Beyond the Archive: Thinking CSCW into EHRs for Home Care

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Abstract— **The current electronic health records (EHR) are not build to adequately support pervasive healthcare, but overcoming certain challenges could change that. In this paper we explicate that point by presenting results of applying participatory design to two scenarios: treating diabetic foot ulcers at home, and providing support for women during their pregnancy. In particular, the contributions of this paper are: (1) to explicate the diversity of the domain, and how this leads to complex issues in practice, (2) to present four particular issues that need to be addressed in the design of EHRs as found through application of participatory design in our two scenarios, (3) to establish promising approaches to handling those four issues, and (4) to present the core of a software architecture that supports these approaches.**

I. Introduction

Health care providers in the western world are facing huge economic challenges due to ageing populations [1], [2] and structural challenges due to demand for increasing patients' control of their own treatment and care [3].

Pervasive Healthcare opens for home situated treatment and care, which is potentially part of the answer to these challenges because enabling treatment at home is cheap compared to hospitalizing patients, and it increases patient satisfaction because many patients are uncomfortable leaving their homes [4]. Home care does not, however, come without challenges of its own. For instance, we face the challenge of enabling collaboration between a set of actors that are rather diverse and rarely co-located.

Currently, the traditional paper based patient records are in the process of being replaced by Electronic Health Records (EHR)[1] in many hospitals throughout the world. In Denmark where this research has been carried out, the government has decided that all public hospitals must have implemented extended EHR systems within the next few years [5].

Research in CSCW (Computer Supported Cooperative Work) are showing indications that these EHR systems are in general not prepared to support the challenges of home care [6], [7], because most EHR systems are mainly (and inappropriately) thought of as archiving systems lacking the necessary mechanisms for collaboration support [8], [9], [10]. In part this originates from a failure to recognize the flexibility of paper based medical records [11], but the shift towards home care brings about problems with e.g. coordination that go beyond the traditional paper based medical records.

In this paper, then, we adopt a broader view of the EHR as being not just a medium of storage, but also of coordination and communication between the actors involved in the treatment of a patient. Additionally we view the work routines around EHR as part of the system.

To be more precise about this point we consider two scenarios: Home based telemedicine treatment of diabetic patients with foot ulcers and Pervasive Computing support for pregnant women. In both cases the situation is characterized by different health care providers working with the same client, turning the care into a team effort [12], [4]. Members of the group all have different points of view, and fields of expertise. The diversity is of course also present in the traditional work conditions for these stakeholders, but once the treatment of demanding conditions such as diabetic ulcers is moved from the clinical ward to the patients' home the dependence on tight cooperation between the clinicians becomes heavier, while at the same time the means to handle this communication with direct face-to-face contact are removed.

This paper describes how we seek to establish knowledge about the challenges for EHR's that arise in home care and the potentials to address these challenges. The paper is organized as follows: After this introductory section, the next presents the two home care scenarios we have explored, and Section III outlines the methodological foundation of this exploration. The main contributions are in Section IV which presents the challenges uncovered in our work, and in Section V where we propose approaches to meet these challenges. In Section VI an overview of the software architecture that supports our proposed solutions can be found. Finally a conclusion in Section VII.

II. Scenarios

A. Pregnancy

The first scenario we explore concerns provision of support during pregnancies to the women and their care team. This

[1]Sometimes the terms Electronic Medical Record/Journal (EMR/EMJ) or Electronic Patient Record/Journal (EPR/EPJ) are used indiscriminately; in this article we shall use the definition set forth by the Royal College of GPs, 2000, according to which EPR denotes a record of periodic care held by a single provider and EHR denotes a fully integrated record of the patient's complete medical history.

team includes their families as well as the primary and secondary health care providers. During our work, we found inefficient workflows and room for improvement:

First, the health care providers need to improve their communication and make less redundant interviews of and notes on the pregnant woman. Second, when a pregnant woman suffers from a chronic disease or for some reason needs extra surveillance, the number of meetings with health care providers explodes. Third, the varying reliability of information available online is a frequent cause of concern [13] to the women. Fourth, the pregnant woman is unable to see more than a fraction of her health care data.

To address these issues we have pursued the idea of providing each woman with a cell-phone sized device aimed at working as entry point for the provision of healthcare services, a Personal Medical Unit (for more on the notion of PMU, see [14]). This device holds information that otherwise would be distributed between general practitioners (GPs), midwives, pregnant women, and maternity wards. It contains all the relevant information with a view for each user of the information. Data can be moved seamlessly between this device and the different computers found in the health care world. Continuous measurements of e.g. blood pressure, temperature and blood sugar can be contained in this and updates from the common EHR will appear automatically. All data can be annotated with explanations, which will help the pregnant woman understand the data she can see.

Such a device would be an obvious target within which to embed sensory equipment: When a pregnant woman contacts e.g. an emergency doctor with a specific concern, it is likely that the arrangement of a face-to-face meeting could in some cases be avoided if the pregnant woman had the right sensory equipment. We are in the process of designing several bio sensors with functionality like measurement of the baby's heart beat and measurement of the stage of the labour.

The scenario is thus about collaboration between a number of actors that are distributed temporally and spatially and are diverse in terms of their point of view and field of expertise. And the main actor, the pregnant women, is in most cases quite resourceful, young, healthy and often also proficient with computers.

B. Home Based Treatment of Ulcers

The other scenario focuses on diabetic patients foot ulcers, which is a quite different and far less resourceful group of patients, since most of them are elderly and often suffer from diabetes related complications as well.

Diabetic ulcers are one of the most costly complications associated with the near epidemic spread of diabetes in the western world [15], [16]. Diabetic ulcers are treacherous and do not show the same signs of incipient infections as normal wounds, and yet the treatment of diabetic ulcers is often put in the hands of generally educated home care nurses and GPs without the necessary expertise to handle the quite delicate diabetic ulcers. Many amputations of diabetic feet could have been avoided, had the ulcer been treated optimally.

To improve the current practice the scenario envisions the experts at the hospital taking control of the treatment performed by the home care nurses in the home of the patient. This is accomplished by providing a common information space and facilities for synchronous and asynchronous communication. When the home care nurse visits the patient to change the wound dressings a video communication link to the expert at the hospital is established, and the expert can take responsibility for the treatment by using the home care nurse as a proxy. Digital pictures of the ulcer are taken and stored in the EHR to get an indication of the healing progress.

III. METHODS

Years of experience in HCI and CSCW has established several understandings of the relationship between the creation of technological artifacts and the patterns for human activities. First of all, any technological development process will also challenge the current use situation, leading to the formation of a new activity system. One of the most widespread ways of actively utilizing this relationship in the developing process is the various flavors of participatory design, where a user-centered and experimental approach lets the designers target technological development and use in parallel. [17]

Both of the above mentioned scenarios have been discussed and explored on a number of experimental, participatory design workshops (5 for the diabetic ulcer scenario, 8 for the pregnancy scenario), and various prototypes and mock-ups have been developed and evaluated. The methodology behind the workshops has been Cooperative Design [18], which has as one of its characteristics that the methods are applicable for both research and system development. The activities of the two projects with a time span of approximately two years are shown in figure 1.

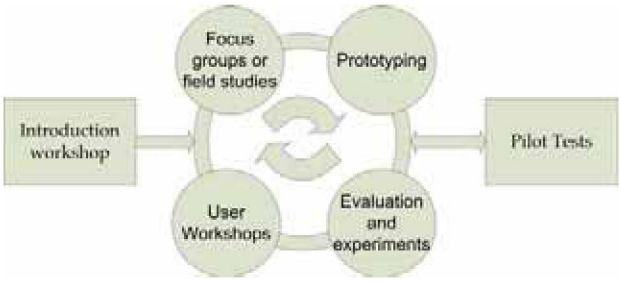

Fig. 1. Activities involving users in the diabetic foot ulcer and pregnancy projects.

As shown in figure 1 the first user activity in both projects were an introduction workshop, where the participants were introduced to the initial ideas of the project. The participants were individuals from the domain in focus. Great care has been taken to get representatives from all perspectives, e.g. not only the various health professionals, but also patients and relatives. In the project with diabetic foot ulcers, for instance, both visiting nurses with and without experience in treatment of ulcers were invited. This was done because the reality for

ulcer patients today is that the level of wound competence of their visiting nurse is more or less random.

In the diabetic ulcer project the total project group consisted of 15 persons apart from the researchers: 1 Doctor, 3 hospital nurses, 4 visiting nurses, 1 general practitioner, 2 patients and 1 relative. As far as possible the same persons attended all workshops. In the pilot test 5 new patients and 5 visiting nurses were included.

In the pregnancy project the group consisted of 8 pregnant women, 1 midwife, 1 general practitioner, 1 hospital doctor, 3 nurses, 1 IT responsible, and 1 EHR super user; 16 people in total.

After the first workshop, the planning of the rest of the process was done on an ad hoc basis, since new ideas and opinions were constantly raised that required changes to the vision of the final solution. The circular form in figure 1 illustrates that some ideas were iteratively elaborated upon during several workshops.

A detailed description of all the workshops will be too extensive in this context, but in the following we will briefly mention some of the techniques deployed at the workshops. The common denominator of the workshops is that problems and potential solutions are addressed in cooperation with the participants, allowing them to get hands-on experience with new concepts and to utilize, during the design process, the tacit knowledge they possess of their field.

When the current situation was explored, focus groups and field studies provided our main source of information. Future workshops [19] and dilemma games [18] were also useful for this purpose, in particular when 'drilling' down into problematic issues of todays situation.

When the focus moved to more design-oriented issues, explorative prototyping workshops [20] gave the participants possibilities for coming up with visionary ideas for potential futures. Later the prototyping activities would shift into a more experimental approach (a technique we have termed 'future laboratories', see [21]), where developed prototypes could be evaluated and discussed.

At some point in both projects a technological concept was ready, and it was desired to test, how it would behave outside the controlled world of the laboratories. Thus, the next step was to repeat some of the more concrete experiments with the technology in an pilot study. In the diabetic ulcer project a setup consisting of mobile videophones for online synchronous collaboration and a shared database for asynchronous collaboration was piloted. In the pregnancy project, the pilot test deployed two different semi-functional prototypes of a personal unit for storing medical information for the pregnant woman.

All activities were video recorded and subsequently transcribed to provide the basis for a thorough analysis. The material was categorized into 'themes' covering both clinical, technological and organizational issues. The technical and clinical findings from both projects have been or will be described elsewhere (see [22], [23], [24], [25], [26])

The findings presented in this article are issues that have an important impact on the role (and architecture) of EHR's in a situation where patients are pervasively receiving health care services from different providers distributed geographically and organizationally.

IV. Findings: EHRs for Home Care

The workshops we have conducted disclosed a number of challenges to the existing EHR's and the work practices around them. First, the personal relations suffer from the remote communication between co-workers. Second, the coordination between the primary (home care and GP's) and secondary (hospital) health sector is problematic, both inherently but even more so when communication is remote. Third, preventive home measurements do not have a natural place in EHR. Fourth, when information is distributed, problems with consistency and integrity arise, that have not been solved in EHR so far. These challenges are presented in this section.

A. Personal Relations

With any technical solution there are some business processes that are changed. In our scenarios we support communication over a distance between people who would normally be face-to-face and communication between people who would never have had synchronous communication. This makes their relations different from what they used to be [8], and different from what was expected when EHR and the business process around it was designed.

We identified the following challenges that must be overcome before EHR can support the development and maintenance of personal relations:

a) Finding common ground between the various persons partaking in the treatment team: During the work it became evident that the most fruitful discussions occurred when a number of different disciplines where represented. If only people with the same perspective were present problematic issues were often overlooked, but when several perspectives were joined on the workshops, these issues were quickly brought into limelight. The common understanding between the participants increased throughout the process, subverting prejudices and allowing the participants to pursue common goals. The same is relevant in a work situation, were common ground is a prerequisite for successful collaboration. Finding common ground is best facilitated by a direct face-to-face dialogue, where facial expressions and gestures can be interpreted by the receiving part [27].

b) Competence articulation in order to negotiate responsibilities and agree on a division of work: Any cooperation between co-workers requires the parties to acknowledge each other and agree on a division of labour. For instance they have to assess each others competencies to establish an appropriate level of trust. This is exemplified in the diabetic ulcer scenario, where the expert doctor needs to be able to assess the competence of the home care nurse in order to decide how complicated tasks can be put into his or her hands.

c) Supporting the many, often tacit, purposes of face to face encounters: When presented with remote communication instead of meetings, the health care professionals participating in the pregnancy workshops were sceptical. One of the reasons repeatedly stressed is the often tacit purposes of face-to-face meetings. For instance, when a pregnant woman visits her doctor, the meeting will always, aside from its immediate purpose, give the doctor an impression of e.g. the pregnant woman's state of mind and general well-being. Nevertheless the clinicians were positive towards the argument that the importance of tacit purposes of a meeting are decreased with very frequent meetings such as the biweekly check-up of pregnant women with diabetes.

Thus, a challenge in home care for the existing EHR systems is to balance the communicative needs against the efforts required to establish the different communication modalities.

B. Coordination

The tacit and seamless way people align and integrate their individual yet interdependent activities has long been a key research topic for the CSCW community [28]. Establishing cooperation between the primary health sector and the hospital experts increases the need for more explicit coordination mechanisms:

d) Asynchronous planning: In the diabetic ulcer scenario the experts' competence is applied to a treatment taking place out of their physical reach. To this end a direct dialogue with the visiting nurse performing the actual treatment is a necessity. For this reason, the project employs direct, synchronous communication via video link. The planning of this meeting can take place asynchronously, as long as it is done with enough time left to wait for an acknowledgement. In other situations, e.g. where the meeting needs to be established quickly or in replanning the meeting, it cannot be done asynchronously:

e) Ad-hoc synchronous replanning: One particular workshop in the ulcer project included a dilemma game in which the participants were asked to role-play the work related to scheduling online visits. This turned out to be a cumbersome task, necessitating a lot of telephone calls between the different parts which in turn were difficult since they do not normally possess each others direct numbers. Both at the hospital and in home care unexpected events are the rule more than the exception, meaning that delays are unavoidable. Thus, an appointment may need to be rescheduled on an ad hoc basis, which is further challenging due to the mobile nature of home care work.

In summary, coordination represents a huge challenge in making EHRs work in a setting where hospital clinicians cooperate cross-organizationally with home care clinicians. The solution lies in a mix of organizational changes and IT-support for the new ways of planning and communicating.

C. Preventive Home Measurement

During a long term course of treatment in home care, periods exist in which some patients will not have an essential need for the clinicians, while it is still important to be on the look-out for incipient complications. In these cases the clinicians could be supported in their remote decisions by measurements taken in the home by the visiting nurse or the patient him-/herself.

In practice, however, this gives rise to further challenges for the EHR design:

f) Consensus about what to measure: In the pregnancy project it was difficult for the participants in the workshops to reach a consensus of what measurements would be relevant. In particular the doctors rarely agreed on how useful different measures would be in different situations. Turning to the diabetic ulcer scenario, most of the patients in question already measure their blood sugar on a daily basis, and since virtually all members of the care team routinely ask for these numbers, they should of course be contained in the EHR system. During the initial phases of the project it was discussed if other measurements would be relevant. There are lots of physiological values that could have a say in wound healing, but the physiological coherence of these values and the condition of the diabetic foot is at best very poorly modelled. A rising skin temperature, for instance, could be due to increased blood flow, which is a good sign, or due to an incipient infection. We thus found that the value of continuous measurements taken by gadgets such as the PMU all comes down to the belief of the doctor which would prescribe it. Moreover, what may seem reasonable to measure with one patient can be inappropriate with others, due not only to their different syndromes and medical histories but also to issues such as the patient's mental strength and feelings about measuring.

g) Reliability and authenticity of self measurements: When patients themselves perform measurements, there is an issue of trust in the reliability and authenticity of the self measurements. Firstly because patients have varying abilities to perform it right even when intending to make a proper measurement. Secondly, "false" measurements may occur, if e.g. an elderly lady lets her grand child try the sensor. These problem worsens when the patient is the only one to interpret the results as this could lead to severe misinterpretations such as a false sense of security or relief.

h) Technical integration of self measurements: The technical integration of the medical devices with the EHR system is a challenging subject in that no golden standard for interfacing remote medical equipment exists and in that the data model of some EHRs does not support continuous data feeds such as may arise from a periodic self measurement. Additionally, the above issue of realiability and authenticity implies that data from self measurements needs to be annotated as such, rather than have the same status as a measurement provided by an experienced physician.

In summary, home measurement can be usable in situations, but integrating such mechanisms into EHRs poses challenges in that different health professionals do not agree on which measurements are relevant on different patients.

D. Distribution of Information

A move towards home care means that members of the care team are increasingly distributed among different organizations and places. Consequently, data exchanged and operated on in the systems they use, must be replicated one way or another. Whereas there are a several solutions to the mere technical challenge of synchronization (see for instance [29], [30]), there are other factors involved; it is not just data that is distributed, but also collection, use and management of information. This is challenging both technically and organizationally:

i) Distributed management of information: When health care becomes pervasive, so does the information on health care, and the patients will be empowered to combat illness and stay healthy by including health care information in their daily information space. A discussion of personal health information management (PHIM) is found in [31]. Considering first the pregnancy scenario, the current situation is that both the midwife, the hospital and the general practitioner each has a patient record for the pregnant woman. In general these cannot be replaced by a single shared patient record, because they vary in level of detail and in perspective, each being shaped by the differing objectives for using it and by the traditions in the field where it is used. Nevertheless, the need to provide a third-party with access to a patient record can arise when visiting, for instance, the emergency service or a foreign doctor during a vacation. In these cases it is necessary for the pregnant woman to have at least some form of read-access to the relevant parts of her patient record.

j) Distributed collection of information: The increasingly distributed management of information is accompanied by increasingly distributed collection of it. For instance, preventive self-measurements take place, typically, in the patient's home and exemplify the need to allow information to flow from a PMU and into the primary patient record. The other direction is also required, for e.g. laboratory results: In the diabetic ulcer scenario the ulcer expert would normally need an occasional sample of the ulcer, which would be done by the home care nurse who would afterwards mail the sample to the hospital laboratory by normal mail. Once the laboratory completed analysis of the sample the result should be readily available to the doctors etc. This kind of functionality already exists in most current EHRs, but should be extended to support the more distributed case as represented by the PMU. Figure 2 shows how measurements performed with a PMU or a biomedical sensor can be routed to EHR via gateways. When collection of information is distributed to be performed at the patients home, the doctors who base diagnoses on them must be sure of the competence of the person who performed the measurement. This assessment of competencies has already been addressed in Section IV-A.

k) Data integrity: While one of the aims with electronic records is to ease the administration of patient records, the ubiquitous accessibility also introduces new complexities for the hospital clinicians, for instance in managing remote patients. As an example, the following episode happened during the pilot test of the diabetic ulcer project: A hospital nurse has participated in a video consultation with one patient and a visiting nurse. Shortly hereafter another visiting nurse calls her on the phone with an enquiry on a different patient. The hospital nurse later posts an answer to the visiting nurse in the online record, but accidentally does so in the record of the wrong patient. This episode shows how data integrity is challenged, when the health professionals are dealing with remote patients: This error would have been less likely if the patient had been standing next to the nurse. EHR systems should provide means to help avoid errors like the one here reported. One simple thing could be to include a picture of the patient's face next to the name in the record.

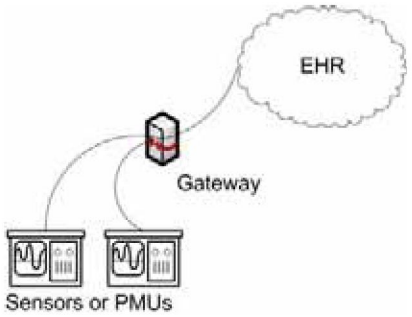

Fig. 2. The EHR connect to biomedical sensors and PMU's via a gateway.

In summary, a shift towards home care thus introduces the largely organizational challenge of deciding who, what and where in regard to collection and management of information, and the technical challenge of supporting this through an architecture that allows exchange of and distributed access to the information held in the EHR.

V. Designing Home Care EHRs

During the analysis of the workshops a consensus was also reached regarding what to recommend for future EHR systems for home care. Our guidelines to address the challenges in Section IV are presented here:

A. Personal Relations Revisited

One of the important conclusions from working with the project participants on the scenarios is the fact that patients want to talk to a person and even among the clinicians face-to-face communication is the best way of ensuring trust and common ground in the collaboration.

Yet, this optimal communication is a limited resource. When communication is unexpectedly needed, the parties are most likely not together. When the health professionals are far away, it can be difficult to come face-to-face with the patient. When frequent meetings are necessary and focus on a single aspect, both parties can feel they waste a lot of time.

Thus, it is useful to be able to communicate remotely and a number of different ways exist. Video conferencing is an old tradition in the telemedicine societies, and it has value as a medium that can be used across distances while preserving some of the rich modality of human dialogue [32]. When face-to-face meetings are impossible, this is still a good solution.

Experiences from the diabetic foot ulcer project show that security and confidence for patients and clinicians can be preserved using video conference.

Other ways of communication, however, are still relevant; pictures, chat channels, email, phone calls etc. It is important to know about the different possibilities and to have a toolbox to choose from. In figure 3 we have listed the different communicative modalities in a triangle that indicates the increasing scarcity of moving up in the levels. The triangle on the left indicates different levels of needs for the communication, which can be balanced against the availability of the communicative modalities. In this way the figure can be utilized both ways: (1) to recommend a communicative modality based on the specific situation, and (2) to indicate how much can be accomplished with a certain communication modality.

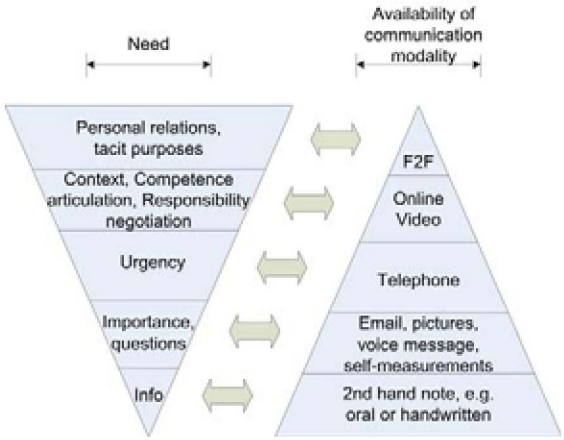

Fig. 3. The relationships between needed communication and available communicative modalities. (F2F: Face-to-face encounter.)

Figure 3 does not, of course, constitute a comprehensive model of what to do when. Nor does it claim priorities between the modalities, e.g. that telephone is better than email. Nevertheless, it indicates that there exists a relationship between the communicative modalities and the needs they are able to accommodate. Consequently a set of guidelines can be established.

Thus, starting from the bottom, when the basic reason for communication is merely passing on nice-to-know information any available communication modality will do, but the higher the importance of the enquiry, the higher the necessity of contacting the person in question directly, e.g. by mail. Urgent matters will need synchronous communicative modalities, and if context and common ground needs to be mediated, a rich communication channel such as online video will be feasible. Finally, if the purpose of communication is that of maintaining a personal relationship, there will be no technical substitute to a face-to-face encounter.

B. Coordination Revisited

Coordination of synchronous communication has proved a tiresome task if not supported by the EHR. During the workshops coordination was found to be hampered by lack of knowledge about where other members of the team were located, even within the hospital where the nurse would occasionally have to ”run down the hallway opening all doors” until she could find of the doctor. Mechanisms for providing location and context awareness seem promising, for instance in the managing of the appointments between the visiting nurse and the hospital experts. Colleagues of ours, Bardram and Hansen [14], equipped mobile phones with, among other features, location tracking capabilities and an awareness mechanism common in Instant Messaging: A user may choose a status like busy or on the phone for others to be seen. Hospital staff could then indicate a status such as ’operating’ or ’consultation’, and it is tempting to believe that technologies like this may support the ad hoc replanning, as described in section IV-B.

But even simple facilities can also be of great help. For instance in the diabetic ulcer scenario the EHR was adjusted to contain basic contact and scheduling information for each person involved with the treatment of a patient. Also the EHR was given a small feature making it possible to assign priority flags to notes made in the EHR. This was combined with a notification system sending a text message to the mobile phone of the doctor in question, if something required his attention. Mechanisms like these ensure that important knowledge can still be distributed in a reliable way and have proven valuable in later experiences from the diabetic ulcer project.

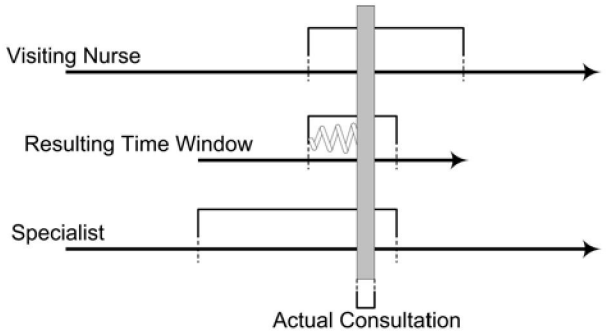

Fig. 4. The time frames for visiting nurse and specialist, and thus the time window in which to establish synchronous collaboration.

Still, technical aids do not suffice, if the schedules of the co-workers do not make it possible to agree on a time for the synchronous communication to take place. Thus, the work routines need revision when introducing EHRs for home care. At the hospital for instance a person needs to be able to handle incoming calls from patient and home care workers and fit this into the work situation. Also the working routines in the local health district need to be adjusted, e.g. so that the home care nurse with a scheduled video link with the patient is not also the nurse who needs to answer the emergency phone. Furthermore, the organizational changes introduced with such telemedicine arrangements would probably affect the whole business model for the involved health care instances [33]. One way of supporting these organizational changes could be to use a “window of opportunity” for synchronous communication as

shown in figure 4. Instead of deciding a time where to start communication, a flexible time frame is set to accommodate the dynamic and unpredictable environment health care is. The figure indicates the boundaries of the window of opportunity for the meeting as sharp, but in practise they are not because the deadlines may be more or less flexible (indicated with a spring in the figure). In particular the level of flexibility is individual and relative. It is relative because scheduling may involve prioritization of the participants' time and activities; e.g. the doctor's time is a scarcer resource than the nurses, but the activities constraining the doctor's participation in the meeting may be more flexible than those of the nurse or the patient.

C. Preventive Home Measurement Revisited

As indicated in figure 3 self measurements are placed as a low-level communicative modality, consisting in the most basic form of an asynchronous message containing a sensor reading. Therefore this measure cannot be used in situations with more advanced needs, such as sustaining a personal relationsship.

The discussion of preventive home measurement in our workshops showed them to be justified in some cases, depending on both the patient's or pregnant woman's resources and the kind of measurements involved. That is, pregnant women and other similarly resourceful groups could benefit from a PMU equipped for home measurements, while a great number of patients cannot. Rather than being inconclusive our data thus suggest that for a PMU it is unlikely that one size fits all patients. This is true even within the group of pregnant women that, while generally young, also include patients with mental disorders or habits of drug abuse.

Therefore an EHR design must enable a tailoring of the EHR to the individual patient (and doctor). This could be accomplished with a module based approach where each module corresponds to a limited functionality and data set so that the EHR for the individual patient is composed of the set of modules that are relevant in the situation at hand.

Every group of patients could be associated with a 'template' module for the EHR in order to ensure some degree of standardization, but it is vital that the patient and clinicians are allowed to deviate from this standard, when tailoring the configuration.

Concerning the challenge of technical integration our design recommendations are described in section V-D.

D. Distribution of Information Revisited

The distribution of information is a fundamental premise of home care as was outlined in Section IV-D. This subsection describes how we handle this distribution in the pregnancy and diabetic ulcer scenarios.

The PMU is, in addition to being equipped for preventive home measurements, also intended to carry a copy of the various patient records used by members of the care team. This makes it very tangible to all involved that the citizen must grant health care providers access to his/her data if need be, as is the case in Denmark. It also, and perhaps more importantly, makes it easier for different health care providers to share knowledge, since the information always follows the patient.

Many of the project participants liked the idea of a having a physical device with the information stored upon it. And even if it is not integrated with the IT systems in use by hospitals and GPs, the benefit of the patient being able to carry and grant access to professionals encountered in e.g. emergency situations or on vacations is substantial. This is supported by the emergence of commercial web-based personal medical record systems such as FollowMe[2] that requires patients to actually scan all health material from paper sources.

In the pregnancy project the management of this distributed data is being developed. Currently, the health care workers and the pregnant women has been introduced to it with simple prototypes explaining the data sharing as in figure 5. These prototypes were implemented with JSP using the built-in view functionality in database systems. The prototypes gave them an understanding of how we imagined data was being shared and how different roles had different views on it.

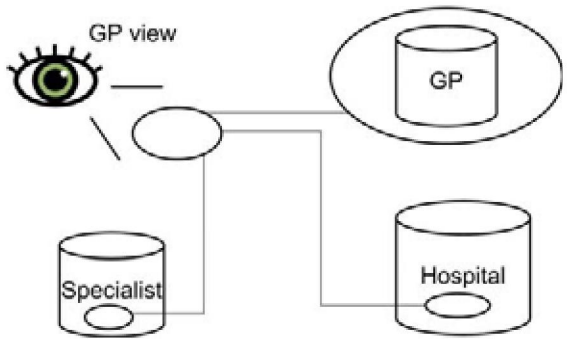

Fig. 5. An example of the view approach: The GP's view consists of the GP's own data plus access to selected parts of the hospital and specialist data.

But the specific patient records we intend to cover with the PMU in the pregnancy scenario are not included in the existing EHR systems. Without concern for integration with these, we are therefore free to merge the records used by the midwives, GP's and hospital doctors into one. This new data model is thus a union of the data available in each of the specialized patient records, without redundancy.

This is not in conflict with the differences among current patient records as described in Section IV-D, because the flexibility of an electronic data model allows the data to be accessed through a view which contain only the information required by e.g. the midwife or GP. By avoiding redundant information in the new and shared data model we achieve the additional benefit of forcing consistency between otherwise redundant data.

VI. Software Architecture

Since we perceive IT support for health care to be a means of individualizing treatment, rather than standardizing

[2]See The Economist (april 30th–may 6th 2005) pp.61 and www.followme.com

it, the overall theme for the architecture is flexibility. Another important theme is *palpability*. Palpability is found in systems that are capable of being noticed and mentally apprehended. Palpable systems support people in understanding what is going on at the level they choose. Additionally they support control and choice by people: Often the default mode is to suggest courses of action rather than acting automatically. Our efforts towards an architecture that supports these goals are convergent with those of the PalCom[3] project. The PalCom project aims to research and develop a new perspective on ambient computing denoted palpable computing. The pregnancy project is a subproject of this.

In this section the core of the software architecture [34] [35] developed in the PalCom project will be related to our findings and suggested solutions. Figure 6 shows the layers of the software architecture. The externally accessible level is the level that the users will be presented to by the PalCom systems. The lower layers can be made visible to the users, if the users request it. The common infrastructure and runtime components include QoS services such as resource management and contingency handling. The runtime environment consists of a virtual machine called PalVM and base components, such as resource awareness and communication primitives. PalVM is

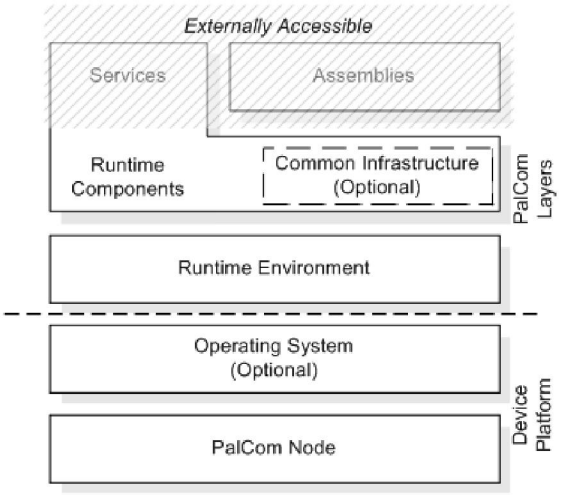

Fig. 6. The layers of the software architecture

better than an off-the-shelf VM, since it is able to run on very small devices and is very flexible with regard to hardware and programming languages. Apart from this, PalVM also has the benefit of being dynamically changeable, that is, the software running can be changed while it is used. This enables us to use the PalCom architecture, also in small or crucial devices that must not be stopped.

In Section V-A, the *personal relations* were discussed and different modalities of communication were proposed. With patients this will often have to be in the form of face-to-face meetings. However, the dependence on synchronous communication can be reduced if technical means such as video, email and phone are available. Since these forms of communication should be pervasively available they have to be supported to the degree possible by whichever set of devices people happend to have around, implying that the software must run on a diverse set of devices yet interoperate smoothly. This is achieved by making the PalVM available on many different platforms. The notion of assemblies being developed in PalCom[36] then support the utilization of and collaboration between services deployed onto such a set of devices.

Adding contact information and adding pictures found in Section V-B, and the addition of annotations to measurements described in section IV-C.h, will most likely imply changes in the data definition as well as in the rest of the system. These changes can be implemented by changing the basic data model and manually tweaking the EHR system(s) to accomodate those changes. However small extensions to the data model are useful in other circumstances. For instance we have learned from industry partners that integrating EHR systems often requires translating from one system's data model to that of another, and that these models are rarely, if ever, entirely compatible. This often leads to "extensions" in which a field present in one model is encoded into e.g. comment fields in the other. This fact alongside our suggested extensions illustrate the need for supporting evolution of the EHR, and thus support for extending the data model should be build into EHR. The way we approach building this extensibility is similar to how the xADL [37] architecture description language is constructed. In xADL, there is a core model, described with the XML Schemas, which may be extended by adding additional schemas. This way, the data model encourages, and is able to accomodate additions that are structured. The distinction between structured extensions and unstructured ones (e.g. encoding additional information in a comment field) is important because it allows for automatic generation, or even dynamic adaptation, of parts of the code that relies on the datamodel (e.g. APIs or tools). Note that we are only arguing support for extensions, rather than a more general class of changes to the datamodel, because extensions, if built right, will not invalidate existing code that relies on the datamodel.

Concerning the challenge of coordination described in Section V-B, our work implies that a mix of organizational and technical means is called for. Coordination among members of a care team requires work schedules to be planned so as to allow synchronous communication to be arranged. A number of the challenges found within this aspect stems from the mobility of the field and this implies that the number and size of the devices carried around should be kept at a minumum. This is supported by the architecture since the core system is able to run on very small devices and on devices that the persons already use, such as mobile phones and PDAs.

As described in Section V-C, a general challenge for home care is supporting individuality, both for the patient, the treatment and the health care professionals around the patient. Realizing this requires an extensible and adaptive software architecture on the PMU. Therefore, the software architecture

[3] An EU-funded project wwww.ist-palcom.org

of the PMU is a service-oriented architecture (SOA) [38]. The software architecture is adaptable and reflects our view that the course of treatment should be tailored to the patient.

Section V-D motivates why data integrity and data management are increasingly important as the information flows more freely. The management of data will be done by using different databases that synchronize following a fixed pattern. To manage the data, the integrity if the data is important and is in our architecture sought met by annotating the data with pictures, signatures and other means of authentication. Also a new focus in the project is to make the right data accessible for the right persons at the right time. We explore ways of associating information with flavours of semantic web services and associative memory.

Also in Section V-D the integration with EHR and other data bases is discussed. It is essential for the palpability, i.e. the users feeling of control and understanding that all expected information is accessible. To meet this need, the communication component supports flexible communication. The devices discover each other with publish-subscribe communication, i.e. notifying on the same communication channel that there are devices who provide and require certain services. After agreeing on a quality of service, the devices form a point-to-point connection whereafter messaging and streaming is possible. The PalCom communication infrastructure provides an abstraction layer over the actual network technology used by the device. By providing such an abstraction dependencies associated with specific network technologies and protocols are hidden, the PalCom Services can thus be deployed on different PalCom systems and Nodes.

VII. Conclusion

Communication and sharing of knowledge and information is essential in the different visions about pervasive healthcare, most of which entail a central data repository at some point. EHR systems are seen as the central artefacts for sharing information between the different health care providers, and are thus one of the requisites for successful deployment of pervasive healthcare.

As the facilitator of the collaboration taking place in a pervasive healthcare setting, it is obvious that the EHR system must be more than a database with pre-determined content and fixed data structures. Thus, many of the findings reported in this paper may at first appear self-evident. Nevertheless, we have not yet seen those features in current EHRs and it is important for researchers in pervasive healthcare to establish a firm understanding of how this can be changed in future EHRs. As a step in that direction we have in this paper reported on the challenges experienced in our work with improving home care.

The two scenarios elaborated upon in this article depict two quite different situations, one with a group of patients typically without the physical or mental surplus to take greater responsibility, and one with a relatively strong person in the center of the action. For this reason we believe that the span of our investigations are representive for many other health care areas and patient groups. The central tenet for the two scenarios remain that of establishing a cooperation based on organizational and technological arrangements that go beyond the archive of traditional EHR systems.

By moving specialized treatment from a hospital setting to the home of the patient the design of EHR face the following challenges:

First, the personal relations: Currently, the work with common information takes place between people who are co-located. This enables them to use optimal communication. In the home care scenarios, things are different. This challenge should be met by future EHRs by allowing multiple ways of remotely communicating and discussing richer data (like video and pictures) between locations. It is important to identify the communication needs in the specific situation and to find a balance between this and the available communicative modalities.

Second, the coordination between primary and secondary health sector: Currently, this is not at a level, where home care can work satisfactorily. Future technology could to the extent discussed in section VI allow for both asynchronous planning and ad hoc synchronous replanning to improve this situation. The real solution, though, is also found in a change of work practices and routines, both on part of the primary and secondary sector in order to allow time windows with possibility of synchronous communication.

Third, preventive home measurement: Currently the technical support for receiving and storing these measurements are not sufficient. Consensus is lacking both in terms of technical integration and, perhaps more importantly, about what measures are actually relevant for the different patients. From a software engineering perspective this finding suggests that a system should be build with a tool-box philosophy to enable a tailoring of the system to every individual health situation.

Fourth, the distribution of information: Currently this can be very random because the patient in some cases needs to be the bearer of their own patient data and thus, the propagation of changes in data can depend on the patient giving the right information to the right people. The situation is also error-prone, because the redundancy of the information can lead to out-dated or even wrong information at some locations. The view of information presented to the individual patient or health professional will need to be tailored to the specific context, but this should be done in a way that forces consistency between the different views.

To meet these challenges we suggest basing the design of EHR on a flexible architecture allowing tailoring of the system to the use context. The architecture presented in section VI distinguishes itself by the high degree of individuality and mobility.

In conclusion, if EHRs are to live up to their expectations as the main informational entity in pervasive healthcare, it is necessary for every individual citizen to make the system fit his or her purposes. By putting the user in the center of the design, as suggested by our architecture, the EHR system

would also be utilizable for daily purposes not strictly related to receiving treatment or care, supporting a shift in perspective from pervasive healthcare to pervasive health.

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