Filling a Gap in eHealth Records:
The Development of a Home Care Records System

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Abstract—The process of developing an eHealth records system over the last six years is described. The work took place at seven care organizations in the United States, the United Kingdom and the Netherlands and was part of a series of pilot studies assessing the effectiveness of a behavioral monitoring system in the delivery of care to at-risk elderly. A research tool created to systematically collect data on alerts, care actions and health outcomes evolved into a home care electronic records system. The system is fully functional on any smart mobile device and can be used with a wide variety of pervasive health care applications or as a stand-alone. Five essential design features that impact the future of such home care electronic records system are discussed.

Keywords—eHealth medical records; home care; mobile devices; self-management

I. INTRODUCTION

Over the last decade, there has been a general acceptance of the need for and use of electronic health care records, first in the hospital setting and later within physician practices. Initially in the United States, because of the cost, in time and money and disruption in the normal care delivery model, there was little enthusiasm for the use of electronic records. However, a combination of "encouragement" from the insurance industry and the insistence by government, the use of electronic records inexorably came to be the norm within hospitals, other institutional settings and physician practices. Even though the use of electronic records is not 100%, there is little doubt that the greater reliability of electronic records, the ease of storage and access and cost savings, will eventually achieve close to universal usage within institutions and among physicians [1, 2].

The home, however, is a different matter all together. Although delivery of care and services in the home has increased significantly and, if projections are correct, will accelerate at an ever more rapid pace over the coming several decades, the development and use of electronic systems to record the care and services has lagged behind the institutional sector. The acceleration of the delivery of care and services in the home is being driven by two main factors: demography and cost. The demographic trends are well known: dramatic increase in the number of elderly, especially the oldest-old; a concomitant increase in chronic diseases associated with aging, e.g., congestive heart failure (CHF), diabetes, dementia; and a decline in the number of informal carers—family members—who can provide care to the expanding elderly populations. Cost projections are similarly daunting: increasing cost for care delivery within the institutional setting; insufficient number of institutions—hospitals, nursing homes, rehabilitation facilities—to provide the care required for the elderly population and insufficient funds to build the large number of additional institutions; and prohibitive costs to government to provide care and services through current care delivery models.

It is generally agreed upon that the only way to meet the increasing needs brought about by the demographic trends, while at the same time not bankrupting national treasuries, is to provide more care and services in the home [3]. This is not a new idea, nor particularly radical, but as more care and services are being delivered in the home, several issues have emerged that raises serious concerns. In the first place, the care being delivered had steadily become more extensive. Whereas ten years ago rehabilitation after a serious illness or accident would have been undertaken in a specialized facility, increasingly these services are being provided in the home on an outpatient basis. But rehabilitation is just one of an escalating number of care services being provided in the home: nutritional counseling; wound care; psychological therapy; and medication adherence, to name several of the major ones. Additionally, the range of products and non-care services supplied to individuals in their own homes has increased significantly over the last few years: oxygen; specialized beds; monitoring systems—behavioral, vital signs, environmental extremes; meals; housekeeping; shopping; companion services. As the care and services have multiplied, so have the number of people providing the services, as well as the number of companies and agencies overseeing the provision of this care and services. Some of these companies/agencies may provide several services and products, but in most cases there are multiple providers and certainly multiple people providing the different services and products. These companies/agencies are, of course, in addition to any services provided by informal carers—family members, neighbors, friends.

Thus, the need for a means of recording and tracking the care and services provided in the home are essentially the same as for institutions: increased reliability; better

coordination; appropriate level of care; and cost savings. As more care and services are delivered by more people representing different companies and agencies, just keeping track of who is providing what becomes increasingly difficult, especially if the individual receiving the care lives alone in her home and is experiencing cognitive decline or other impairments. Scheduling of visits and deliveries, ensuring the correct product or service, avoiding duplication all become difficult if records are scattered among various agencies, companies and individuals and are rarely, if ever, shared. It is also extremely difficult to evaluate if the care and services are having the desired impact on the individual if there is no systematic way to track the care and services. In other words, if records are non-existent or scattered there is no way to measure outcomes resulting in the inability to determine if the care and services are appropriate. The lack of systematic and comprehensive records also makes it difficult for other care providers, e.g., physicians, specialists, to make informed care decisions, since the reliance on the patient to remember specifics about the care and services in the home has proven to be suspect at best. In addition, if electronic records of care and services in the home do not exist, it is obvious that they cannot be linked with the records that have been created in the hospital and the physician practice, resulting in an incomplete record of care. Finally, even though delivering care and services in the home is more economical than in institutions, it still costs money and someone has to pay for it. As a result, from the point of view of the client receiving the care and services, as well as the insurance company and the government, there is a discernable need to track the care and services to ensure that what is paid for is provided and that everyone was paid appropriately.

This paper reports on the inception, design, development, implementation, testing and evaluation of an electronic records system developed for care and services delivered in the home: the Home Care Informatics System (HCIS). The first iteration of the HCIS was developed in 2006 and in the last six 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 September 1, 2012, the HCIS, in one of its iterations, has been used for over 400 clients receiving care and services in their own homes. Although at present the HCIS has only been used in conjunction with a behavioral/lifestyle monitoring system, it is designed to be used independently of any monitoring system.

II. Three Stages of Development

The HCIS developed out of a comparative research project on the effectiveness of a particular behavioral monitoring system—QuietCare®— as a passive emergency response system within different care delivery models. The sequential research began in 2003 and eventually encompassed 14 care organizations in three countries [4, 5, 6]. As part of the research, it was essential to track the care

actions taken in response to an alert generated by QuietCare® in order to evaluate if the particular alert brought about an appropriate response by the care provider. Until 2006, the research had relied primarily on anecdotes (case studies) to understand how QuietCare® was used to help provide information to care givers on the needs of their clients. Although hundreds of such case studies had been collected and analyzed over the first four years of the research, there was no systematic means for the collection of data on the alerts, care actions and the health outcomes that could be subjected to a more rigorous analysis. 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, a new research instrument had to be developed.

A. Stage 1—2006-2007

Research at Selfhelp Community Services, Inc. was undertaken on the use of QuietCare® within a care management model in a Naturally Occurring Retirement Community (NORC) in Queens, New York. In this care model, eleven 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 [7]. The first iteration of the instrument was labeled 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. At the initial meeting of the study team, it was 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)
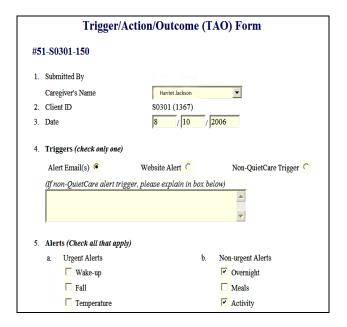
Figure 1.   Web-TAO

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 the HCIS. 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 Community Services. 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.

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 have been reported elsewhere [5, 7], and even though these quantitative results are interesting, they did not drive the development of the informatics system as much as monthly care review meetings with geriatric social workers, supervisors, administrators and researchers at which the entire study was discussed, in general, and the Web-TAO, in particular.

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. It was at the second meeting that two issues that would drive much of the development of the TAO came to light: 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 objective for these meetings was to review what had happened to each of the clients over the previous month in order to assess how QuietCare® had impacted the delivery of care, it was not surprising that the TAOs were the focus of the discussions—the TAOs did contain a comprehensive record of each alert, care action and outcome for each of the clients— but it was surprising how the social workers utilized the TAOs during the reviews. They placed the TAOs for each of the clients together and then worked their way chronologically through the TAOs. (All of the TAOs had been printed and each social worker brought the TAOs for their clients to the meeting.) By their actions, the social workers were constructing an on-going record for each of the clients by putting TAOs for the particular client together into a single "pile". This is what gave me the idea that the information contained in the TAO could be put together into an electronic record. This transition from a research instrument

to an electronic record did not take place during the Selfhelp Community Services pilot, but the idea was planted and germinated quickly in the second stage of the development.

Another issue of concern on the part of the social workers over the use of the Web-TAO is the evaluation of their jobs. 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 Community Services 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. These issues were not resolved before the study ended, but as discussed subsequently, it remained a vexing problem for the future development of the TAO/HCIS. 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.

B. Stage 2—2007-2008

As the Selfhelp Community Services 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 Community Services 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 Southwark Local Authority. 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 Community Services, 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 Community Services, the Web-TAO implemented at Southwark had slightly enhanced information sharing ability which allowed easier access to individual client's records by authorized personnel.

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, have been published elsewhere [4, 8, 9]. Also similarly, even though the quantitative results from Southwark are interesting, they did not drive the development of the electronic records system, but instead, it was 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 Community Services. 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 Community Services. 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. Additionally, by the end of the study, the carers were, on a regular basis, sharing information from the Web-TAO with family members of several of the clients.

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 my 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.

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

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. 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. Unlike at Selfhelp, the fear that the information stored in the Web-TAO could be used to evaluate the work performed by the carers was not raised at Southwark, but this issue resurfaced in the Netherlands.

C. Stage 3—2008-2012

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 2012. As of September 1, 2012, QuietCare® units had been installed in the residences of 192 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. A second care organization, Zorgroep, which provides similar services and care as Proteion, is involved in the larger study, but its role is secondary to Proteion both in the number of clients served—128 clients for Proteion and only 64 for Zorgroep—and administrative responsibilities. Thus, similarly to how the three London organizations were combined, 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 192 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, it was possible 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. Of course, the content of the Web-TAO, e.g., check-boxes, auto-populated fields, instructions, had to be translated into Dutch. The care delivery model at Proteion and Zorgroep 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 the two organizations' 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. This problem was solved by developing the capability for the Web-TAO, renamed the Home Care Informatics System (HCIS), to be accessed on any smart mobile device. Since each of the care workers had a smart phone, this solved the problem of access and entry of information. However, it also raised other challenges. First, everything had to be reformatted 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, there was 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)

Figure 3.   HCIS on smart mobile device

Similarly to both the Selfhelp Community Services and London studies, the quantitative results from the Dutch Study have been published elsewhere [4, 6, 10]. Also similar to the two previous studies, although the quantitative results from the Dutch Study are important for developing the HCIS, they did not prove as valuable as findings from other sources: direct interaction with care workers and administrators at Proteion and with the Dutch research team. This interaction allowed for the direct observation of the HCIS "in-the-field" which aided in modifying the system to operate efficiently on smart devices. By February 2009, a fully functional HCIS was operational for use by care workers at Proteion and Zorgroep. This iteration included all the features that had been developed during the Selfhelp Community Services and London Studies and the Dutch Demonstration Project: 1) wherever 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 helped 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 and Zorgroep; some of which were not easily resolved. The first issue revolved around how care was provided on weekends and holidays. At both organizations, 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 care workers at the two organizations are participating in the Study, these substitute care workers are often 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 included 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 arose as to who should have access, how should they obtain access and who was 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 [4].

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 Community Services. It was believed

that these concerns could be fairly easily resolved by discussions of interested parties. 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 the performance of carers.

III. DISCUSSION

Six 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 can be used on a smart device, to a full-fledged electronic records informatics system (HCIS).

The system that is currently in use in the Netherlands is significantly different in scope, operation and potential customers than the one envisioned six years ago. In fact, it was only a little over two years ago that I 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; the HCIS can be easily integrated with any other electronic records system; and it can be used as a billing tool. 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 residential monitoring system, e.g., behavioral, vital signs, environmental; and 4) it can be used either as a stand-alone system or with other pervasive health care applications.

Although it was not my intention in 2006 to produce an electronic medical records system, this was the result of six years of work with the seven different care organizations. In retrospect, the transition from a web-based research instrument (TAO) to an electronic records system (HCIS) appears intentional, but it wasn't. The transition was driven by the needs of the individuals within the care organizations (end-users), who kept asking for new features and used the existing features in ways that I had not anticipated. Again in retrospect, it is clear that, not being researchers, these carers were much less interested in systematically collecting data on which to assess the effectiveness of behavioral monitoring than in using the newly available tool—the TAO/HCIS—to provide more effective care to their clients. As a result, I relinquished a degree of control over the development process, which at times was both frustrating and difficult, but it was the only way that my overall goal— to produce a system that the caregivers <u>would</u> use, rather than something we thought the caregivers <u>should</u> use— could be accomplished.

IV. CONCLUSION AND FUTURE WORK

Based upon the six years of working on various iterations of the TAO and HCIS, the main conclusion is that it is possible to create an eHealth system for home care and that such a system can be used effectively to coordinate care and services and contribute to the maintenance of independent living. However, five key design issues appear to underlie the successful development and implementation of such an electronic records system for the home. First, the records system must be usable on smart mobile devices. Experiences, in both London and the Netherlands, make clear that any electronic records system must be able to be accessed and updated on a wide range of smart mobile devices, because by definition, providers of care and services are constantly traveling and rarely have timely access to computers. If the HCIS had not been "made" mobile, the Dutch carers would not have used it.

Second, any home care electronic records system must be able to be seamlessly integrated with other electronic health care records systems, e.g., hospital and physician practices. Although the information contained in the HCIS has been provided to physicians and other health care specialists in both the United Kingdom and the Netherlands, the system itself has not been linked to other electronic records systems. Discussions were held in 2009 with representatives of the participating care organizations about developing, if not full integration, linkage between various electronic records systems—health and fiscal—and the HCIS. At this time, such linking was premature, but it is clear that the full potential of any home care electronic health record system will not be achieved without its integration with other electronic health records. How and when this will occur depends largely on the wider acceptance of systems such as the HCIS. Once home care systems are widely used their integration with other electronic systems will take place rather quickly.

Third, any home care electronic records system must be flexible enough to be used with a variety of pervasive health care applications. The HCIS has been completely integrated with QuietCare®, a behavioral monitoring system, in the Netherlands and, although the project did not materialize, it was designed to be used with a vital signs monitoring system. The value of the HCIS as a means of recording the care actions and health outcomes brought about by alerts generated by QuietCare® indicate that the full potential of any monitoring system will not be achieved without some type of electronic records component. Consequently, the further development of pervasive health care applications for use in the home must incorporate some type of electronic records system or they will remain little more than passive emergency response systems [6, 11].

However, if home care electronic record systems are to achieve their full potential their use cannot be restricted to only pervasive health care applications, but they must be able to function as stand-alones. Demographics clearly indicate that the population that can benefit significantly

from the use of pervasive health care applications is relatively small and that the vast majority of individuals receiving care and services in their homes will never have the need for such systems. And yet, the amount of care the majority of individuals living in their own homes needs will continue to increase and thus, the need to have a means of recording the care and services continues to grow. The need for any home care electronic records system to be able to stand alone became apparent during my work in the Netherlands and the HCIS has been modified so that it can be used without a monitoring system being installed. As yet, no test of the stand-alone capability of the HCIS has been undertaken, but discussions with several potential partners are on-going.

Finally, the need for any home care electronic records system to operate as a stand-alone raises the final design issue—the requirement that any system be able to be used for self-management, especially the self-management of chronic diseases. Once again, the demographic trends indicate that as the populations of all industrial societies increase, the number of individuals with chronic diseases, e.g., congestive heart disease, diabetes, will skyrocket. The need for these individuals, particularly at the early stages of the disease, to manage their health while living at home, is essential for the financial stability of every national health care system. An at-home electronic health care record is ideally suited for this purpose because, not only can it be used to track the disease state itself by recording and analyzing essential conditions, i.e., blood glucose level, it also can be used to chronicle specifics about care provided by both informal and formal carers. These issues have been discussed elsewhere [6], how the use of the HCIS has brought about a coordination of care among different formal and informal carers in studies in the United States, the United Kingdom and the Netherlands. These findings suggest that one of the more significant contributions of electronic home care records systems will be their ability to adapt to the ever changing care needs of individuals.

Although achieving the above design imperatives does not guarantee the successful creation and use of home care electronic records systems, ignoring these issues certainly increases the probability of failure. Unfortunately, there is no single road map to developing a successful home care electronic records system, but if one can learn from the adoption process of institutional and physician practice systems, the path will be long, expensive and difficult.

However, as the past has also shown, the gains from undertaking the effort to create and implement electronic records systems are well worth the effort.

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