

Supporting Stakeholder Needs by Ceding Control: The Benefits of Listening to End-Users

Anthony P. Glascock, Ph.D., David M. Kutzik, Ph.D.
Department of Culture and Communication
Drexel University
Philadelphia, PA 19104

Abstract—This paper reports on the progressive design process and actual use and evaluation in situ of an informatics system—the Home Care Informatics System—that transmits information obtained by home based pervasive health care systems to caregivers and clients in a timely manner and easily usable format. Since 2006, three versions of the system have been tested in a series of studies with care provision organizations in the United States, the United Kingdom and the Netherlands. Findings from the studies have driven the development of the different iterations with the result being a customized model of pervasive health care that relies on the needs of the end-users, rather than the goals of the developers. Barriers encountered during the testing, that appear to be generalizable to the successful adoption of pervasive health care systems in general, are discussed and possible solutions suggested.

Keywords—informatics; care provision; health care records; behavioral monitoring

I. INTRODUCTION

One of the greatest challenges facing the integration of pervasive health care technologies in general, and home based monitoring specifically, into health care practice is transmitting the information obtained by these systems to caregivers and clients in a timely manner and easily usable format. Although a growing number of home based pervasive health care systems has been developed in the last decade—vital signs, behavioral/lifestyle, environmental [1, 2, 3]—the development of technologies, i.e., **informatics**, that translate the resultant data into usable information and transmit this information to end users—health care professionals, emergency responders, clients, family members—has lagged behind [4, 5, 6]. In fact, informatics is most often ignored completely in the development of the Home Based Monitoring Systems (HBMS) technology, with the prevailing assumption being that if the technology can provide the data, the end-users can figure out what to do with it. Thus, wide spread adoption

of the home based systems has been slow and the full potential of these various systems unmet [7, 8, 9].

This paper reports the progressive design process and actual use and evaluation in situ of one such informatics system: the Home Care Informatics System (HCIS). The first iteration of the HCIS was developed in 2006 and in the last four years three separate iterations have been used within seven different care delivery organizations in three countries—the United States, the United Kingdom and the Netherlands. As of December 31, 2010, the HCIS, in one of its iterations, has been used with over 300 HBMS installations for periods of six months to over two years. Although at present the HCIS has only been used with behavioral/lifestyle monitoring systems, it is designed to be used with any home based system and can be configured to be accessed on any smart mobile device.

II. THREE STAGES OF DEVELOPMENT

A. Stage 1—2006-2007

The HCIS was initially conceived of and developed as a research tool, rather than an informatics system that could be used in the actual delivery of care. In 2006, we had begun working with our sixth care organization as part of the Caring Home Study which was a comparative study of how QuietCare[®]¹ functioned as a passive emergency response system within different care delivery models [8, 10]. Up until we began to work with this particular care organization, we had relied primarily on anecdotes (case studies) to understand how QuietCare[®] was used to help provide information to care

¹ The QuietCare[®] system uses a sensor array in the home to collect data on the following everyday activities: 1) wake up time; 2) meal preparation; 3) medication adherence; 4) overnight toileting; and 5) general activity. In addition, the system monitors the ambient temperature in the residence and provides “possible fall” notification. The data are translated into actionable information and displayed on a PIN secure web site that can be accessed by formal and/or informal caregivers [10].

givers on the needs of their clients. We had collected literally hundreds of case studies, some dramatic—lives saved after falls or heart attacks—but most relatively mundane—a change in medication as a result of a decline in meal preparation. However, what was lacking was a way to systematically track, quantify and analyze data produced, not only by the QuietCare® alerts, but by the actions of the caregivers as they responded to the alerts. A thorough review of the literature indicated that no such research tool existed that could automatically accomplish the goal of collecting such data and thus, we set out to create such a tool.

Although Selfhelp Community Services, Inc. provides a wide variety of care throughout the five boroughs of New York City, the study we undertook with them focused on the use of QuietCare® within a care management model in a Naturally Occurring Retirement Community (NORC) in Queens. In this care model, thirteen geriatric social workers provided care management services to over 200 residents within the three buildings of the NORC. Twenty-seven of these clients agreed to have QuietCare® installed for a six month period and to have the social workers use the resultant data in care management decisions [11]. Before the study began, it was mutually agreed that a data collection and management system would be part of the study and that all of the geriatric social workers would use the instrument and that both the researchers and the supervisors/administrators at Selfhelp would have access to the findings.

The first iteration of the instrument was in place as the study began in July 2006. This iteration was named the **TAO**: standing for **Trigger**, the QuietCare® alert; **Action**, the care action taken by the social worker in response to the alert; and **Outcome**, the health or care outcome brought about by the care action. A brief example illustrates the initial design of the TAO:

QuietCare® sends to the geriatric social worker an alert indicating an increase in overnight toileting for a particular client—the **Trigger**;

The social worker who receives the alert, phones the client to inquire about the client’s behavior—the **Action**;

Finding out that the client was frequently in the bathroom because of a stomach flu, the social worker contacts the client’s physician to obtain a prescription for medication—the health **Outcome**.

For the first month of the study, even though the social worker received the alert on her computer, she filled out a paper form with the relevant information, which was then entered into a computer data base for analysis. During this first month at the initial meeting of the study team—geriatric social workers, supervisors, administrators and researchers—everyone agreed that the paper version of the TAO was time-consuming to fill out, redundant with other forms that had to be filled out by hand and could not be easily shared with co-workers and supervisors. Thus, a computerized web-based

version of the TAO was created and put in operation in the sixth week of the study. (See Fig.1)

Trigger/Action/Outcome (TAO) Form

#51-S0301-150

1. Submitted By
 Caregiver's Name: Harriet Jackson

2. Client ID: S0301 (1367)

3. Date: 8 / 10 / 2006

4. Triggers (check only one)
 Alert Email(s) Website Alert Non-QuietCare Trigger
 (If non-QuietCare alert trigger, please explain in box below)

5. Alerts (Check all that apply)

a. Urgent Alerts
 Wake-up
 Fall
 Temperature

b. Non-urgent Alerts
 Overnight
 Meals
 Activity

Figure 1. Web-TAO

The Web-TAO form took about five minutes to fill out, could be easily shared with others and, most importantly, could be updated as more actions and outcomes occurred. In the short run, this last feature proved beneficial for the social workers as they could quickly and almost effortlessly update the Web-TAO records for individual clients. In the long run, the need to have an update capability proved essential in the development of an effective informatics system for HBMS. This is because, although the alert is a discrete event, care actions and health outcomes are not discrete, but instead roll out over time. The previous example of the TAO narrative has all three elements as discrete events—one Trigger, one Action, one Outcome—and this example corresponds to approximately 40% of the TAOs collected at Selfhelp. However, a majority of the TAOs corresponded more to the following example:

QuietCare® sends to the geriatric social worker an alert indicating an increase in overnight toileting for a particular client—the **Trigger**;

The social worker who receives the alert, phones the client to inquire about the client’s behavior—the **Action**;

Finding out that the client was frequently in the bathroom because of a stomach flu, the social worker contacts the client’s physician to obtain a prescription for medication—the health **Outcome**;

The social worker phones the client's daughter to report that her mother has the flu—**Second Action**;

Daughter visits her mother the next day finding out that her mother is no better—**Third Action, Second Outcome**;

Daughter phones social worker reporting on mother's condition—**Fourth Action**; social worker visits client, determines that she is dehydrated, phones physician—**Fifth Action**;

Physician decides to have client admitted to hospital—**Sixth Action, Third Outcome**;

Client is discharged after two days in hospital—**Seventh Action, Fourth Outcome**.

All of the above actions and outcomes were the result of the single alert and could now be entered into the Web-TAO as the events rolled out over time. As a record of care provided and outcomes generated, the Web-TAO proved extremely helpful to the geriatric social workers as they could more systematically track the progression of care and outcomes. However, the realization of how multiple care actions and outcomes could be gathered together in a single record proved invaluable for the future development of the informatics system that eventually became the HCIS.

We have reported the quantitative results, e.g., number and type of alerts over the six months, number and type of actions and health outcomes, of the study elsewhere [10, 11], and even though these quantitative results are interesting, they did not drive the development of the informatics system as much as several other findings. These findings were largely derived from two main sources: first, monthly meetings with geriatric social workers, supervisors, administrators and researchers at which the entire study was discussed in general and the Web-TAO in particular; and second, interviews undertaken with the social workers, clients and family members of the clients.

It was at the first of these meetings that the social workers strongly suggested that the TAO be put on the Web. At subsequent meetings suggestions were made to: add auto-populated fields to the Web-TAO; use check-boxes whenever possible; allow for easier follow-up entries; allow access to individual records by other social workers and supervisors. In addition to these specific suggestions, several issues that would continue to challenge further development of the informatics system came to light. The two most important of which were: 1) how could the information contained in the Web-TAOs be most effectively used in the delivery of care to clients; and 2) should the Web-TAOs be used by supervisors to evaluate the work performed by the social workers? Since the social workers had not had anything like the Web-TAO prior to the study, there was a rather steep learning curve for each of them. The monthly meetings, at which the social workers and supervisors shared ideas, were extremely beneficial in learning the best way to employ the information contained in the Web-TAO in providing care. Sometimes the

discussions dealt with rather simple issues: is the printed record to be filed in a special Web-TAO file or in the client's file—the conclusion, in the client's file—to more complicated issues: should the records be shared with members of the client's family and if so, what can be shared, how should it be shared, should family members have access to the Web-TAO? The answers to these questions were, it depends; on the relationship between the client and family members, on the relationship between the social worker and the particular family member(s).

The concern raised by the social workers over the possible use of the Web-TAO in the evaluation of their job performance initially surprised us, because we did not even think about a supervisory function for the Web-TAO when we developed it. However, it was apparent after that second meeting that the information within the records could be used to evaluate work performance: how quickly did the social worker respond to the alert; how effective were the actions she took; did she follow up to determine the outcome of the action; did she recommend services provided by Selfhelp to the client—increasing revenue for the organization. For the supervisors, the Web-TAO provided an objective basis on which to evaluate the work performed by the social workers; for the social workers, the Web-TAO allowed supervisors to question their actions and professional conduct using information that had not been available previously. The issues surrounding the use of the Web-TAO in worker evaluation was not solved before the study ended but as discussed subsequently, it has remained a vexing problem as the development of the TAO/HCIS continued. However, perhaps the most important thing that we learned from both sources was that just because "rules" for the use of the TAO are created at one care organization does not mean that the rules will transfer to another organization. Every organization's culture is different, meaning that the process of rule creation as well as the rules themselves will be different.

The second source that provided valuable guidance for the further development of the TAO/HCIS was interviews undertaken with the social workers, clients and family members of the clients. Much of the information in these interviews dealt with issues other than the Web-TAO, e.g., the HBMS, but valuable insight into how the information in the Web-TAO could be used in care provision was obtained. Specifically three points were made by almost all of the social workers and the majority of family members. First, there were advantages to be gained by developing an on-going record of care actions and subsequent health outcomes. Social workers, in particular, were pleased with the ability provided by the Web-TAO to track changes in their clients' level of functioning, as well as benefits brought about by new treatment protocols. Second, perhaps even more valuable from their perspective was that this information was in one place and it could be easily accessed and shared with other social workers and supervisors. Third, both the social workers and family members appreciated how the information within the Web-TAO could be used as a basis for discussions about the health status of the client/relative. The social workers very much liked the fact that they could use information contained in the Web-TAO as a starting point for conversations with

family members. In addition, the social workers could share selected portions of the Web-TAO with family members in order to support care decisions. These findings indicated that any further development of the TAO/HCIS had to retain and, where possible, enhance the features that these care providers found most useful.

B. Stage 2—2007-2008

As the Selfhelp study was concluding, a new study commenced in London. Once again, the study consisted of the installation of QuietCare[®] in the residences of elderly individuals who were at risk for a variety of health and functional reasons and who were provided services by a care organization. However, unlike the Selfhelp study in which all clients lived independently and had their care managed by a single care organization, the London study involved several residential types and more than one care organization. All residents lived in Southwark, an area of Central London south of the Thames, and were provided services from one of three care organizations—Southwark Falls, Oasis and Hyde Housing. Although the organizations were “independent”, they all operated under the broad umbrella of the National Health Services (NHS) and the specific “town” of Southwark service area. Thus, the work undertaken by “carers” in these organizations was much more coordinated than would be found in three independent organizations in the United States. Each organization did provide services to a well-defined population: Southwark Falls, individuals living independently requiring a moderate level of care and services; Oasis, individuals living independently requiring a more intensive level of care and services; and Hyde Housing, individuals living in congregate housing requiring a very high level of care and services provided by residential staff. However, even though these organizations were “independent” and served distinct populations, for the discussion of the development of the TAO/HCIS it makes sense to view them as a single entity and to aggregate their clients. Therefore, the following discussion will refer to the Southwark Study and 97 clients rather than the individual care organizations and their clients: Southwark Falls—45; Oasis—16; Hyde Housing—36.

Based on the development work undertaken at Selfhelp, the Southwark Study began with a fully operational Web-TAO that had the ability to easily update a report as care actions and outcomes rolled out over time. Some changes had to be made in the Web-TAO’s check-boxes and auto-populated fields to conform to the particular care management models used in Southwark and to make the Web-TAO more “British”, e.g., English English rather than American English. Also based on development decisions made at Selfhelp, the Web-TAO implemented at Southwark had slightly enhanced information sharing ability which allowed easier access to individual client’s records by authorized personnel.

Similarly to our work at Selfhelp, we have reported the quantitative results from the Southwark Study, e.g., number and type of alerts over the eight months, number and type of actions and health outcomes, of the study elsewhere [8, 12, 13]. Also similarly, even though the quantitative results from Southwark are interesting, they did not drive the development

of the informatics system as findings from other sources, primarily a series of three meetings in London with carers from the three organizations and discussions by email and phone with carers about their usage of the Web-TAO.

Within the first six weeks of the study, it became apparent from the analysis of the material being entered into the Web-TAO that the carers were using the system much differently than the social workers at Selfhelp. This was due, in the first place, to the fact that the carers at Southwark had a working Web-TAO from Day One and there were no delays in implementation. Second, the nature of the culture of care at Southwark was different from at Selfhelp. At Southwark, the culture was extremely collaborative and although particular carers had primary responsibility for specific clients, all carers engaged with all clients in some fashion. The Web-TAO was immediately conceived by these carers as a tool to allow for easier sharing of information among all carers rather than just a record of responses—actions and outcomes—to triggering alerts. Therefore, the ability for all members of the care team to not only see the information, but to contribute to the information stream became paramount.

The cultural imperative to share and contribute to the information of clients was very quickly reflected in the Web-TAOs. Instead of discrete, although often lengthy records of actions and outcomes the Southwark Web-TAOs took on the appearance of “blogs” in which numerous carers listed their actions and the subsequent outcomes for particular clients. On the surface, this change appeared to be trivial, but in actuality it altered our entire thinking about the structure of the Web-TAO. The Web-TAO had already mutated from a research tool to a care provision tool that tracked responses to QuietCare[®] alerts, and now it had transformed again from a limited record of what transpired when an alert occurred, to a more comprehensive electronic record of all care being delivered to a specific client over time.

Fig. 2 is an example of a typical “blog” for a single client. This example page not only shows the comprehensive nature of the information recorded, but also illustrates how many carers became involved in contributing care for this client, including specialists from outside the original set of carers. It also became apparent that the “Smart Team”—the newly formed group of carers at Southwark who were now charged with making full use of the Web-TAO as a care tool—had other ideas for the use of the Web-TAO. One was to be able to send the “blog” to a client’s physician prior to an appointment in order for the physician to have all relevant care information. This required no modification in the Web-TAO and was implemented before the mid-point of the study. Another idea was to allow the “blogs” to be sorted by alert, particular carer, type of care actions and date of entry. Although technically not a complex undertaking, the challenge was to understand the use to be made of such a sorting feature, before creating it.

Trigger	-Wake up
Actions	-Phoned client -Visited client -Spoke to care professional Care Coordinator, GP -Contacted other person Spoke to OASIS Support Worker -Other action taken: Support worker spoke to client face to face, spoke to the surgery concerning the medical health of the client, GP to call back.
Outcomes	10/25 10:04) Client has been complaining of hip pain for the last two days but on prompting to attend GP surgery or to have home visit, she declined. When support worker visited, she found out that the client appeared unwell and movement was very slow.. Client had not eaten since last night so Support Worker prompted nutrition and medication and asked the client's permission to call GP to look at her hip. Client has agreed and a call has been made to book for a GP to examine the client. GP is aware of the needs, we have left a telephone message on the Next of kin's mobile number and Care Coordinator has been informed. GP visited and assessed Mrs B yesterday. She prescribed paracetamol for pain relief as it was found out that the arthritis in her hip was causing her so much pain. Client is still not able to get out of bed earlier but we hope that the pain will subside. Plan: Monitor the effect and report to GP as the condition changes. Care Coordinator to note. (10/26 10:47) GP stated that Mrs B appeared confused when examined and advised her to increase her fluid intake and contact the Specialist Mental Health Care Coordinator to assess the situation. (10/30 11:42) Following GP's prescription for pain relief, QuietCare showed that Mrs B visited the bathroom at 4.53 am and got out of the bedroom at 9.59 am which was unusual from recent data. She has been on pain relief since Friday 26th October and there appears to be a marked improvement in her health.

Figure 2. Web-TAO blog narrative

Unfortunately, the sorting feature was developed too late for it to be fully implemented in Southwark, but it became a key feature of the next iteration in the Netherlands. One issue that was not raised during any discussions at Southwark was the fear that the information stored in the Web-TAO could be used to evaluate the work performed by the carers. Initially, we assumed that the lack of concern over this issue was based on the differences between the health care systems in the United States and Europe. However, our experiences in the Netherlands disproved this initial assumption and brought the issue of using the Web-TAO as a means of evaluating a worker's performance to the forefront.

C. Stage 3—2007-2011

Our work in the Netherlands began in late 2007 as part of a demonstration project to evaluate the role of behavioral monitoring in the delivery of care both in the home of at-risk elderly and within an institutional setting in the Limburg Province. The initial demonstration project ran for six months during which time QuietCare[®] was installed in the residences of 12 individuals living independently and 13 individuals living within a sheltered housing facility. The success of the demonstration project led to a much larger study that began in 2008 and is scheduled to end at the end of 2011. As of December 31, 2010, QuietCare[®] units had been installed in the residences of 160 individuals living independently throughout the largely rural Limburg region. The lead care organization for both the demonstration project and the larger study is Proteion Homecare North Limburg, a full service care organization that provides both services and care in the home and within institutional settings. Two other care organizations,

which provide similar services and care as Proteion, are involved in the larger study, but their role is secondary to Proteion both in the number of clients served—145 clients for Proteion and only 40 for the other organizations—and administrative responsibilities. Thus, similarly to how we handled the London organizations, it makes sense to view these organizations, as well as the demonstration project and larger study, as a single entity and to aggregate the clients. Therefore, the following discussion of the development of the TAO/HCIS will refer to the Dutch Study with a total of 185 clients, rather than making reference to individual care organizations or differentiating between the demonstration project and the larger study.

Since the demonstration project in the Netherlands began as the London Study was winding down, we were able to provide the Dutch with an enhanced Web-TAO which had the ability to produce “blogs”, which we renamed the Client's Journal, as well as a means of sorting the information by type of alert, date, client, care worker and type of care action and, of course, we had to translate the content, e.g., check-boxes, auto-populated fields, instructions, of the Web-TAO into Dutch. The care delivery model at Proteion required their care workers to spend a considerable amount of each day traveling to and from the residences of clients throughout Limburg Province and they spent little time at Proteion's administrative headquarters. In addition, few of the care workers had access to laptop computers and therefore their ability to both access the Web-TAO and to enter information became a real concern. We solved this problem by developing the capability for the Web-TAO, renamed the Home Care Informatics System (HCIS) for this iteration, to be accessed on any smart mobile device. Since every care worker had a smart phone, this solved the problem of access and entry of information. However, it also raised other challenges. First, we had to reformat everything so that it could fit the small screen of the mobile devices. This led to an even greater reliance on check boxes and auto-populated features and to the development of more efficient scrolling features. Second, we had the challenge of making the HCIS display properly on the various smart devices used by the care workers. By the end of the demonstration project in the late summer of 2008, a fully functional HCIS was being used by the care workers. (See Fig. 3)

Similarly to both the Selfhelp and London studies, we have reported the quantitative results from the Dutch Study, e.g., number and type of alerts over the eight months, number and type of actions and health outcomes, of the study elsewhere [8, 14]. Also similar to the two previous studies, although the quantitative results from the Dutch Study are important to understanding HBMS and its use in care delivery, for developing the HCIS they did not prove as valuable as findings from other sources. The first author spent eight weeks in Maastricht, Limburg Province, during the transition period between the demonstration project and the larger study.



Figure 3. HCIS on smart mobile device

During this time he had numerous meetings with care workers and administrators at Proteion and with the Dutch research team to discuss issues pertaining to the further development and use of the HCIS. This also allowed for the direct observation of the HCIS “in-the-field” which aided in modifying the system to operate efficiently on smart devices. In addition to frequent contact by phone and email, we had access to everything entered by the care workers into the HCIS which has allowed for both troubleshooting and to detailed analysis of how the information in the HCIS Client Journals are used in care giving. Finally, the first author spent another week, during the summer of 2009 in Maastricht, meeting with research staff and care workers.

By February 2009, a fully functional HCIS was operational for use by care workers at Proteion (See Fig. 3). This iteration included all the features that had been developed during the Selfhelp and Southwark Studies and the Dutch Demonstration Project: 1) where ever possible the HCIS used check-boxes and auto-populated fields; 2) the Client’s Journal feature was fully operational and allowed entries by any authorized personnel; 3) the Journal could be sorted by alert, date, care worker, type of care delivered and outcome; 4) there was a new feature that allowed additions to a previous entry, but not the elimination of the original entry; 5) it was fully operational on a wide variety of mobile devices; 6) a series of pop up prompts to help the user navigate through functions and avoid common errors; 7) additional security features had been developed to ensure that only authorized individuals could access and contribute to a client’s record; and 8) a read-only feature had been made operational.

During the next few months several issues were raised by the care workers and administrators at Proteion; some of which were not easily resolved. The first issue revolved around how care was provided on weekends and holidays. At Proteion, and the other care organizations involved in the

Dutch Study, a team of care workers provides a range of services to a particular client, e.g., nursing care, rehabilitation services, shopping, house cleaning. One member of the team, usually, but not always a nurse, is designated the primary care worker. Although all team members have the ability to access and contribute to the HCIS, it is the primary care worker who is chiefly responsible for maintaining the HCIS record. The problem arises when the primary care worker, or for that matter any member of the team, is not on duty, i.e., weekends and holidays, and services are provided in the client’s residence by a care worker who is not on the team. Since only a small percentage of Proteion’s care workers are participating in the Study, these substitute care workers almost always are unfamiliar with the HCIS and lack access. Thus, care is being delivered, but the HCIS record is not being updated. Although this issue does not directly concern the technical development of the HCIS, it certainly impacts the implementation of the HCIS. A second issue that impacts directly on the implementation of the HCIS concerns the use of the HCIS record during care review meetings. These meetings include both individuals who have knowledge of and access to the HCIS and others who have neither. Since the client reviews are more thorough when everyone at the meeting has access to the information stored in the HCIS record, the question arises as to who should have access, how should they obtain access and who is in charge of making access happen? Once again, not a technical but, instead, a work rule issue. Ultimately, issues like these will only be solved when the care organization fully adopts the HCIS and all care workers, supervisors and administrators use the system. Until this occurs, ad hoc actions that attempt to solve the problems in the short run with the least disruption to normal work flow are the only recourse [8].

Perhaps the most vexing concern with the use of the HCIS in the Netherlands was over how the information stored in the records could be used by supervisors and administrators in the evaluation of work performance. On the surface, the concern expressed by the care workers in the Netherlands was similar to those raised by the social workers at Selfhelp and thus, we believed, could be fairly easily resolved by discussions by interested parties, as was the case in the United States. This did not happen. This is such a serious issue for the Dutch that there have been discussions about the need for national legislation that would prevent the information stored in the records from being used to evaluate a care worker’s performance.

III. DISCUSSION

Four years of development of the TAO/HCIS has resulted in a journey from a technology that was initially envisioned and implemented as a research tool (TAO), to a web-based care provision tool (Web-TAO), to an interactive journal/blog that could be used on a smart device, to a full-fledged electronic records informatics system (HCIS). Table 4 summarizes the evolution of the features from prior to the introduction of the TAO to the current HCIS.

	Pre-TAO	Paper-TAO	Web-TAO	HCIS
Entry	Paper	Paper	Computer	Mobile Device
Record*	Paper	Paper	Electronic	Electronic
Forms	Forms	Form Structure	Check and Text Boxes	Check and Text Boxes/ Narratives
Updating	No	No	No	Yes
Sorting	No	No	No	Yes
Sharing	Sharing Forms Possible	TAO Forms Shared	Record Shared by Email	Record Shared on Mobile Device

Figure 4. Evolution of Features

The system that is currently in use in the Netherlands is significantly different in scope, operation and potential customers than the one envisioned four years ago. In fact, it was only a year ago that we fully recognized that the HCIS is, in actuality, an Electronic Medical Records system (EMR), similar to those employed in hospitals and general medical practices. Thus, the HCIS has many features in common with these institutionally based systems: it allows for the creation of interactive records of care that can be accessed by any number of authorized individuals; the records can be sorted by any number of domains; and the HCIS can be easily integrated with any other electronic records system. However, there are features that differentiate the HCIS from these other systems: 1) it was specifically created to be used to record the delivery of care and services in the home; 2) it can be used on any smart mobile device; 3) it can be seamlessly integrated with any HBMS system, e.g., behavioral, vital signs, environmental; and 4) it can be easily adapted to be used with other pervasive health care applications.

Although it was not our intention in 2006 to produce an EMR, this was the result of our four years of work with the seven different care organizations.² At each of these organizations, we let the needs of the care organizations (end-users) drive the development process which resulted in us having to continuously redefine our goals to meet those of the organizations. Giving up control of the development process to the degree we did was both frustrating and difficult, but it was the only way that we could accomplish our overall goal—to produce a system that the caregivers would use, rather than something we thought the caregivers should use.

Even though the latest iteration of the HCIS is still operational in the Netherlands, development has not ended. If we have learned anything from the last four years it is that the needs of organizations are always growing and evolving and thus, the HCIS must also evolve or people will stop using it.

² The HCIS, even though differentiated from other EMR systems by its focus on the home environment and mobile platform, still faces some of the same barriers to adoption as other more traditional EMR systems [15], [16]. Additionally, although the need for a home-based EMR system has been recognized, there has been little progress towards wide implementation of such systems. [17], [18].

Given that our underlying philosophy of development is to listen to the end-users and respond to their needs, we are fairly certain that there will be another iteration of the HCIS. This iteration will, no doubt, have enhanced features that we currently see no reason to enhance and features that we have not even imagined. However, the next iteration will also have a greater chance of being used than if this process does not occur.

IV. CONCLUSION

After Based on our work with a specific HBMS product (QuietCare[®]), the key to the wide spread adoption of the home based systems appears to be dependent on the development of a dedicated informatics system that links the data gathering technology to the end-users, whether professional carers, informal caregivers or the clients themselves. Without such a dedicated system that has been customized to particular needs, end-users are left to try to figure out what the data means, how it can be used and how it fits into existing care delivery models on their own. In our experience, this leads to high levels of frustration on the part of those individuals who are to trying to use the data produced by the HBMS in caregiving, which in turn leads to the slow decline in the use of the information, which ultimately leads to the discontinuation of the use of the HBMS. This is especially true when the HBMS is being “tested” as part of a pilot study [4], [8], [14].

However, the nature of the informatics system that is developed to link the HBMS technology to the end-user is crucial to success. Four key design issues appear to underlie the successful development and implementation of such an informatics system. First, the system must be customized to the specific needs of the end-user organizational culture. The one-size-fits-all approach in which a software system is developed and then imposed upon the care delivery model of an organization with the assumption that the individuals at the organization will change what they do in order to use the system is doomed to failure. Second, and closely linked to the first, developers must get out of the laboratory and find out about the organizations in which the system is to operate: what type of clients do they serve; what information do they need to effectively deliver care; how is the information used; what type of care is delivered; how is the care delivered; and how can the new information provided by the technology be integrated with existing information. This type of knowledge can only be obtained by immersing oneself in the culture of caregiving; it cannot be gained in the laboratory or by focus groups or cursory marketing surveys.

Third, it is vital to understand that the introduction of any new technology, regardless of how beneficial in the long run, is disruptive in the short run. Introducing an informatics system can be very disruptive. Other words may be used for what happens during this introduction of a new technology, i.e., transformational, but the bottom line is that something new always disrupts how people do their jobs and thus, there will always be resistance by those having to change. Consequently, it is essential to get people to buy into the new system by including them in the design and implementation. Without the buy-in, the new system will not be successful. Finally, closely related to the third point, it is essential to plan for extensive and

on-going training in the use of the system. Even if there has been an initial buy-in, there will be problems down the road and continual training is essential to the long run success of adoption of the technology. A benefit to on-going training is that, in our experience, some end-users will make more creative use of the information provided and sharing such breakthroughs at these training sessions is helpful to everyone using the information and to the effective implementation of the system.

Although achieving the above design and development imperatives does not guarantee the successful adoption of an informatics system, or for that matter, any other pervasive health care technology/system, not having a plan to deal with them increases the probability of failure significantly. Unfortunately, there is no single road map to developing a successful plan, other than to pay attention to the needs of the people who are going to use the technology and include them at every stage of the development process and have patience. New technologies are never adopted overnight, i.e., the partial adoption of electronic records systems by hospitals has taken over a decade, and to assume that they will be, leads PHC developers to get discouraged and move on to the next big thing, rather than to maintain focus on the original idea. Perseverance in the drive for adoption of any new PHC technology is as important, if not more so, than the cleverness of the technology in and of itself.

REFERENCES

- [1] A. Logan, et al., "Mobile phone-based remote patient monitoring system for management of hypertension in diabetic patients", *AM J HYPERTENS*, vol. 20, pp. 942-948, 2007.
- [2] M. Parker, "Optimizing resilience in the 21st century", in *Resilience in Aging: Concepts, Research and Outcomes*, B. Resnick, L. Gwyther and K. Roberto, Eds., New York: Springer, 2011, pp. 317-330.
- [3] M. Alwan, "Passive in-home health and wellness monitoring: overview, value and examples", *EMBS, Annual International Conference of the IEEE*, pp. 4307-4310, 2009.
- [4] A. Glascock and D. Kutzik, "From the home to a BlackBerry: informatics-based telehomecare, in *Proceedings of the Ambient Intelligence Forum*, P. Mikulecky, T. Liskova, P. Cech and V. Bures, Eds. Amsterdam: IOS Press, 2009, pp. 112-120.
- [5] S. Levy, D. Bradley, and M. Swanston, "The technology prescription: linking telecare and informatics by using a need-led paradigm", *HIIJ*, vol. 8, no. 2, pp. 88-94, 2002.
- [6] B. Celler, N. Lovell, and D. Chan, "Using information technology to improve the management of chronic disease", *MJA*, vol. 171, pp. 518-521, 2003.
- [7] A. Glascock and D. Kutzik, "It's all about the information: the role of informatics in telecare", in *Selected Papers from the 4th International Conference on Aging, Disability and Independence*, W. Mann, Ed. Tampa: University of Florida Press, 2008, pp. 71-85.
- [8] A. Glascock and D. Kutzik, "A care informatics approach to telehomecare applications", in *The Handbook of Research on IT Management and Clinical Data Administration in Healthcare*, A. Dwivedi, Ed., Hershey, PA: IGI Publishing, 2009, pp. 368-382.
- [9] J. Barlow and J. Hendy, "Adopting integrated mainstream telecare services—lessons from the UK", in *Eurohealth*, vol. 15, no. 1, pp. 8 – 11, 2009.
- [10] A. Glascock and D. Kutzik, "The impact of behavioral monitoring technology on the provision of health care in the home", *JUCS*, vol. 12, no. 1, pp. 59-79, 2006.
- [11] D. Kutzik and A. Glascock, "An evidentiary report of QuietCare[®]: Selfhelp Community Services", unpublished.
- [12] A. Glascock and D. Kutzik, "An evidentiary study of the uses of automated behavioral monitoring", in *Conference Proceedings of the 21st International Conference on Advanced Information Networking and Applications*, Niagara Falls, Ontario, Canada, vol. 2, pp. 858–862, 2007.
- [13] A. Glascock and D. Kutzik, "From sensors to informatics: creating communication protocols for caregiving", in *Proceedings of the 3rd IET Conference on Intelligent Environments*, Ulm, Germany, pp. 325-332, 2007.
- [14] C. Willems, A. Glascock, D. Kutzik and J. Rietman, "The role of an informatics-based telehomecare in a person-centered service delivery model: findings from a feasibility study in the Netherlands", unpublished.
- [15] R. Holden and B. Karsch, "The technology acceptance model: its past and its future in health care", *J BIOMED INFORM*, vol. 43, pp. 159-188, 2010.
- [16] A. Boonstra and M. Broekhuis, "Barriers to the acceptance of electronic medical records by physicians from systematic review to taxonomy and interventions", *BMC Health Services Research* 2010, vol. 10, pp. 1-17. Retrieved from <http://www.biomedcentral.com/1472-6963/10/231>, on 4/14/2011, 2010.
- [17] P. Nutting, et al., "Initial lessons from the first national demonstration project on practice transformation to a patient-centered medical home", *ANN FAM MED*, vol. 7, pp. 254-260, 2009.
- [18] V. Vimarlund, N. Olve, I. Scandurra and S. Koch, "Organizational effects of information and communication technology (ICT) in elderly homecare: a case study", *HIIJ*, Vol. 14, pp. 183-193, 2008.