

# Understanding Patients: Participatory Approaches for the User Evaluation of Vital Data Presentation

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## ABSTRACT

The objective of our research was to undertake first steps to analyse patient access to their electronic health records (EHR) as a crucial universal access issue: Why is patient involvement becoming a key issue, what approaches are available to learn more about patient attitudes and needs, which concrete outcomes can be obtained from such research? The paper outlines a reference scenario for tele home monitoring of chronically ill patients including measurement devices and system environment, provides an assessment of selected participatory approaches like questionnaires, interviews and group discussions, and reports about universal access design issues from a patient perspective. Concrete conclusions concerning access devices and presentation of EHR contents are developed. To allow all citizens equality in access, to benefit from advances in eHealth and to avoid a "Medical Divide", creativity, innovations and support are needed to progress towards a true Information Society for all also in the health arena.

## Categories and Subject Descriptors

H.5.2 [Information Interfaces and Presentation (e.g., HCI)]: User Interfaces - Evaluation/methodology

J.3 [Life and Medical Sciences]: Health

## General Terms

Design, Experimentation, Human Factors.

## Keywords

Patient, Electronic Health Record, Telemonitoring, Universal Access, Participatory Approaches, Assessment, Validation.

## 1. Context and Objectives

In the context of the eHealth focus of its RTD Framework Programme [4] The European Commission supports the Thematic

Network "Information Society for All" (IS4ALL). This project seeks to establish a wide, interdisciplinary and closely collaborating "network of experts" to provide the European healthcare industry with a comprehensive information package detailing how to appropriate the benefits of universal design [6]. The specific technological/scientific objectives of IS4ALL are to consolidate existing knowledge on universal access into a comprehensive code of design practice [13], translate the consolidated wisdom into concrete recommendations for emerging technologies in a key application domain, Healthcare Telematics, and demonstrate the validity and applicability of the recommendations in the context of concrete Healthcare Telematics scenarios [6, 12].

Electronic Health Records (EHR) were chosen as the candidate domain for experimentation and foresight by IS4ALL because EHRs increasingly constitute the cornerstone of advanced medical systems, while they drive the daily activities of a wide range of users in different contexts of use [3]. Particularly relevant are health professionals and support staff in hospitals/institutional settings or private practice (surgery as well as home care), non-medical stakeholders in the health care system (administration, insurance etc.), and more and more citizens/patients.

However, very little is known about patient involvement and their active empowerment to participate in the management of their illnesses. The objective of our research was to undertake first steps to analyse patient access to their health records as a crucial universal access issue: Why is patient involvement becoming a key issue, what are the consequences for health care information and management systems, what approaches are available to learn more about patient attitudes and needs, which concrete outcomes can be obtained from such research, what are the implications for universal design of EHR?

The concrete field of application chosen was telemonitoring of chronically ill patients at home, a field where many new approaches and devices are showing up on the market in various countries [1], an indication of the perceived relevance and market potential of this type of patient involvement.

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## 2. Patient-Centred Health Services and the Need for Universal Design

### 2.1 The Shifting Health Care Paradigm

The traditional health care model is based on a highly structured, hierarchical delivery system dominated by physicians and with patients as mere receivers of health services which are usually provided by public/government institutions - with strict boundaries between local/GP services and stationary services in hospitals. This model is shifting towards accepting the citizen/patient as a self-determined individual. This new paradigm of patient-centred, seamless health care processes requires - when taken seriously - the full involvement (to the extent sensibly possible) of citizens in all aspects of their health, and during all stages of the health care value chain, from health information and prevention all the way through to rehabilitation and long-term care. And it implies that the term *patient* has to be expanded towards meaning 'citizens concerned with their health or the health of their friends/relatives'.

Home care is a prime example to demonstrate this new paradigm of collaborative and collective organisation of health care and its universal access issues. All industrial societies are ageing. This has profound socio-economic and health sector implications [14], underlined, e.g., by the dramatic increase of the old age dependency ratio - the ratio of the number of people aged 65 and over to the number of people between the ages of 15-64 - from 2000 to 2030 (e.g. by 85% and more in France, Germany, Italy and the UK; more than 100% in Japan) [15]. And as the number older and very old people increases, so will the number of citizens suffering from chronic diseases. To cope with the resulting challenges to our societies, telemedicine and e-health applications hold promise to provide better care, and allow for independent living [10,19]. In parallel, the costs per service can be expected to decrease [20].

### 2.2 Benefits of Better Patient Communication

Research has shown that improved communication with patients and allowing them to remain in an environment they are familiar with and comfortable in leads to better medical outcomes and, at the same time, renders more quality of life to older people [16,1]. For patients who are actively involved by their physicians into the health care delivery process, better results were experienced [9]. Patients of doctors who give more information and engage in more positive talk report higher satisfaction and compliance, better recall and understanding, and more favourable health status ratings and clinical outcomes [5,7]. At the same time, distrust is reduced and also the likelihood of complains, disputes and even lawsuits [8]. On the other hand, in this context also ethical and legal implications like the patients' privacy and security concerns including a fear of third party access to electronically recorded health and medical data need to be taken into account [11].

Patients are already today interested in accessing their health data [17, 18]. Both for individual social (improved medical outcome, quality of life, empowerment of patients) and economic reasons (pressures to contain costs in the health system; ageing of our societies) we expect strong support for this concept in coming years. To realise it and have it accepted by more patients, the implementation of design-for-all concepts will be mandatory.

## 3. The Context of Use: Tele Home Monitoring

### 3.1 Patient Population

Based on a variety of considerations, we have selected for our research patients suffering from End Stage Renal Failure (ESRF) being treated by continuous ambulatory peritoneal dialysis (CAPD), and who, at the same time, also suffer from high blood pressure. These target users cover the whole spectrum of potential user dimensions like old/young, mobile/homebound, various degrees of disability, digitally challenged/experienced IT users, technology open minded and active/uninterested and care-oriented, participating in the labour force/retired.

End-stage renal disease (ESRD) (or end-stage renal failure - ESRF) is the stage in chronic renal disease in which renal replacement therapy, dialysis or kidney transplantation, is needed to sustain life. ESRD is generally an irreversible state.

Out of this universe of patients, we have selected a particular type of target users: severely ill patients suffering from at least one other disease (heart disease), and quite often being multi-morbid (e.g. also suffering from diabetes). The five patients involved covered three female and two male patients, an age bracket of 45 to almost 80 years old (with three out of the five patients beyond 65), a very experienced (and very old !) PC user and a patient with absolutely no ICT experience. Insofar, our results must only be judged on a qualitative level. - For these patients, four vital signs, namely body weight, blood pressure, pulse rate and electrocardiogram (a graphic record of the heart's electrical activity) are particularly relevant and need to be measured daily.

### 3.2 Measurement Devices

The majority of the overall patient population are frail or elderly people. For them measurement devices need to be unobtrusive, very simple to use, and robust. Specific features should be large displays and large numerics for easy reading of the measurements; one button operation; voice and light prompts to support required behaviour; battery powered to allow mobile use at home; fully automatic data transmission; and no wiring between measurement devices and the home hub. Wires look ugly, and one can trip over them.

### 3.3 System Environment

For our participatory requirements and assessment tests, a modular set of TeleCare measurement devices equipped with a radio transmitter, capable of sending the measured information reliably to a Home Hub was being used. This eliminates the need to cable patients' living quarters, and also provides a degree of freedom to move the devices within the home. Once the patient has completed a measurement, for example blood pressure, the data are automatically transmitted to the Home Hub. The Home Hub is a microcontroller communication link that uses TCP/IP, MSCHAP, plus encryption to send the data over conventional phone lines to an ODBC database, located in a hospital or other secure setting. An NT server, running a standard SQL database and a web browser, automatically collects incoming patient data, presents it to the database for entry, and allows care providers with the appropriate authorisation to review the data as web pages via Intranet, or secure virtual private Networks. Integration of these data into another EHR is possible.

### 3.4 Patient Access to their Data

Options to extend the present system towards allowing patients direct access to their vital data concerned two aspects:

- preferred access mode/device
- presentation format of vital data to patients from their EHR

The telemonitoring devices themselves should not be modified because this might impair their extreme ease of use, their interoperability with other components of the system, and their usability in different contexts. Alternative platforms had to be considered: these included a web based software solution with access via fax machine/paper, PC, or TV. No operational model of such system components and their interoperation was available, i.e. for the technical platform we had to rely on the experience and imagination of our patients and experts.

With respect to the presentation format of patient data from their EHR we were in a more favourable position: Here we relied on screen shots available from the web-technology based service software presently in use on the server in the physician's office. On the standard interface he/she sees the graphical trend of the patient's weight and, in tabular form, all other data measured. To have a closer look at any data or combination of data, he can click on the relevant buttons on his screen to select them, request a graphical presentation, or adjust the time period reported on. All data can also be presented in tabular form.

For security and privacy reasons, presently no external access to the server in the hospital or the physician's office is possible. However, various screen shots of patient data as recorded by the system based on their telemonitoring data were obtained.

### 4. Involving the User: Assessing Participatory Approaches

To obtain empirical results useful for developing and improving data access and presentation to patients, a variety of participatory approaches are available, the more important ones being: questionnaires, face-to-face or telephone interviews based on a formal questionnaire or on an interview guide, and group discussions as brainstorming sessions or focus group meetings. All participatory methods can, in principle, be applied for a variety of purposes, and may, e.g., be used to assist in an exploratory manner, for problem identification, in clarifying the issues relevant to a particular topic, but also in the detailed evaluation of devices, products and interfaces.

Our collection of data and information relied on a variety of these methodological approaches:

- Informal, only slightly structured interviews and (sometimes very intensive) discussions with physicians in their office and patients in their home.
- Interviews based on formal, partially structured questionnaires (using predefined questions with a limited number of response options as well as open questions), face-to-face and over the telephone with patients.
- Focus group meetings with care personal and people involved in providing telecare and social services.

All methods/techniques employed proved useful for specific application contexts. It turned out that...

visits of and interviews with physicians and patients...

are a time consuming, but extremely useful procedure to much better understand the application context, the relationships and interactions between physician and patient, their attitudes, expectations, problems, or non-verbal issues which may support (or interfere with) the consensual sharing of patient vital data and information, and access to their EHR.

formal, partially structured interviews...

proved very valuable to obtain a more in-depth understanding of specific issues of patient access to their EHR. An important aspect was that in such an interview situation each patient was 'alone' and could freely speak about his or her attitudes and expectations, but also about their computer literacy (or illiteracy), their individual interests and preferences in accessing their own data, the implications seen for their relationship to the physician, etc. Attempts to discuss such issues in a focus group/group discussion setting failed. Contrary to reports by others about discussion groups, there did not exist much interest in sharing such opinions with other patients. In view of the wide differences in individual interests, capabilities and experience with computers and the Internet, involvement in handling their disease and motivation to take an active part in managing it, but also in the socio-economic environment and education/income situation of patients, this result is not surprising.

group discussions...

lead to a multitude of very useful and interesting suggestions and hints with respect to another group of concern for our research, namely care providers or other professional people who have considerable experience with such patients and their socio-economic environment and their usage of ICT. It turned out that meetings with a clearly defined focus and purpose, pre-structured by providing topics and issues for discussion, lists of concerns, examples or pictures of potential access devices, print-outs of screen shots etc. were much more fruitful than open brainstorming sessions without such prompts.

### 5. Empowering Patients: Design Conclusions

Key generic results of the participatory methodology used to elicit Design-For-All recommendations relate to general conclusions, access devices, and presentation of EHR contents.

#### 5.1 General conclusions

Although legally a patient has the right to access his or her complete EHR, only those data of particular importance for the patient, which he can understand, interpret in their relevance and assess with regard to their implications for life style, behaviour and medication, should be pre-selectable for access by the patient. In other words, only a (flexible) subset needs to be specifically, easily accessible in a different non-physician/care provider mode by the patient. This patient subsystem must be flexible with respect to

- data to be selected for inclusion
- the set available for viewing by patients,
- the range of access devices used for viewing the data,
- modes of presenting the data and adjusting their presentation

## 5.2 Access Devices

In general, to initiate the concept of patient access to their EHR and support its diffusion, those modes of access and access devices should be used which patients are familiar with:

**Paper:** Most patients state as first priority a presentation of their weekly or monthly data on a piece of paper. Easy, flexible, on demand access would be via a telefax machine attached to their telephone, a printer connected to the PC or laptop available in the household (with a connection to a telecom network), or as an extension to a TV set-top-box.

**Telephone:** It is the most widely used and familiar access device and a 'must' for severely ill chronic patients. But even modern ISDN telephones do not have displays suited for presenting the type of data under discussion. Insofar, a telephone is only suited as an 'intermediate' access device for other modes of presentations via a fax machine or a screen.

**PC/laptop:** A computer is not unusual in the household these days, and even old people get more and more into using them, also for accessing the Internet and its Web services [17]. One of the involved patients, who is almost 80 years old, turned out to be very computer literate, and not surprisingly his preferred access medium is his PC.

**TV:** Accessing their EHR via a TV screen is still a new idea for most patients. But as a TV set is available in all households and more than 40% even of older people are used to accessing information via teletext [17], it is not surprising that they would, in principle, very much favour such an access device (except for those being used to a computer).

## 5.3 Presentation of EHR contents

Briefly summarised the results obtained when presenting and discussing appropriate screen shots, at the generic level some general observations are particularly relevant. Patients must be able to

- select those data from the universe of information which are particularly relevant for their very specific situation
- access these data any time they want
- switch from a graphical to a tabular presentation format
- change the time period shown (weekly, bi-weekly, monthly)
- switch from seeing only one data set to two or three shown in parallel

## 6. Outlook

The above discussions sketch only initial steps to open EHR also for access by patients and to better involve them in the management of their disease. To further develop patients' access to their own EHR both functionally and technically, one has to

- feed the patient data and information from the central server (in the physician's office or the hospital) directly back to the individual patient's home,  
or
- store the data in addition (immediately while measuring) on an electronic storage device in the patient's home.

They should be made available in appropriate formats on a screen using a set-top-box for a TV set (or a PC) and remote control. As technology develops, an alternative to be considered will be a touch screen (e.g. on a web pad or tablet PC connected to a residential gateway), and voice input to manipulate access, data selection and presentation.

For sight-impaired and blind people an output device suited for the presentation of graphs of time series data is needed.

A pressing issue, which already at this stage needs policy attention, is what we term the "medical divide": A quite considerable share of the population, particularly many older, disabled and frail people, (but also those with no or little education and/or on low income, and also people who have been disappointed by what they find (or cannot find) on the Internet and who are not interested in e-health services) will be left out of these developments and cannot or will not participate in the benefits and advantages e-health offers for them unless user-friendly interfaces and design-for-all features are fully taken account of. Also for this reason patient access to their health records is a crucial universal access issue. Creativity, innovations and support are needed to integrate all patients, to progress towards a true Information Society for all, to assure equality in access to medical and health services.

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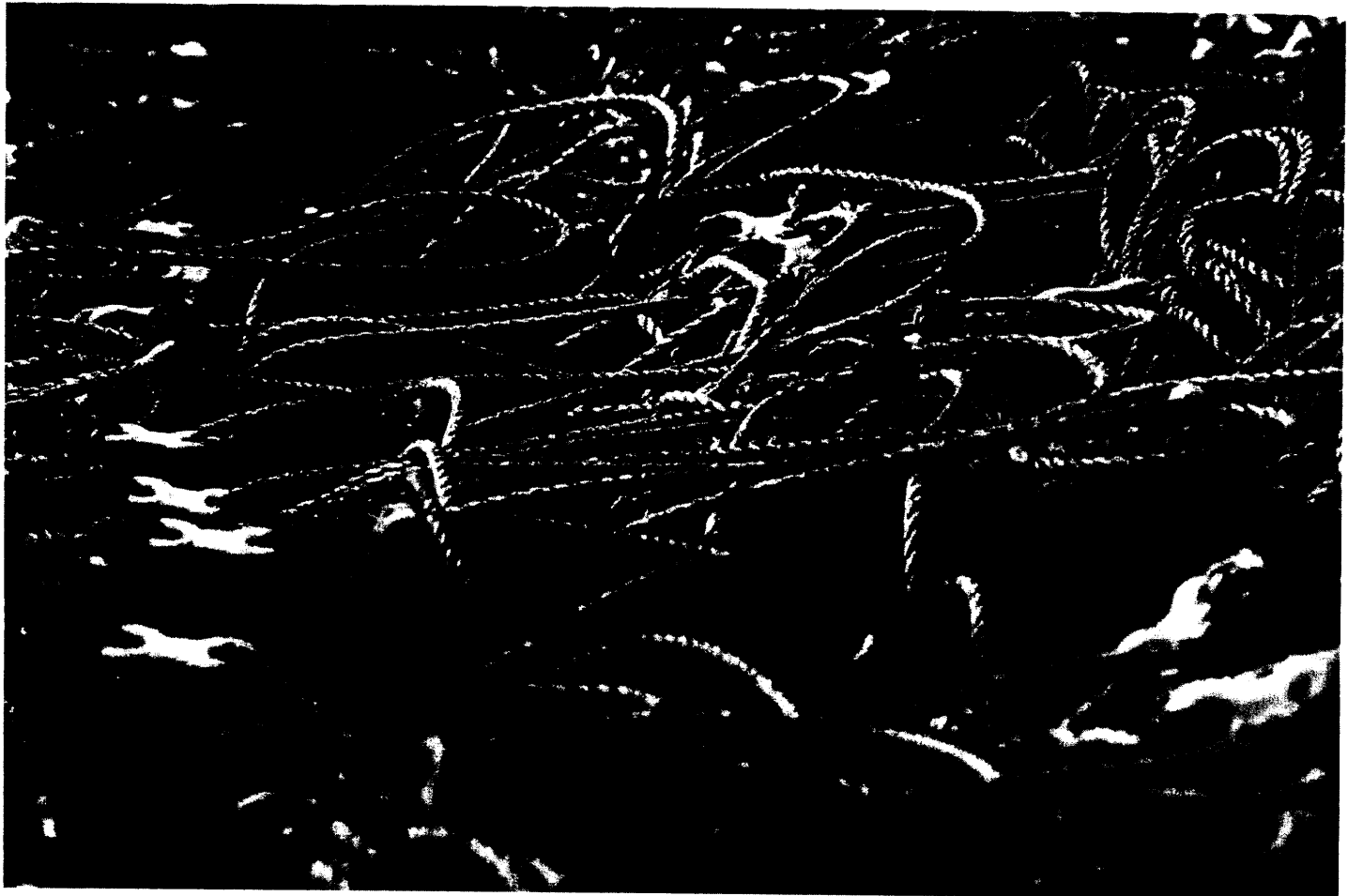
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