of information overflow into account. If the users are confronted with too much information they will not be able to process it, and therefore a thorough selection of which information each user group should access has been performed and implemented in the virtual health record. Easy access to the virtual health record is also crucial in order to facilitate and not hamper the work at the point of care.

Technical problems, mainly relating to the mobile technology, remained an issue throughout the test period. The development of more stable solutions, both with regard to synchronization of offline applications and the connection to the Internet are needed in order for mobile applications to reach their full potential in a health care setting.

The need for standardized solutions for sharing information in healthcare remains an important issue. The integration architecture presented here is rather to be seen as a complement to current standardization work, providing a technical solution for integrated care, an implemented case study and a method for integration that may also be used for communication between different standards.

Preliminary evaluation of the virtual health record showed that enhanced information access and knowledge transfer results in an organizational development and better inter- and intra-organizational efficiency for the healthcare providing organizations. Time consuming search for information, such as phone calls and fax messages, was reduced as relevant information became available at the point of need. Furthermore, the healthcare personnel have gained insight into their own and each others work processes leading to a better mutual understanding of the needs of all involved professionals and a better overview over the entire care process [12].

Future work

The current implementation of the Old@Home mobile virtual health record is rather limited in scope. In order to validate the solution further, we hope to implement the virtual health record at other test sites, with other feeder systems and perhaps slightly different organizations. Even more interesting would be to adapt the virtual health record to a broader domain, for example advanced home care where different types of medical devices could also be connected to the integration platform, include other types of feeder systems, such as administrative and planning systems, and continue the evaluation with larger user groups.

Further effort need also be put into the standardization issue, and the Old@Home ideal schema will be updated to reflect the results of the work currently performed on the national level in Sweden.

Conclusions

In conclusion, the suggested virtual health record architecture, using triggered publishing as integration method, makes mobile access to information from different feeder systems and interaction with them possible. This enables a seamless flow of information between different care providers involved in integrated home care and patients and their relatives, ensuring a higher quality of care.

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