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Establishing User Requirements for a Patient Held Electronic Record System in the United Kingdom

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In the UK, in emergency situations, health professionals rely on patients to provide information about their medical history. However, in some cases patients may not remember their medication, long term illnesses or allergies, or be able to communicate this information. As a national, on-line integrated patient record system has not yet been established, a patient held electronic health record has been proposed. This paper summarizes the results of a survey to establish the public's and health care professionals` requirements for such a system.

INTRODUCTION

In many areas of health care in the UK, particularly emergency care, health professionals rely on patients to provide information about their medical history. However, reliable information may be difficult to acquire from patients who are unwell, confused, or have communication difficulties. It has been suggested that patients taking responsibility for their records would improve safety (Hall 2007).

In the UK it is not customary for people to routinely carry identity cards or personal information. In the event of an accident, this often makes it difficult not only to discover who the person is, but also to know whether they have a long term illness, life threatening allergy, are undergoing medical treatment or who should be contacted in an emergency.

A national, electronic medical records database is currently being constructed which when completed, would allow records to be accessed in more areas than is currently possible. However, this system is still in its infancy and it is not yet certain what level of information it will include (e.g. medical information a person feels is important for medical staff to know, non prescribed medication) or its level of uptake. This is very much a top down approach, initiated by the government and management. What is proposed in the current study is the design of artifact(s) which have high levels of patient and health professional support, and which contain information which patients feel medical staff need to know in the event of an emergency.

Although previous studies have shown positive attitudes towards patient held records (Phipps 2001; Hampshire *et al.* 2004) and electronic patient held records (NHS Management Executive 1990), there is still much to learn about users` views on these. Patient held, paper based records related to maternity and child health have been used effectively for a number of years (Phipps 2001; Hampshire *et al.* 2004), yet this practice has not been adopted by other parts of the health service.

Interestingly, an electronic form of patient held records was successfully trialed in the UK, between 1989-1992 (NHS Management Executive 1990). 13 000 patients were provided with smart cards containing health information that only they and health professionals treating them were able to access. The results showed that the majority of participants were in favour of having the cards and became more positive about them once they had taken part in the trial. However, the use of the cards was not continued as the technology at the time limited its wider feasibility.

To date, few studies have identified the design requirements for patient held health records in the UK, such as the preferred form of device, methods of data entry, access rights or the information content, and compared these requirements to those of health professionals.

The aim of the current study was to collect information about the views of the general public and health professionals with regard to patient held electronic record devices. In particular this will:

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

The emergent requirements are being used by designers to produce concept designs, which will, in the next phase of the research be evaluated in focus groups, prior to the production of a working prototype. This paper details the results of the initial information gathering phase undertaken to establish user requirements.

PROCEDURE

Measurement Instrument

Two ‘similar’ questionnaire surveys were designed to collect attitudes to patient held records and requirements for a patient held record device from the public and health professionals. The questions were based on material derived from a preliminary literature review, five focus groups (with a total number of 25 participants) and interviews with ten health care professionals. Participants from the focus groups and interviews were generally in favour of a patient held health record system, but voiced concerns about security. Indeed the security of personal information at the time of the study was a major issue in the UK, with several cases being reported in the media concerning the loss of government held information.

Similar questionnaires were designed for the public and health professionals. The first part of each questionnaire asked participants to supply demographic information to check that the sample included participants with a wide range of demographic characteristics. Participants were then asked about their experiences of using patient held records. Following this, a brief description of the proposed patient held record device was given and participants asked questions about using this. A final series of questions related to user requirements.

Each questionnaire was piloted with ten participants and minor adjustments were made as a result of their comments. These helped to reduce ambiguity and increase validity and reliability. Changes included removing questions which appeared to be duplicating others and improving the clarity of the remaining questions.

Participants

Over 500 participants took part in the survey. Approximately half of these were members of the public and half were health care professionals. For the public survey, participants had to be sixteen years or older. Convenience sampling was used to include customers in pharmacies across the UK. These included participants from a range of ethnic backgrounds and social classes. Members of the public who had problems with their eyesight or English literacy were assisted to complete the questionnaire.

Focus groups were held for groups of people who were unable to participate in the survey. One of the groups consisted of people who did not speak English and their views were included using the services of an interpreter. Another group of disabled participants were unable to write and so would not have been able to complete a questionnaire. Groups of elderly people, teenagers, health care professionals and those with long term health problems explored the questionnaire items in more detail than was possible during the survey.

Ethical clearance was obtained to consult health care professionals. These were drawn from doctors, nurses, ambulance staff, pharmacists, physiotherapists, occupational therapists and other health professionals. Quota sampling was used in order to achieve similar numbers of individuals from each professional group. Data was collected in different areas of the UK in order to include participants from different geographical locations and working environments.

Analysis

Answers were coded and entered into separate databases for the public and professional surveys. The analysis used the Statistical Package for the Social Sciences (SPSS) to produce frequencies. Open ended questions were thematically analysed to establish the main themes from the responses, with content analysis used to establish the most common responses.

RESULTS

258 questionnaires were completed by members of the public. The age of the respondents ranged from 17-89, with a mean age of 45 years. 43% were male and around two thirds of white European origin. Just over a quarter considered themselves to have long term health problems. 13% had used some form of patient held health records which were mainly maternity records.

85% of the public said they would find a patient held record device useful, especially if they were too ill to give information to a health professional. Positive comments from the focus group participants included, `Patient records seem to be a good way forward in both giving patients responsibility and ensuring information is passed on.` Another said, `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.` Several of the participants who had problems understanding English felt that a device would be particularly helpful for them.

The most common concern was the possibility of losing the device and unauthorized people gaining access to the information, which was indicated by 64%. Later, focus groups explored concerns about data security. Groups of disabled people and health professionals were especially worried that the information kept on devices might be used for fraudulent purposes. Elderly participants and those from an ethnic background felt that carrying health cards posed no more of a risk than carrying bank cards. Participants suggested features which could be incorporated into the design in order to improve data security. These included the encryption of data and personal identification numbers as the means of accessing information. There was also support for the device having an access log that recorded who had accessed and/ or altered the information.

The disabled participants felt that a great deal of health information is personal and private. Those who participated in the focus group were not happy to share their personal identification number with someone else in order to gain help to input and alter information. A health professional suggested that only professionals with their own access codes should provide this assistance. If professionals were to use their own access codes this would provide accountability for the accuracy of the information entered.

260 questionnaires were completed by health care professionals. 39% were male, 79% of white European origin and over half were under the age of forty. Data was collected from five professional groups: doctors (14%), nurses (23%), ambulance staff (23%), pharmacists (20%) and others (20%). Approximately half of this group had used some form of patient held health record, and cited the major benefit of doing so as being access to health information. The concerns of this group related to inaccuracy of information (74%), loss of records by the patients (80%) and unauthorized access (75%). Some 94% of the health professionals said they would find a patient held record useful, and in this case the most common reason was to overcome communication problems.

Informational requirements

Survey participants were given a list of items from which to select those that should be included on a device. Table 1 shows the number of participants who thought each item should be included:

Table 1. Shows the number of participants who thought each item should be kept on a device

Item	Public participants	Professional participants
Current medication	225 (92%)	241 (99%)
Name	224 (92%)	237 (98%)
Allergies/ intolerances	223 (92%)	241 (99%)
Blood group	222 (91%)	186 (77%)
Long term conditions	217 (89%)	235 (97%)
Next of kin	214 (88%)	216 (89%)
Age	212 (86%)	227 (93%)
NHS number	182 (75%)	171 (71%)
Health problems in the past	182 (74%)	218 (90%)
Address	168 (69%)	210 (86%)
Disabilities	153 (63%)	184 (76%)
Dietary information	143 (59%)	135 (56%)
Living will and donor information	133 (55%)	167 (69%)
Implants	132 (54%)	152 (63%)
Carer contact	122 (50%)	168 (69%)
Religion	102 (42%)	112 (46%)
Information about social service care	94 (39%)	140 (58%)
Non prescribed medication	83 (34%)	110 (46%)
Ethnicity	83 (34%)	87 (36%)

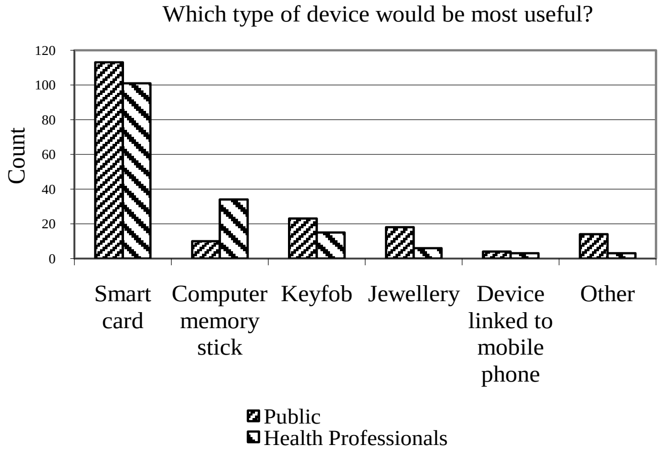
The items that most of the members of the public surveyed thought should be kept on patient held record devices were current medication, name, allergies, blood group and long term conditions, and most thought that all health professionals should be able to access these items. However, over three quarters also agreed that access to other information should depend on the role of the health care professional.

For the health care professionals the most important pieces of information to be held on the device related to allergies, current medication, name, long term conditions, age, major health problems in the past and next of kin. The majority of these participants thought that all health professionals should be able to access the most important pieces of information. Again, the majority of participants supported the use of a restricted access system, where the viewing of certain pieces of information was restricted to particular groups of professionals. As one health professional said, `Your paramedic probably only needs to know about four things about you, whereas the hospital consultant would probably want to know a few more details.`

In terms of entering the information, most of the members of the public surveyed wanted to either update the information themselves or let their primary care doctor do it. Their preferred location for this task was overwhelmingly at the doctors surgery (86%), through keyboard entry (71%). The majority of the professionals agreed that either the primary doctor or the patient should enter the information. Also, over half of the professionals wanted to see information presented in a hierarchy of sub menus with emergency information presented first.

Regarding the preferred form of the device, 62% of the public and 60% of the professionals preferred a smart card over USB sticks, key fobs, jewellery and devices linked to a mobile phone. As one health professional pointed out, `People are used to carrying cards around so are more likely to remember to do so.` The graph shows the preferred forms of devices for the public and professionals.

Graph 1. Shows the number of participants who preferred each device form



The results formed the basis for a set of design requirements. These included having a portable design form which carried a person`s name, photograph and national medical number on the front. Current medication, long term conditions and next of kin were to be kept on the device in an encrypted form, with capacity for more information if the person wanted. The information should be input using a computer and should be displayed on a screen. The device should be provided free of charge and be compatible with systems already in use. These requirements were used in the production of concept designs which were evaluated in a later stage of the project.

DISCUSSION

Prior to conducting this survey, it was not certain whether the public or health professionals would be receptive to the idea of patient held electronic health records. From the earliest stages of the research we have found widespread support for this initiative from all public user groups. Mindful of the need to consider both those who will carry and those who will have to use the information, we have surveyed both major stakeholder groups and found little resistance to the scheme and a willingness to include most categories of information.

However, there is a level of conservatism in the ability to envision the format of the device. The public are most amenable to using the sort of device that they are most familiar with, i.e. the smart card. There are benefits in this design as such a device can be easily carried in wallets with banking and travel cards. More importantly, emergency services would know where to look for such information.

The results have been used to draw up a list of user requirements that are being used to produce early prototypes of patient held electronic record devices. In the current phase of the work we are investigating different designs for the card, including the use of colour coding for various life threatening conditions, and personal identification.

In terms of interface design, a cycle of iterative development has led to a working prototype which is currently being evaluated in terms of its aesthetics, ease of use and the ease with which different levels of access can be associated to different types of information

The research highlights that the main barrier to use is security of information. Given that the data can only be accessed using a personal identification number, and will only include information that the individual is willing to enter and share with others and that a similar level of authorization will be required by health professionals to read it, such fears appear to be exaggerated. The software developer is currently considering how the potential for fraudulent use of devices can be minimized by setting up mechanisms to prevent the use of devices that have been reported as lost or stolen.

Future stages of the research will entail the development of more detailed usage scenarios, prototype development and testing of the device and evaluation of the usability of the interface.

Once a usable interface has been developed which enables the input, storage and retrieval of health information, a small scale trial will be undertaken. It is believed that at this stage more sophisticated and pertinent barriers to use will emerge from both health professionals and patients - relating to liability, changes in working practice, and factors associated with taking responsibility for updating and carrying health records. Such factors are ones which all stakeholders in the health service need to consider. In such a way it is hoped that the legacy of the project will be not just in a prototype system, but in taking a more holistic view of health provision, with patients working alongside health professionals to look after and manage their health.

The final stage of the research will use the experiences of the project as a starting point for a series of dissemination activities across the UK which will broaden discussion of responsibility for health care.

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REFERENCES

Hall, J. (2007)`Workshop discussion paper: what roles for the patient in patient safety research?` *Patient Safety Research Conference* Held September 2007 at Porto

Hampshire, A.J., Blair, M.E., Crown, N.S., Avery, A.J. and Williams, E.I. (2004) `Variation in how mothers, health visitors and general practitioners use the personal child health record.` *Child: Care, Health and Development* 30, (4) 307-316

NHS Management Executive (1990) *The care card: evaluation of the Exmouth project*. London :HMSO

Phipps, H. (2001)`Carrying their own medical records: the perspective of pregnant women.` *Australian and New Zealand Journal of Obstetrics and Gynaecology* 41, (4) 398-400