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Creating an Electronic Patient Held Health Information Card

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Abstract

In many areas of health care, professionals rely on patients to provide information about their medical history. However, patients may not be able to remember details or communicate essential information relating to, for example, current conditions, medication and allergies. Currently no central system exists which serves all the UK. Therefore, an electronic, patient held health record system has been proposed as a way of improving patient safety. This development has been driven by a user centred process, from requirements capture to iterative development, longitudinal trials and dissemination. Through this process the project has raised debate and awareness amongst the public and medical professionals about power relationships within the health service and the need for the public to take a greater responsibility in matters related to their own health.

Keywords

user centred design, health, IT systems

Although it has been suggested that patients taking responsibility for their records could improve safety, few studies in the UK have considered attitudes towards this, the design of such a system or potential barriers to use. An American study by Ross *et al* (2005) found widespread support for shared medical records across a broad range of ethnic and socioeconomic groups. In the UK, a study by the Department of Health (2008) reported that although the majority of participants were in favour of electronic records, reassurance was needed that records would not be viewed by other organisations.

For many years, paper forms of patient held health records have been successfully used in the maternity care (Phipps, 2001) and child health (Hampshire *et al*, 2004). These are rarely extended to other areas of health care. A patient held electronic record system was successfully trialled in the UK, between 1989-1992 (NHS, 1990). 13 000 patients were provided with smart cards containing health information that only they and the professionals treating them were able to access. Although the trial was successful, technological limitations meant that this was not continued or extended.

In terms of the design requirements for patient held records, Jones *et al* (1999) found that almost all the patients who participated in the study thought that a patient held record system should include information about medications, allergies and vaccinations. Liaw's (1993) study of doctors showed that allergies, adverse drug reactions, relevant medications and immunisations should be included. Giglio and Papazian (1986) conducted a trial with four types of patient held record devices in the USA, finding that a wallet sized card was most preferred because it was the most portable.

The aims of the current study were to assess the public's and medical professional's attitudes towards a patient held, electronic health system, with a view to informing policy and the development of a prototype device. The project therefore followed a *research through design* approach, with the development of the MyCare card (see Figure 2) acting as a catalyst to

discussions about the content and ownership of health care records and how such a system could work in practice.

The user centred approach adopted meant that the starting point was not prescribed at the outset. Instead decisions on the form of the device and the interface were informed by the attitudes and user requirements of patients and health professionals. This information was fed into the design of prototype systems, which were evaluated in the laboratory through the development process by usability experts, health professionals and representative end users. User trials were concluded with a month long, limited real world trial to discover how the cards might be used by people who have different health needs. Finally, dissemination activities were undertaken via roadshows to demonstrate the project to the wider public and discuss the implications of such a system for the health service. The paper provides an overview of all stages of the project

The MyCare Project

Stage 1: Attitudes towards patient held records and user requirements

The aim of this stage was to collect information about attitudes towards and requirements for a patient held electronic record device and to

- assess levels of support for patient held records
- identify potential barriers to the acceptance of patient held record devices
- identify what form of device would be acceptable as a means of carrying electronic health records
- determine what information devices should contain and who should be able to access this

Separate surveys were conducted with 258 members of the public and 260 health professionals. In the public survey, participants had to be over 16 and visitors to the pharmacies used for data collection. These were situated in different socio economic areas of London and the Midlands. Pharmacies provided the opportunity to collect data from participants with a wide range of demographic characteristics and who were concerned with their health at the time of the survey. The age range of the participants was 17-89, with a mean age of 45 years. 43% were male and approximately two thirds were of white European origin. 61% of the participants lived in the Midlands, 39% in London. 26% considered themselves to have a long term health problem and 13% had been given part of their records to look after.

The survey of health professionals included doctors, nurses, ambulance staff, pharmacists, physiotherapists, occupational therapists and others. Collection was carried out at their places of work in different areas of the UK, including the Midlands, South West and Wales. 50% had used a form of patient held record in their practice. 85% of the public and 94% of the health professionals thought that patient held electronic record devices could be helpful for sharing information. Over 60% of all participants stated that they would prefer a device in the form of a smart card.

More detailed comments were provided in focus groups, such as *‘Patient records seem to be a good way forward in both giving patients responsibility and ensuring information is passed on.’* Another participant thought patient held records would be useful for anyone who had a serious allergy, saying, *‘Well, I’m allergic to penicillin and if I ever had to go into hospital and was unconscious and didn’t have anything with me, they wouldn’t know I was allergic to penicillin and they would probably give me penicillin so I think that’s a good idea if you had a card with all the details on.’* The findings from earlier studies were confirmed, with the most common concern for the public being that unauthorised people would gain access to the data (64% were worried about this).

94% of the health professionals said that they would find a patient held record device useful, with the most common benefit being *‘to overcome communication problems’*. 75% of the health

professionals were worried about data security, 80% were concerned that devices might get lost and 74% that the information might not be kept up to date.

The most popular pieces of information that the public participants thought should be recorded were current medication, name, allergies, blood group and long term conditions. The informational requirements of health professionals was not significantly different, including allergies, current medication, name, long term conditions, age, current and previous health problems and next of kin. For both groups, the majority thought that all health professionals should be able to access important pieces of information, but that some form of role based access was necessary to restrict access to highly personal information.

62% of the public and 60% of the health professionals indicated they would prefer a smart card with little preference being shown for other designs (such as computer, key fob or jewellery). 68% of the public indicated that they thought the device should be provided free of charge. Only seven people were willing to pay over £20 for the service.

The present survey replicates the findings of previous research (see above) regarding the type of information which should be included on the device, the form of the device and the level of support for shared medical records. The most common concern for the public related to unauthorised access to the data (64% expressed concern about this). Health professionals were concerned about devices being lost and the currency of information. This is a real concern as a patient held, card based system, requires card owners to take responsibility for the provision of accurate, up to date information and for carrying the card with them at all times. Without such buy in, and widespread adoption, this system will fail as valuable time will be lost searching for cards, reading out of date or inaccurate information, which could have life threatening consequences. Indeed, part of the rationale for having a wallet sized card was that people were familiar with, and used to carrying information in this format.

It is therefore imperative for both members of the public and health professionals to understand and value the potential usefulness of this service and for the device to be easy to use by all demographics regardless of IT and health literacy. For most people, the type of details included on the card will not need changing often. Although this means a reduction in the onus of keeping items up to date, it may mean that they will forget about the card, or not remember to update it when circumstances change.

Advantages of the wallet sized card over other design forms are portability, familiarity and it being inexpensive to produce. A 'card' format may also be more acceptable as an input device (e.g. as opposed to a piece of jewellery) as it can be accommodated into existing readers. Additionally the design of the card could convey essential medical information in a visual format – immediately alerting the health professional to emergency conditions.

The survey also revealed that the public had misunderstandings about the operation of the current health service, assuming that all health professionals had access to their records at all times. In the UK, this is not necessarily the case, especially in emergency and out of hours care. It is only relatively recently that a computer based, central system has been introduced. Paper based notes completed by medical professionals still form a major part of the health record system. They may not include detailed information relating to health and well being, which could provide vital information about the overall condition of the patient. For example, it may be useful to record the use of alternative medicines (especially where these might have notable side effects), or patterns of migraine, insomnia or allergic reactions etc.

Accordingly, members of the public without long term medical conditions may not understand the need for such a system or how such a system would benefit them. This could be indicative of a narrow conceptualisation of health and wellbeing, a reluctance to participate in a dialogue about

health or to understand wider issues around health literacy. Similarly, not all health professionals thought the issue was of relevance to them.

From the survey a set of requirements were established for the software designer. Other users groups (such as the elderly, those with disabilities and communication difficulties) were encouraged to take part in the evaluation of the prototypes.

Stage 2: System Development

System development took place over 18 months, with the release of concepts, semi functional and fully functional prototypes for evaluation. An early prototype is shown in Figure 1. A detailed account of the technical development has been presented in Rybnovik et al (2009). In order to meet the requirements of the users and convenience/ease of use, a traditional smart card was combined with a USB stick as shown in Fig. 2. The USB/ card design combines the advantages of both smart card and USB media types. USB mass storage devices are supported by most computers.

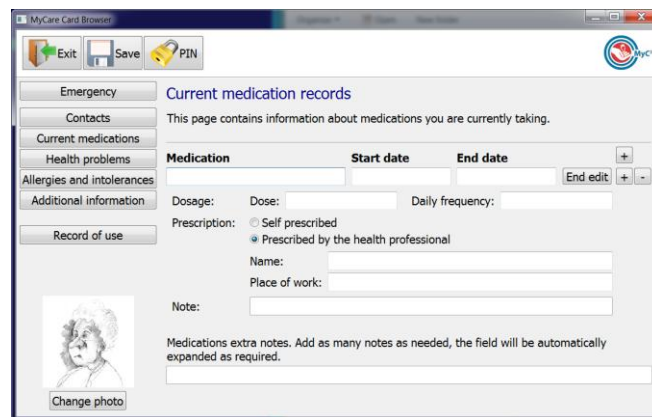


Figure 1: Example of early *MyCare* interface

The *MyCare Card Browser* aimed to be user-friendly, Open Source and community driven, easily extensible, cross-platform, portable, stable, secure and achievable with reasonable development resources and time. To reduce the cost of the development and to minimize dependency on major computer systems manufacturers, Open Source software tools and programmatic libraries were utilized.

Mindful of user concerns about security and unauthorized access, conventional USB mass storage protocol was utilized to store user's medical data, security and authentication data, and the browser software itself on the *MyCare Card*. All data is stored on the card in files, which are available to the operating system services via standard portable disk drivers. The system runs off the card, and information is stored on it. This is different from government initiatives, where data is held centrally and uploaded by health professionals. In the *MyCare* system all data is stored on the card, and entered by the users who type in their pin number to open the system. Medical professionals can access the material on the card by entering their own health number. If the card is lost, the pin number acts as a deterrent to ward against misuse. As the system is standalone, it is not possible to access to user data in other systems.

In further development, for security reasons, additional USB device protocols will be implemented. to protect *MyCare Card* user medical data and software files from unauthorized access and from accidental corruption. Therefore, files access algorithms implemented in the *MyCare Card Browser* are isolated into interface classes to allow future embedding of security protocols, without affecting other software parts or the overall source code structure.

The welcome page of *MyCare* allows the entering and changing of passwords. The system then comprises a small number of pages in which the user can fill in personal details (including next of kin and GP), allergies, current medication, medical problems and medical history. An access log shows when and what information has been updated and by whom. As the system has been designed to be used by members of the public with limited levels of computer literacy and medical expertise, of central importance was ease of use, learnability and memorability (as the system may not be used regularly).

Stage 3: Evaluation

The evaluation programme aimed to:

- inform the development of the interface and the device
- uncover emergent requirements
- include groups which had not been consulted in the initial survey

A mixed method approach was adopted to the evaluation. Participants were required to verbalise as they used the interface (with breakdown analysis (Woodcock and Scrivener, 2003) being used to focus on usability issues). This was followed by semi-structured interviews and a SUMI questionnaire (Kirakowski, 2007, 2008). Transcripts were thematically analysed (Aronson, 1994). The three main stages included;

1. Evaluation of the early device designs using focus groups. Taking an inclusive design approach, focus groups included participants who had communication difficulties due to disability and language barriers, who would have had difficulties completing a questionnaire or taking part in a walkthrough evaluation. Separate focus groups were conducted with older adults, people with disabilities, people who did not speak English, and people who were not confident about using computers. Several of the participants who had disabilities would have to rely on others to help them to use the system, or in the case of the older adults and those who were not confident about using computers, would require training and assistance to do so. The focus groups provided an opportunity to discuss how such assistance might be provided.
2. Evaluation of early versions of the software commenced with a walkthrough method with five usability experts. The feedback was used to amend the prototype which was then evaluated with 20 members of the public and 10 health professionals
3. A month long user trial of a working prototype in a real-life environment with members of the public. The information entered on to the devices was assessed by five health professionals in order to gauge its potential usefulness.

The initial evaluation occurred on a system with limited functionality (and no help system).

Although the system was rated as average on all SUMI scales, participants felt that it was a system they would use if available. Usability issues included:

- Lack of on-line help and support for conducting tasks
- Lack of system feedback (especially on save)
- Use of inappropriate or unfamiliar computer and health terminology
- Poor structure to the forms
- Failure to automatically update information on the summary form
- Inappropriate task formulation for entering medications and health problems.
- The page allowing restriction of access to certain groups of health professionals was poorly received by both health professionals and end users. End users could not understand how to do this; health professionals were worried that they might be denied access to important information. Following discussion this was dropped. By keeping a card, the user acknowledges

that its contents should be accessible to all medical professionals (with an authorized pin number)

An emergent need from the later usability sessions was for an additional form where other information could be entered – almost like a health diary. In the final system this was a free form text field

For the final stage evaluation, 49 *MyCare Card* units were tested in a real life trial. The front of the final wallet sized card is shown in Figure 2 below. This contains spaces for the patient's name, photograph and NHS number. The hole in the top left of the card can be used to attach the card to a key fob or chain. The series of circles along the bottom can be used to visually indicate important medical conditions.

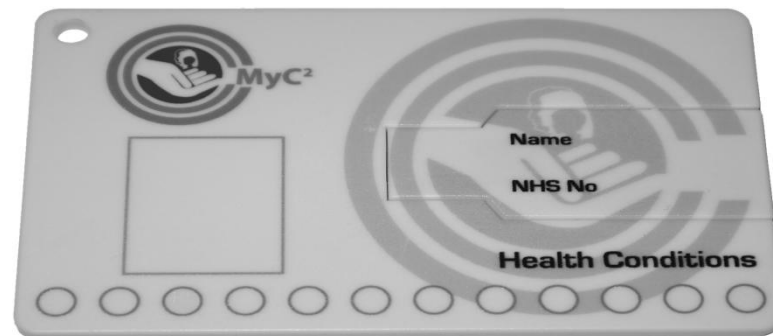


Figure 2: The final version of the *MyCare card*, with integrated USB

Participants were trained to use the cards, asked to input health related information (which could be their own or follow a fictional scenario), and to carry the card for one month, updating the information as necessary e.g. when they went to the doctor, or took medication. They were asked to keep a record of any problems they experienced and discuss these in an interview at the end of the trial.

Not all the participants were able to use their device the whole time. Difficulties experienced are considered to be representative of those that real users would experience, including forgetting the Pin number, detachment of USB stick, inability to easily insert the USB in the computers, preferred computer suddenly failing to recognise the device, loss of device. Five people declined to take part in the trial as they were not PC users.

The age range of the participants was 18 to 94, with a mean age of 41 years. The sample included 57% women. 29% were students, 39% had professional jobs, 8% had manual jobs, 18% were retired and 6% were carers. 55% of the participants considered themselves to have a long term health problem. 16% were parents who used a card on behalf of their young child. 18% were classified as having low computer ability, 22% had medium ability and 59% a high ability. 24% stated that English was not their first language.

At the end of the trial the majority of the participants thought that the system had been useful. Those who had long term health problems were more likely to state that they would use such a system in the future. Suggestions were made for additional features and the improvement of both hardware and software.

In the second stage of the trial, five health professionals reviewed the information contained on a sample of the cards and assessed its potential usefulness. They also made recommendations on design and usability and where the system could add value to current services e.g. by showing where medicines may adversely interact with each other or if the interface could warn the patient that he might be allergic to the medication.

Although they all felt that the card provided a useful guide to information and would be particularly helpful where no other patient information was available, they all expressed concern over the accuracy of the information. One nurse said, *'The more information you have on a patient, the better care you can give.'* All the professionals stated that they would check the information with other sources if this was possible. As one pointed out, *'Patients don't know what is relevant or important. People may not want information known and withhold information.'*

Concerns were also expressed with regard to the amount of time it might take to help patients to maintain their records. Two professionals did not think they would have time to do this. As one of them said, *'I can't see how you could sit down with the patient to see if they have added it correctly.'* Another stated *'I don't think it would work in hospital.'* Additionally if professionals did not receive any direct benefit for helping the patients input information, they might not be persuaded to do so. One of them was also concerned that the necessary equipment, training and organisational support might not be available.

This final trial was seen as providing valid information on how the system would be used in the real world. Additionally it generated usability and design problems with both the hardware and software, and new design requirements and features. This part of the evaluation revealed a number of barriers to use, which although in some cases had been anticipated, had not been regarded as insurmountable.

Stage 5: Public Dissemination

Dissemination to the general public was carried out through a small roadshow featuring banners, leaflets and a software demonstration, as a means of attracting people in libraries and shopping centres in various UK cities (Milton Keynes, Preston, Coventry, Redditch, Nottingham and Bristol). Questions used to stimulate discussion included:

- Do you think you would use the *Mycare* system?
- What problems would you have with this?
- What sort of things would stop you or other people using the system?
- Would you be interested in recording your health details on a card, even if you were well?
- What sort of information would you include?
- How do you feel about being responsible for providing health information?
- Do you think the public and health professionals should work together as partners to manage health problems?
- Do you think that you know enough about your health to be able to record useful information?

Informal discussions enabled a range of views to be expressed without the restrictions of a formal interview or focus group, although people were encouraged to contribute their opinions by filling in comment forms. Results were analysed thematically. 122 people participated, their comments confirming many of the prior findings, for example, those with long term medical conditions, or who had relatives with health problems were more likely to see the value of the system.

Problems with current NHS systems included the failure of information to be relayed between medical professionals and failures to be able to remember medical details when needed. One participant with several health problems stated that he was more worried that people would not know about his health problems when they were treating him than about the risk of a breach of confidentiality. Another participant stated, *'I have experience with consultants. You see many, never the same one. And they look on the computer but the information hasn't been uploaded yet, and it is frustrating. With this, it can be all there, wherever you go, whoever you see. Everything is kept together'*

A community support officer thought, *'it would be good for the police if somebody is collapsed so we could get their name and know about any health conditions.'* A police officer confirmed that she often had to find out information about people who were unable to provide it themselves, such as those who were intoxicated or had been involved in accidents. In these circumstances she would look in their pockets. If she could find information that could be read from a card, detailing the person's identity and their existing health conditions, that would be very useful.

Reasons for not wanting to use the system included not being able to use a computer and participants not seeing the benefits of the system for them. As one of them said; *'If you had health problems you would probably be more inclined to carry it. I'm healthy so I don't know if I would bother.'* Others had a general, deeply-held mistrust of electronic data systems. As one said *'I would not trust any kind of electronic record and I intend to get out of the government database. There is no way of making this kind of thing properly secure.'*

Most participants were ready to take responsibility for their health information. As one of them said, *'this is good because you can put on the information that you want; it puts patients in control.'* Another said she would be more confident about the information being accurate if she had provided it, saying *'It would be good to get people to put the information in; there would be fewer mistakes. You could always get someone to check it.'* Another participant said that she liked the *MyCare* system because, *'it would change the power balance with doctors.'* She went on to explain that she thought it was wrong that doctors were considered to be all powerful and patients expected to accept their views. However concerns were expressed regarding whether the system would provide information in a usable form, and whether the level of cooperation required between the public and health professionals to make *MyCare* work was possible.

Discussion

The study has shown the potential of an electronic patient held health system to improve communication between the public and health professionals. A user centred iterative approach ensured that the design was based on user feedback. However, for any new system to be accepted, it must work with those already in use. The integration and interoperability with central health services was beyond the scope of this project. However, uptake of an 'independently developed' system will depend on the development of appropriate infrastructure, co-operation from the central system and education and training of users. Adoption of a card system would require the public to take on new responsibilities and knowledge and health professionals to support them and adopt new working practices. A full scale trial with buy in of the NHS and associated healthcare services, support staff, and members of the public, would identify how *MyCare* and other systems could be used in conjunction with existing and future health care information and record systems.

In conclusion, one of the main aims of the project was to assess whether the UK public and medical profession were ready to accept and use a patient held system. Although there is support for sharing medical information, attitudes expressed by participants revealed mistrust of government initiatives towards centrally kept records and an unwillingness by healthy individuals to appreciate the need to keep their own personal records. Health professionals were concerned about the currency of the information, and its accuracy as revealed by their unwillingness to accept the accuracy of information entered by their patients without it being verified by other sources.

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Author Biography

Jackie Binnersley

Jackie worked as a nurse before becoming a research assistant and then as PhD student at Coventry University. She is in the final year of her PhD, which is concerned with the attitudes of the public and health professionals towards the use of patient held health records.

Andrée Woodcock

Andree is Chair of Educational Ergonomics and Design at Coventry School of Art and Design. She was Principal Investigator on this project with Dr Kyriacou, Professor of Biomedical Engineering. Her interests include usability evaluation, ergonomics and applied research in areas of current social concern – such as crime and the design of public spaces, assistive technology and low carbon vehicles.

Victor Rybynok

Victor Rybynok received a higher education diploma in Computer Systems and Networks Engineering from Moscow Institute of Electronic Technology in 2001, an MSc in Medical Electronics & Physics from Queen Mary, University of London in 2003. In 2009, he received a PhD degree in Biomedical Engineering from City University London. His current work in biomedical technology involves the development of non-invasive methods for the blood chemical composition analysis using diffusion spectroscopy techniques.

