If They Designed It, Why Don’t They Want It?
The Lack of Acceptance of an eHealth Data Records System

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Abstract—Although the design of an eHealth data records system was largely driven by carers themselves, ultimately these same carers did not want to use the system once a series of pilot studies ended. The reasons for this lack of acceptance of the system by carers at seven different care organizations in the United States, the United Kingdom and the Netherlands are explored. Four reasons are put forward to explain this lack of acceptance: 1) the ability of the system to be used to evaluate job performance; 2) the pilot study model; 3) reluctance on the part of the carers to alter work routine; and 4) the system’s introduction is premature.

Keywords—eHealth data records systems; mobile devices; acceptance of innovative technologies

I. INTRODUCTION

The adoption of eHealth records systems has been much slower in the United States than anticipated as well as in most European countries. This is the case even though the United States “government set aside $27 billion for an incentive program that encourages hospitals and providers to adopt electronic records systems” [1]. Although there is some debate over the reliability of eHealth records systems [2], there appears to be little doubt that the greater the ease of storage, access and cost savings will eventually achieve close to universal usage within institutions and among physicians [3, 4]. If the pace of adoption in hospitals and physician practices has been slow, the pace of adoption of eHealth data systems for use to chronicle care and services in the home has been even slower. There is little debate that the delivery of care and services in the home has increased significantly and will accelerate at an even more rapid pace over the coming several decades because of two basic 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; and a decline in the number of informal carers who can provide care. Cost projections are similarly daunting: increasing cost for care delivery within the institutional setting; insufficient number of institutions 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 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 [5]. As more care and services are being delivered in the home, several issues have emerged that raise serious concerns. In the first place, the care being delivered has steadily become more extensive. Whereas a decade ago rehabilitation after a serious illness or accident would have been undertaken in a specialized facility, presently many of 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: oxygen; specialized beds; monitoring; meals; housekeeping; shopping; companion services. As the care and services have multiplied, so have the number of people providing the services. These companies/agencies are, of course, in addition to any services provided by informal carers. 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 outcomes of the care and services. The lack of systematic and comprehensive records also makes it difficult for other care providers 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 eHealth 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. 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 discernible 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 development of a wireless ehealth data records system: the Home Care Informatics System (HCIS) and the problems associated with acceptance and use of it. In the next section, the three stages of the development of the HCIS are outlined; in section three the reasons for the lack of acceptance on the part of the carers are analyzed; in section four a comparison is made with another electronic records system that has had similar difficulties with acceptance; and in the last section future scenarios for such records systems are explored.

II. THREE STAGES OF DEVELOPMENT

It is necessary to briefly explain the rationale for allowing the end-users (carers) to play a major role in the design process of this particular ehealth data records system. Results from a previous innovative ehealth project [6] had indicated that if end-users did not “buy-in”, then the new technology would not be used. Thus, it was decided that in this project as much control, as possible, over the design of the system would be ceded to those individuals who were actually going to be using the system to aid in care delivery. This approach appeared to make sense at the time, but given that even after ceding control to the users, there was great reluctance on their part to employ the system, questions about the wisdom of this decision must be raised.

A. Stage 1—2006-2007

The first iteration of the system was created to systematically collect data generated in one of a series of pilot studies to test the effectiveness of a behavioral monitoring system [7, 8, 9]. This particular pilot study took place at Selfhelp Community Services, Inc. in Queens, New York and involved eleven geriatric social workers who provided care management services to over 200 residents. Twenty-seven of these clients agreed to have the system installed for a six month period and to have the social workers use the resultant data in care management decisions. The problem was that there was no way to systematically collect information on the care actions that they took in response to an alert. The instrument created was labeled the TAO: Trigger, the system’s 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:

The system sends an alert to the geriatric social worker indicating an increase in overnight toileting for a particular client—the Trigger;
The social worker 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.

At first, the social workers filled out a paper form with the relevant information, which was then entered into a computer data base. The carers viewed the paper version of the TAO as time-consuming to fill out and redundant with other forms. In response to these criticisms, a computerized web-based version of the TAO was created and this new version became the first design change driven by its users.

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. However, a majority of the TAOs corresponded more to the following example:

The system sends an alert to the geriatric social worker indicating an increase in overnight toileting for a particular client—the Trigger;
The social worker 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.

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 in real 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.

Once this alteration was made, the carers had other suggestions: add auto-populated fields; use check-boxes whenever possible; allow for easier follow-up entries; and allow access to individual records by other social workers and supervisors. At the first care review meeting, after these changes were made, two issues that would drive much of the development of the TAO surfaced. 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 the monitoring system had impacted the delivery of care, it was not surprising that the TAOs were the focus of the discussions but it was surprising how the social workers utilized the TAOs. They placed the TAOs for each of the clients together and then worked their way chronologically through the TAOs. By their actions, the social workers were constructing an ongoing record for each of the clients by putting TAOs for the particular client together into a single “pile”. This “piling up” was the first care record and would drive much of future development of the ehealth system.

The second issue raised by the geriatric social workers concerned the ability of the Web-TAO in the evaluation of performance. 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 ehealth system.

B. Stage 2—2007-2008

As the Selfhelp pilot was ending, the pilot in London began. 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—all of which 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. However, even though these organizations were “independent” and served distinct populations, for this discussion it makes sense to view them as a single entity, the Southwark Study, and to aggregate their 97 clients.

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. 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 primarily due to the fact that the culture at Southwark was extremely collaborative and, although particular carers had primary responsibility for specific clients, all carers engaged with all clients in some fashion, and thus, the Web-TAO was conceived as a tool to allow for easier sharing of information among all carers rather than just a record of responses to triggering alerts. Therefore, the ability for all members of the care team to not only view the information, but to contribute to the information stream became paramount. The cultural imperative to share and contribute to the information of clients resulted in a modification that allowed for much longer narratives to be entered into the system which, as a result, took on the appearance of “blogs” in which numerous carers listed their actions and the subsequent outcomes for particular clients. Fig. 1 is an example of a typical “blog” for a single client.
for the physician to have all relevant care information. This required the creation of a new security function that limited who could send and what could be sent to individuals outside the Southwark Smart Team. A second suggestion 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. This change took time and the requested feature only became fully operational near the end of the study.

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 in both a residential and institutional setting [10]. During the first stage (2007-2008) of the project the behavioral monitoring system was installed in the residences of 12 individuals living independently and 13 individuals living within a sheltered housing facility, while in the second stage (2008-2012) the system was installed in the residences of an additional 230 individuals living independently throughout the largely rural Limburg Region served by two care organizations. Similarly to how the three London organizations were combined, it makes sense to view these two organizations, as well as the demonstration project and larger study, as a single entity and to aggregate the 255 clients into a single Dutch 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”. Of course, the content of the Web-TAO, e.g., checkboxes, auto-populated fields, instructions, had to be translated into Dutch. The care delivery model at the two care organizations—Proteon and Zorggroep—required that their care workers spend a considerable amount of each day traveling to and from clients’ residences. Thus, they spent little time at the two organizations’ administrative headquarters, limiting their ability to both access the Web- TAO and to enter information on computers. 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. This change in the structure of the HCIS to a wireless mobile service raised several design 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 different smart devices used by the care workers.

Working directly with the carers during the demonstration project allowed for a series of other suggestions to be incorporated into the HCIS: 1) the Client’s Journal feature allowed entries by any authorized personnel; 2) the Journal could be sorted by alert, date, care worker, type of care delivered and outcome; 3) there was a new feature that allowed additions to a previous entry, but not the elimination of the original entry; 4) a series of pop-up prompts helped the user navigate through functions and avoid common errors; 5) additional security features were developed to ensure that only authorized individuals could access and contribute to a client’s record; and 6) a read-only feature was added. Even with these modifications, two issues remained unresolved. The first issue concerned how the HCIS was used during care review meetings at which time the care delivered to specific clients was discussed and decisions on future care made. These meetings included both individuals who had knowledge of and access to the HCIS and others who had neither. Since the client reviews were more thorough when everyone at the meeting had 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? Although this issue does not directly concern the technical development of the HCIS, it certainly impacts the implementation of the HCIS and its long term use. The second issue concerned whether the information stored in the HCIS 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. It was believed that these concerns could be fairly easily resolved by discussions of interested parties. This was not the case, and this issue remained unresolved at the end of the pilot.

D. Summary of Changes

Below is a summary of the changes made to the HCIS in response to the expressed needs of the people using it. A review of these changes brings into focus how much the TAO/HCIS changed during the six years studies in response to the wishes of the users.

**Selfhelp**

1. The TAO was put on the web;
2. A feature that allowed the sharing of TAOs was created;
3. Check-boxes were added;
4. Auto-populated fields were added;
5. A feature that allowed the follow-up entries was developed.

**Southwark**

1. Changes made to conform to British English;
2. Enhanced sharing capabilities developed;
3. Security features added to allow sharing of data beyond the Smart Team;
4. A blog structure was created that allowed data to be entered by multiple carers;
5. A feature that allowed the sorting of the blogs by alert, carer, care action taken, health outcome and date.
The Netherlands

1. It was translated into Dutch;
2. The blogs became the Clients’ Journals;
3. The system was made to be operational on any mobile device;
4. A feature that allowed additional carers to enter data was developed;
5. More auto-populated fields and check boxes were added;
6. A feature that allowed entries to be corrected without erasing the original was developed;
7. Additional search features were added to the system;
8. A read-only feature was created.

III. LACK OF ACCEPTANCE

The most frustrating aspect of the seven pilot studies was that even though the vast majority of the modifications made to the ehealth data system were in direct response to the expressed desires of the carers, ultimately they did not use the system. Although perplexing, this result does provide a vivid lesson for anyone trying to introduce a “new technology” into an existing work culture. In order to assess the reasons for this lack of acceptance, questionnaires were administered to all eleven social workers at Selfhelp, while individual carers were interviewed in the Southwark and Dutch studies. In London, 70% of the carers were interviewed by phone and in the Netherlands approximately a third of the carers were interviewed in person. Findings from the questionnaires and interviews indicated that there were three reasons for the lack of acceptance: 1) fear on the part of the carers that the information would be used to evaluate work performance; 2) the nature of the pilot study model and its impact on the carers’ commitment; and 3) unwillingness of the carers to change their work routine.

A. Evaluation of Performance

Analysis of the carers’ answers from the seven locations showed that the carers in the United States and the Netherlands were fearful that the information contained in the HCIS would be used by supervisors to evaluate their job performance. Two brief examples illustrate this ability of the information contained in the HCIS to evaluate the carers’ performance. Each alert generated by the monitoring system is time stamped, as is every care action taken by a specific carer, and as a consequence, there is a concrete record of whether the carer responded to the alert and how long it took the carer to respond. In addition, the HCIS contains specific information on the type of response and the health outcome for each client over time, allowing supervisors to compare the work of different carers. It is this ability to compare the work of different carers which appeared to disturb the carers the most. And, it is indisputable that the HCIS allows this type of comparison to be made and for performance reviews to be based upon the information contained in the system. Not surprisingly, supervisors viewed this ability as an advantage because it documents performance, whereas, carers viewed it as an intrusion into their professional decision making.

B. Problems with the Pilot Study Model

The deficiencies of the pilot study model employed in the testing of the behavioral monitoring system have been detailed elsewhere [6], but some of these issues relate directly to the lack of acceptance of the HCIS. There appear to be four problems with the pilot study model. First, only a small number of carers were involved in the pilots at each of the organizations resulting in the studies being marginalized. At Selfhelp, only eleven of almost 200 social workers were involved in the study; while in London fewer than a dozen carers within the entire Southwark Local Authority had any role in the study and in the Netherlands, fewer than 5% of carers at the two organizations were involved in the study. Second, in no case was the HCIS used by the carer for all of her clients; instead it was always used for a small fraction of clients—on average no more than 20% and in only two cases over 50%—meaning that the carer was employing two different systems to record care. Third, information derived from the questionnaires and interviews showed that, because the carers knew when the pilot was to end, many carers put little effort into using the HCIS because they knew when it would go away. Finally, the HCIS was never part of “normal” care, but was always viewed as something that was just being “tested”. As a result, the majority of carers responded logically by putting less and less effort into its use as the pilot progressed.

C. Unwillingness to Change Routine

Even though information from the questionnaires and interviews showed the importance of the previous two factors in the lack of acceptance of the HCIS by the carers, an even more important reason was their unwillingness to change their normal routine that did the most damage. There is no doubt that the HCIS required carers, at least initially, to do more work and undertake tasks which were unfamiliar. For example, in the Netherlands, carers, instead of just writing a couple of lines on a piece of paper kept in the client’s residence were expected to type in information on their smart phones before driving to their next appointment. They were also expected to update this information as additional care was delivered and even track and record health outcomes over time. These tasks were viewed as especially egregious since not all of their clients were in the pilot study and, therefore, they had to employ two different recording systems. Finally, it was difficult for the carers to see the value in this extra effort, because the benefits of better and more coordinated care were in the future, whereas the extra work had to be done every day.
D. Summary

Yet even with the problems outlined above, initially, in each of the care organizations, carers entered usable, and in some cases extraordinary, information on the care actions undertaken and the resultant health outcomes. This was especially true for the London studies, but it also occurred, albeit in a minority of cases, in New York and the Netherlands. The problem was that within four months the information the carers, at each of the organizations, were entering was increasingly uninformative and by the end of the pilots a majority of the carers had stopped using the HCIS altogether. This experience, although frustrating, does provide some guidance to anyone trying to introduce a “new technology” into an existing organization.

IV. Discussion

The last of the pilot studies ended December 31, 2012 and currently the HCIS is not being used within any care organization. Thus, it would be fair to conclude that the HCIS is a failure, even though the HCIS is very clever and its design was driven by the desires and stated needs of its users. If it is not being used, there must be something fundamentally wrong with the concept and its implementation. However, there is one mediating factor that may require reevaluating the conclusion that the HCIS is a failure: the HCIS is not the only such system that has encountered problems of acceptance.

There has been a second wireless, ehealth records system that was developed and tested in Germany [11]. Even more interesting than the fact that two researchers independently developed such a system is that the problems of acceptance on the part of the users in the German study are parallel. The first problem that the carers had with the system was its GPS feature, which tracked their every movement. Thus, if a carer stopped on the way to a client to pick up her dry cleaning, her supervisor would know it. Additionally, with the GPS in place, supervisors could determine how long a carer spent in the residence of a client and could compare productivity of different carers. Even after the GPS feature was turned off, carers were concerned about the ability of the system to monitor their actions.

Also similar to the problems that were encountered in the seven pilot studies, the carers in the German study complained about the amount of time it took to type data into their wireless device. Responding to these complaints, the German researchers enabled a feature that allowed information to be entered by voice. Although this change was a direct response to the desires of the carers, the carers were still unhappy with the time it took to enter data and the need to check the accuracy of the information once entered. Finally, similar to my experience there were problems with the sharing of information among the various carers and the use of the information in the provision of care. Once again, there was a disconnect between the work of the carers and the benefits to their clients.

Two studies, however independent in conception and parallel in findings, do not necessarily contradict the conclusion that the HCIS is a failure, but it does suggest though, that it is necessary to rethink why the lack of acceptance occurred in such varied locations and what this means to the future of this type of wireless ehealth data system. It does not appear unreasonable to conclude that the main reason for the lack of acceptance is that developers, have underestimated the reluctance on the part of carers and their supervisors to change the way they do their jobs. In other words, it is a cultural and not a technological issue.

V. Conclusion

Two main findings are apparent from the material presented above: 1) it is possible to create an ehealth data 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; and 2) the success of such a system is dependent on issues that do not concern design and functionality, but instead on its acceptability by the people employing the system. Even when much of the system’s design was driven by these users, there was a lack of acceptance on the part of these very same people. Three reasons were put forward as the main factors for this lack of acceptance: the potential use of information in the system for the evaluation of job performance; the pilot study model; and the unwillingness of the carers to alter their normal routine. However, there may be an even more fundamental reason for the lack of acceptance of this particular wireless home care records system: its introduction is premature.

Many business experts have argued that new ehealth technologies, such as the HCIS, will not be widely adopted until the traditional care models can no longer meet the needs of the burgeoning elderly population [12]. Then, and only then, will administrators at care organizations be forced to introduce new technologies and compel their workers to use new systems. Until this point is reached, care will continue to be provided in the usual way, even as it becomes more difficult to achieve the goal of providing cost effective and timely care. The behavior of the Dutch carers speaks directly to this argument. Even with the HCIS readily available on their mobile devices, they preferred to write down their actions on pieces of paper that remained in the client’s residence, even though the paper record could not be easily shared, updated or used in care reviews. Why? Because there was no compelling need and administrators deferred rather than forced them to use the new technology. Adequate care could be delivered without the use of the new system, so why change what one normally did, especially if it was only part of a pilot study that was going to go away in a few months anyway?

The slow pace of the adoption of electronic medical records in hospitals and physician practices provides a valuable lesson to those of us who are championing the use of ehealth systems. The United States government has encouraged the use of electronic medical records and even mandated their use wherever possible. Insurance companies have wholeheartedly endorsed the use of electronic records and have attempted to induce their use through economic
incentives. Nevertheless, the pace of adoption has been slow as individuals complain about the cost in time and money. What is largely left unsaid is that, even with the incentives, given a choice, most administrators would not adopt the systems because currently there is no compelling need to adopt them. Are they more efficient? Probably. Is it worth the cost? Probably not. Is it worth the cost given the increasing expense and growth of the health care system that will stretch the system to the breaking point? Absolutely. But, this requires change today in anticipation of a future need and this is difficult for people to accept, especially when it disrupts their daily routine. This same set of questions can be applied to the HCIS and other ehealth data systems and the endpoint is, not surprisingly, the same: a demonstrative future need that requires change before people are ready to compel such a change. When will the dynamics change, two years from now, five years from now, a decade from now? It is not possible to predict with any certainty the exact date, but there will be a time when electronic record systems similar to the HCIS are part of the normal care model and people will wonder why they weren’t in use earlier.

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