

## Chapter 21

# Participatory Insight to Universal Access: Methods and Validation Exercises

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**Abstract.** Participatory methods can, in principle, be applied for a variety of purposes to gain insight into the context of use of an artefact or the way in which tasks are performed by end users. Consequently, participatory methods are equally valid for problem identification, clarification of the issues relevant to a particular topic, but also for the detailed evaluation of devices, products and interfaces. Typically, participatory methods facilitate rich empirical data sets useful for design teams and evaluators. In our case, participatory methods have been used to facilitate access to medical data by patients at home. To this end, 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, user trials, task analysis and group discussions such as brainstorming sessions or focus group meetings.

### 1. Involving End-User Communities

Participatory usability inspection takes as its basic premise the view that product developments should be driven from user requirements rather than from technological capabilities. End users should be encouraged to participate in design wherever possible. Thus the starting point for usability evaluation and systems design is to understand the user population in some detail, and understand what they may need from products before going too far down the path of deciding about specific design solutions. Design is often driven by technical feasibility that can lead to a poor match to users' needs. Participatory approaches are conversely concerned with ensuring that products:

- have real value for end users
- are matched to user capabilities
- are fit for the purpose for which they were designed

From this perspective, participatory approaches place emphasis on tools and techniques that assist developers in understanding more clearly the end-user demands they are designing for and the attributes of those people who will be influenced by a design. However, involving patients who are elderly, frail or suffering from certain illnesses in participatory usability inspections and systems design requires some degree of sensitivity on the part of evaluators and designers, and an awareness of the way in which most cultures stigmatise health problems. These cultural factors in turn influence the way information is captured. For example, self reports from patients often underestimate their difficulties, as problems in coping are seen as being a reflection on oneself rather than being due to a poorly designed system environment.

Since many requirements for products emerge out of direct experience of using prototypes or mock-ups, these problems can at best be dealt with by an iterative methodology rather than a linear evaluation and design approach which moves directly from requirements capture through specification and implementation. For that reason participatory approaches support iterative design, recognising that in many cases developers may have to enter several cycles of “development and evaluation” before a satisfactory solution is reached. Participatory approaches emphasise the importance of obtaining good feedback about how products perform in actual use, and it is noted that this is often a lacking in design activities. Many design solutions have previously failed to gain information about how the final product will be used and consequently they are not sufficiently sensitive to the changing and developing needs of different end-users. Unlike other approaches, participatory approaches cover not only the design of the product itself but also other, wider factors that can dramatically affect the success or failure of a product - for example, factors such as the environmental context in which the product will be used, etc.

At the heart of participatory end-user involvement is thus the concept of usability. If products and services do not have the necessary usability characteristics they are unlikely to be successfully applied. In consequence, it is very important for developers to take into account the characteristics of different end-users, the things they do and want to do differently, and where and when they want to do them. This Chapter offers advice on how to get the relevant design knowledge about these issues.

## **2. Description of the Participatory Approach and Methods**

The key concept of participatory approaches is a design for all philosophy or strategy, based upon the principle that products should be usable by as wide a range of the population as possible. Design for all is based on the notion that by ensuring that the least able can use a product, one maximises the numbers of potential users, and also creates products which can be easier for the more able to use as well.

### **2.1 Problem Being Addressed**

The concept has much to offer, as by designing for less able groups it becomes possible to accommodate larger numbers of able people as well. For example, ensuring that health care information is accessible not only for medical practitioners

but for their patients as well allows for appropriate lifestyle accommodation of the patients and at the same time makes it easier for practitioners to tele-monitor patients' health status from distance, unless excess of certain threshold values calls for professional intervention. Therefore, most generally participatory approaches allow user-involved and consensus-based design of systems to be used by different end-user communities.

## 2.2 Devices / Techniques Used

There are a variety of instruments or devices that can be used to plan and organise a participatory inquiry. Some of them are described below.

### 2.2.1 Short Visits to End-User Sites

#### *Description*

Generally visits aim at some kind of contextual inquiry. They are best carried out by a group of researchers who develop a medium- to long-term relationship with an end-user target group (i.e., physicians and patients) who are interested in providing data. Holtzblatt and Jones (1993) have identified the following steps to organise visits for contextual inquiry:

- Identifying the customer: identify the groups that will be using the new technology or are using similar technology, and arrange to access organisations within the groups that give a cross section of the overall target population
- Arranging the visit: write to the targeted organisations identifying the purpose of the visit, a rough time-table, and how long of the visiting time the exercise will take. Ensure that some feedback from the visit is possible before leaving. Ensure that the participating end-users understand how many visits evaluators intend to make over the time period of the evaluations.
- Identifying the users: a software product will affect many people not just the patient as end user, but also presumably his family, relatives and friends. Evaluators should ensure that they understand the key persons in this context who will additionally be affected by a new system or changes in the current one.
- Setting the focus: Evaluators should beforehand select what aspects of the users' usage problems they wish to make the focus of each visit, and write down their starting assumptions. They should make a statement of purpose for each visit, and after the visit, evaluate to what extent they have achieved their purpose.
- Carrying out the interview / observation: Evaluators should stay with the selected users until they have managed to answer the questions they have raised in 'setting the focus'. Very often this may involve inviting the user to directly share and comment on the evaluator's notes and assumptions.
- Analysing the data: the process of analysis is interpretative and constructive. Conclusions and ideas from one round of observations have to be input to the next round, and an evaluation of the results so far should be one of the purposes of subsequent visits.

*When to use it*

Short visits for contextual inquiry is one of the best methods to use when evaluators really need to understand the patients' usage context. The environment in which people make use of a system or a service really influences how they use the product. Thus, this technique is highly effective for finding out about usage practices in domains evaluators know nothing about. The technique is best used in the early stages of development, since a lot of the information the evaluator will get is subjective, e.g., how people feel about their health problems, how they deal with it by using technological means, etc. In conclusion, short visits as a complete micro-method is summarised in Table 1.

**Table 1.** Short visits for contextual inquiry

<b>Name of method</b>	Short visits for contextual inquiry
<b>Problem being addressed</b>	Gain a better understanding of the relationship physician/patient, their respective expectations, interactions, attitudes and views
<b>Device/technique used to address the challenge</b>	Open, unstructured interviews/discussions
<b>Procedure</b>	Gain confidence of the person to be visited, explain relevance of the research, arrange an appointment
<b>Outcomes</b>	Better understanding of the specific situation of the patient, gain trust of both physicians and patients re further questioning and for pilot experiments, first hypotheses to be pursued in further research
<b>Assumptions</b>	Only a stepwise approach fully involving physicians and patients will motivate them to participate in such research

**2.2.2 Questionnaires***Description*

The questionnaire provides a structured way of gathering information. It allows for the same question to be asked in the same way to a number of informants. This enables statistical analysis of the data to be used, which allows a large amount of information to be summarised in a convenient form. A questionnaire can be constructed to investigate user experience with a product, their need for a new product, identification of how well they do with the technology they use etc. A typical questionnaire consists of a limited number of questions with pre-defined answer categories, focused on the topic of interest. It can also consist of some more open questions where the informants need to write in answers in their own words. Questionnaires are usually distributed to a sample of the target population and the responses are collected and then summarised using statistical analysis. Such a

questionnaire can also be used in an interview situation where an interviewer reads the questions and fills in the answers on behalf of the subject.

*When to use it*

Questionnaires are often used when there is a potentially large number of users of a product, and a developer wants to obtain information from as large a sample of these as possible. Questionnaires can be a cost effective way of obtaining background information, as the use of postal questionnaires is much less resource intensive than conducting large numbers of personal interviews, and is particularly useful when informants live some distance from each other. Postal questionnaires can be used to collect a wide range of information, including background information about the persons themselves, and their opinions regarding existing equipment and future design options. One advantage of questionnaires is that the informant can spend all the time they want in filling out the form, allowing them to make up their mind without any external pressure. For some disabled informants, this might ensure responses that would not come out in an interview or group discussion. Postal questionnaires, which do not require the respondent to identify him/herself, may also make it easier for the respondent to answer personal or potentially embarrassing questions, due to the anonymity which such techniques may provide, compared with other methods. Questionnaires can vary in the degree to which they are structured, and for postal use structured questionnaires are likely to be of most value. Structured questionnaires are useful for obtaining simple factual information, rather than complex opinions however, as respondents are forced to make simple answers to questions or to chose from limited sets of options. More open questions can be used to some extent in postal questionnaires, but as there is no opportunity to discuss the question and answers with respondents, their use in these cases is limited. Less structured questionnaires are more appropriate for use as part of personal interviews, where any ambiguity in question and answer can be resolved. In addition, less structured questionnaires are more appropriate for addressing issues, which are inherently complex e.g., the requirements that a person may have for products in the future.

### **2.2.3 Interviews**

*Description*

Interviews are conducted talking to an informant, either directly or on the telephone. Individual opinions and subjective preferences about products can be collected. The interview can be performed in a structured manner using a questionnaire which is filled in by the interviewer (see previous section) or it can be more open ended using an interview guide that describes the areas the interview should cover. Since the interview is conducted on a one-to-one manner, it should be possible to create an atmosphere that facilitates good responses, which clears up misunderstandings about the questions and ensures that the informant expresses what he/she really means. It can also be performed in the informant's home or workplace. People who also have problems in expressing their opinions in groups should be interviewed instead.

*When to use it*

Interviews can be carried out at any stage of the design process as a means to gather information. They can be used to identify detailed user requirements and to be informed about the user's experience with a particular product. In the user requirements stage, unstructured or semi-structured interviews should be used to allow the process to be user led. In later phases of design more structured forms, such as an administered questionnaire may be used. The interview is especially appropriate when questions are of a sensitive nature, or complex information is involved, as is often the case in the Assistive Technology area. It is also suitable when it is suspected that the interviewees might be low on motivation to participate or give information. Interviews are a more time consuming method to use than questionnaires, particularly if data are collected from a large number of informants. However, if the number of informants is small (and especially if the informants have problems filling in a questionnaire) the interview is the most cost efficient method. If the information is recorded using a tape recorder, a considerable amount of time is used transcribing the tape. It is often more efficient to use two interviewers, and let one take notes throughout the interview whilst the other asks the questions. Finally, Table 2 describes interviewing, as a complete micro-method.

**Table 2.** Interviews

<b>Name of method:</b>	Formal, partially structured interviews (patients)
<b>Problem being addressed</b>	Gaining a better understanding of specific design issues and identification of patient priorities, capabilities and needs
<b>Device/technique used to address the challenge</b>	Structured questionnaires, paper copies of screen shots
<b>Procedure</b>	Mailing of explanatory letter and questionnaire, screen shots; arrangement by telephone of a time slot for a more detailed telephone interview or for a visit to the patient's home; realisation of the interview and writing a record of the results; integration of results from all interviews
<b>Outcomes</b>	Structured assessment and record of design issues, priorities, solutions preferred, etc.
<b>Assumptions</b>	Patient involvement and knowledge of their expectations, attitudes and experiences are key ingredients for developing guidelines for design-for-all access by patients to their EHR

### 2.2.4 Brainstorming

#### *Description*

Brainstorming is one of several techniques to facilitate group creativity and is one of the oldest and best known. The idea is to let people come together and inspire each other in the creative, idea generation phase of the problem solving process. Brainstorming is used to generate new ideas by freeing the mind to accept or criticise any idea that is suggested, allowing freedom for creativity. The tool has been broadly used in design. However, there has been a wide range of studies intended to evaluate the efficiency of the technique, and the majority of these studies shows that people who is working in isolation produce more and better ideas than when working as a group. So, why is brainstorming still so popular? One important reason is probably that the group process as such is rewarding and creates a feeling of ownership of the result. In the brainstorming process everybody in the group can take credit for good ideas. The result of a brainstorming session is hopefully a couple of good ideas, and a general feel for the solution area.

**Table 3.** Brainstorming

<b>Name of method:</b>	Focus groups, brainstorming with care personnel, experts
<b>Problem being addressed</b>	Obtaining a more detached, objective assessment of patients' situations, needs and capabilities re accessing their EHR
<b>Device/technique used to address the challenge</b>	Semi-structured, open discussions
<b>Procedure</b>	Meeting in a pleasant environment, creation of an open, trustful atmosphere, provision of lists of potential access forms/devices; copies of screen shots; list of issues and topics to be covered
<b>Outcomes</b>	Structured lists of issues and problems, suggestions for solutions, generalisable assessments of priority issues, of patients' capabilities and needs, recommendations for seamless integration into the overall care process
<b>Assumptions</b>	People who regularly care for and have contact with these patients are in a better, more neutral position to assess universal access and interface design issues than individual patients who can only report about their individual experience and expectations and who may under- or overestimate their capabilities, may be too shy to admit their real access problems etc.

*When to use it*

Brainstorming is usually applied in the very early stages of design. Especially when there are people with different backgrounds that can give different input to the design process, brainstorming may be a good start. Table 3 summarises the method described above as a complete micro-method.

**2.2.5 User Trials***Description*

In user trials, “real users” test a product trying it out in a relatively controlled or experimental setting, where they are given a standardised set of tasks to perform. The result can be a “problem list” which contains valuable information for designers regarding the potential for improving the usability of a product. Time spent completing a task or the number and types of errors made in use, is information that can be used to compare two different products or two versions of the same user interface. Subjective statements about acceptance are normally part of the results of such trials. The testing procedure originates from experimental psychology, and may be performed in a very formal way, performing controlled experiments and using statistical analysis techniques. However, in this section we will describe a simpler or more “qualitative” approach to such trials, requiring that observers have an understanding of the system to be tested so that they can easily deduce from the user’s behavior that a problem has been encountered. In doing this, knowledge of the user group is, of course, also very valuable in interpreting the results of such trials. In this situation, the observer must however, be aware that there is always a possibility of “seeing what you want to see”. Using more than one observer will minimise this problem and is to be encouraged as a general procedure to follow. In usability laboratories, it is also common to videotape users interactions with the system being evaluated, as this allows particular events to be reviewed after the trials are completed, and also acts as a useful record of problem interactions. This also can be particularly useful as a medium of communication, allowing others to see the problems experienced by users in the trials. For a more detailed guide to usability testing see Dumas and Redish (1993).

*When to use it*

User trials are normally applied when a prototype product is running, or when a complete product is to be evaluated. Low-tech mock-ups and prototypes may also be used. They are often used before a final product design has been agreed on, and are commonly used on pre-production prototypes. They are often used as a simpler way of evaluating products compared to more extensive field trials, which commonly take place when a more completed product is to be evaluated prior to market release. Table 4 summarises the method in terms of the criteria applicable to complete micro-methods.

**Table 4.** User trials

<b>Name of method:</b>	User trials in controlled or experimental settings
<b>Problem being addressed</b>	Trying out a product or service with targeted end-users in a relatively controlled experimental setting, where they are given a standardised set of tasks to perform.
<b>Device/technique used to address the challenge</b>	Observation of prototype or mock-up application by targeted end-users/ Evaluation of appropriate thinking aloud protocols <sup>7</sup>
<b>Procedure</b>	Compare usage of different system versions or different versions of the same user interface.
<b>Outcomes</b>	“problem list” which contains valuable information for designers regarding the potential for improving the usability of a product or service.
<b>Assumptions</b>	When using such techniques with frail or severely ill patients, it is important to take into account, that such users may require long periods of time to become comfortable using a new alternative products and services , and in addition some of the problems users are likely to experience with new products will only manifest themselves after extended periods of use.

### 2.2.6 Task Analysis

#### *Description*

Task analysis can be defined as the study of what a user is required to do, in terms of actions and/or cognitive processes, to achieve a task objective. The idea is that task analysis provides some structure for the description of tasks or activities, which then makes it easier to describe how activities fit together, and to explore what the implications of this may be for the design of products. This can be particularly useful when considering the design of interfaces to products, and how users interact with them. Task analysis can be applied to studying how users use existing products, and such an analysis will assist in the process of understanding the difficulties they face in using existing products, and improvements that might be needed. Task analysis techniques can also be used in a predictive fashion to represent how users may operate products that are being developed. Such representations can act as a vehicle for communication between developers and others involved in the development process e.g., end users or their representatives. Task analysis techniques can also assist in the development of training manuals for products, as the structure that is implicit within the design of an interface is more easily revealed when represented in such a way. Task analysis techniques can also be used in the development of evaluation plans, as an understanding of what activities are the most important to the user or have critical consequences for their safety helps place priorities on any

evaluation studies planned. Information on how often different activities need to be performed is also particularly useful to have for these purposes.

An important point to be made is that in order to be maximally effective, such an analysis should be extended to encompass all of the user's interactions with a product or device. In addition to everyday tasks, more infrequent tasks such as maintenance and cleaning, as well as known types of misuse, should be included in the analysis. All forms of task analysis are concerned with the description and representation of tasks or activities, and provide organisation and structure to that description. This can be useful when describing an existing set of activities performed by a person, but also is of value when trying to design a new product. Thinking through the sequences of activities that a person would need to go through to use a product can assist in identifying whether these are organised logically or not, and can assist in designing and redesigning the operations needed to use a product. Two processes are usually followed when a task analysis is conducted. The first of these is some understanding of sequence or dependency between different activities. Thus it is important to understand a particular activity in the wider context. For example, a person using a communication aid may want to communicate hunger, but first needs to attract the attention of the person with whom they want to communicate. After they have communicated hunger, there is a need for them to be fed. The second process is one of representing how activities or tasks fit together. This is a process of representing how large tasks can be decomposed into smaller components, and the logical relationship between these. A common technique used is called hierarchical decomposition, which means breaking larger activities into smaller activities until a sufficient level of detail is reached. A good way of achieving such decomposition is to repeatedly ask the question "how" to break activities into smaller units. For example in a communication aid where an identified activity is to attract the attention of the teacher, this might be further de-composed into the child having to press a specific button on the communication aid, repeating the key press in the event of no response by the teacher etc. One well-known approach, which breaks tasks or activities down into smaller units, is the Hierarchical Task Analysis (HTA) technique developed by Shepherd (1989). In addition to decomposition it is also common when using task analysis to explore how activities fit into a wider context. It can be useful to repeatedly ask the question "WHY" in order to assist in this process, with activities becoming increasingly more abstract.

#### *When to use it*

The technique should be used during the analysis phase of design to ensure proper description of user activities. It can be used to analyse interactions with an existing system or as a means to structure discussions about a hypothetical product. Task analysis data can be used as input to the detailed design of interfaces to products, and can also be used in planning evaluation studies. In later stages of the development the current solution can be checked against the original task or activity analysis to see how the design deviates from the intended solution, and what consequences this leads to. Table 5 summarises task analysis as a complete micro-method.

**Table 5.** Task analysis

<b>Name of method:</b>	Task analysis (patients)
<b>Problem being addressed</b>	Gaining a better understanding of what a patient is required to do, in terms of actions and/or cognitive processes, to achieve a task objective
<b>Device/technique used to address the challenge</b>	Interviewing or observing patients and taking notes
<b>Procedure</b>	The first part of the analysis is to understand the activities to be represented by interviewing or observing patients and taking notes. This is followed by the representation of the activities in some way (e.g., flow charts, hierarchical decomposition and state transition diagrams), and a process of verification to confirm that the representations are correct reflections on the state of affairs.
<b>Outcomes</b>	Structured description of how activities fit together, what activities are the most important to the user or have critical consequences for their safety
<b>Assumptions</b>	Task analytical annotations act as a suitable vehicle for communication with patients, thus helping place priorities on developing guidelines for EHR product design

### 3. Method Validation

In this part of the Chapter we will describe how some of the above methods have been used in the context of the reference scenario of Chapter 9 to facilitate insight to universal access. Our collection of data and information relied on a variety of these methodological approaches appropriate for the question(s) under consideration, the respective situation of the persons involved, and their adequacy to elicit the information required for our research:

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

### 3.1 Visits (Informal Interviews / Discussions)

Before undertaking any validation exercise of this kind, it is important to establish a well-founded rapport with all persons involved, be they physicians, nurses, care takers, patients or family members. The purpose is to gain their acceptance and to obtain their trust and confidence. It was expected that this would indeed help to motivate them to participate.

Unless a contact exists already in some other context, initial approaches can be made by letter (perhaps with a short written note about the purpose of the exercise), or by phone asking for an initial telephone exchange of 10 to 15 minutes at a time convenient to the other party. The purpose is to present the project and the objectives of contacting the physician and to allow him/her to ask questions etc.

If the response is positive and the physician signals enough interest, a face-to-face meeting lasting 30 to 60 minutes should be agreed upon. Considering the usual time burden on most medical professionals, these and the following contacts/steps should be planned carefully with sufficient lead and follow-up time.

Patients or their family members should always only be approached after their physician or care personnel have agreed to this, and perhaps only after they have introduced their patients to the researcher. Involving a project participant who is a medical doctor and therefore has professional experience in dealing with both sides is definitely an asset. A short list of discussion points with the physician may include the topics listed in Figure 1:

- |   |
|---|
| <ol style="list-style-type: none"> <li>1. Context of the research project/exercise, participants, funding</li> <li>2. Purpose and objectives to be achieved, next steps and overall work process, timetable</li> <li>3. Workload/demand on time anticipated for the physician, for the patients</li> <li>4. Selection criteria for participating patients, support in contacting the patients, next steps and time frame</li> <li>5. Ethical issues and their formal solution, confidentiality issues concerning patients</li> <li>6. Research methods and tools, analysis, expected results</li> <li>7. Expected benefits/utility for physician, his/her patients, society, ...</li> <li>8. Devices to be used, technical prerequisites and support, costs and their reimbursement</li> <li>9. Authorship of research results, potential publications in medical journals etc.</li> <li>10. Any open questions, unsolved issues, formal agreements as needed</li> <li>11. Exchange of telephone numbers, formal points of contacts in case questions or problems surface, or when emergency support is needed, etc.</li> </ol> |
|---|

**Fig. 1.** Informal interviews - discussion points for physicians

With patients, only a selection of such points should initially be discussed so that information is adequate and comprehensive, but not beyond their comprehension. Participation of a nurse or a first contact in the doctor's office will be helpful to faster

gain their trust and motivation to participate. One or, at most, two researchers should participate in such informal interviews so that the other party is not overwhelmed. Observing these points and approaching carefully selected physicians known to be open to new approaches, experiments or research, we usually encountered interest and openness to participate. Once their doctor was convinced of the benefits of the project, patients - with rare exceptions - were usually more than happy to participate, too.

It turned out that visits and slightly structured 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 the EHR by both physician and patient. At the same time, this helps to gain acceptance by these actors, to obtain their trust and confidence, to motivate them to participate, and thereby to prepare the ground for more formal analyses to follow.

### 3.2 Interviews

More formal, structured interviews, which contained both closed and open questions were devised, based on earlier experience as well as on questionnaires available from other research projects and the literature. In order not to overtax the time of the physicians or the patients, they focused on the primary objectives of the study and key assessment questions derived there from. As only a small sample of persons was interviewed, the demographics section was short - a detailed analysis, by, e.g., social status, is not warranted with a very small sample.

Of course, such questionnaires have to be in native language, and words used have to be at a linguistic level appropriate for the person interviewed. They were applied to the same persons with whom - at the start of the exercise - informal discussions as described above were undertaken. In the Appendix to this Chapter, excerpts from patient questionnaires translated into English are presented to stimulate the development of related questions in similar situations.

Formal, partially structured questionnaires 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 perceived for their relationship with the physician, etc.

### 3.3 Focus Group Meetings

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, and in the socioeconomic environment and education/income situation of patients, this result is not surprising. We observed this also in other contexts; this may be different with respect to the “average” citizens not suffering from any specific, severe chronic disease (with which some patients have already lived for many years) or for patients with an acute disease with which they have no experience and about which they have no knowledge, or for family members “only” interested in helping somebody, learning more about a certain disease etc.

On the other hand 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 socioeconomic environment and their usage of ICT. Here our concern is a relatively homogeneous group of persons who are experienced in sharing knowledge and experience, who are used to observing activities of other persons and to supporting them in performing such activities, who can interact and are prepared to accept different opinions, to elaborate on ideas presented by others, to be constructive and helpful in improving the situation of patients and frail people at home. 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. to support some kind of “artificial walkthrough” were much more fruitful than open brainstorming sessions without such prompts.

Because physicians as well as individual patients may have very specific and individualistic observations and suggestions (depending on former experience, personal situation, individual preferences and habits, etc.), focus group discussions may prove very useful in providing a broader, more generic perspective, and also lead to useful assessment results otherwise more difficult to attain. They were undertaken with two groups: On the one hand with a small group of carers and nurses involved in directly dealing with individual patients, on the other hand with a few selected professionals involved with, or planning to deliver, telecare services to older people. This provided us with more generic insights from the perspective of both patients in their respective individual settings and providers marketing and sustaining such services and their perceptions of user needs, attitudes and expectations. The Appendix to this Chapter presents excerpts from a focus group discussion guideline translated into English:

#### **Introductory items:**

Welcome  
 Introduction of each participant  
 Context of research, study or exercise  
 Objectives and purpose of meeting  
 Duration of meeting, procedural rules etc.  
 Expected outcomes, benefits

<b>Generic issues:</b>
Role and relevance of patient access to their EHR data Set of data most relevant/useful for patients (in different situations) Generic issues of data access and presentation (i.e., selection of data for presentation, flexibility of selection and presentation format, level of competence of patients, technical versatility and computer literacy, etc). Motivation of patients and their involvement in the management of their disease Etc.
<b>Specific topics:</b>
<b><i>A) Access devices</i></b>
Available in patient home (paper/fax, telephone, TV, desktop computer, etc) New types (cellular phones, PDAs, tablet PC/mobile pads, etc) Appearance (size, weight, signals for status, etc) Menu/general presentation issues Usability Quality (waterproof, sensitivity to falls, etc) Reliability General functionality (battery life, buttons, key board, acoustic signals, etc)
<b><i>B) Presentation of EHR data</i></b>
(Discussion may be supported by pictures/copies of screen shots, etc. The following items may be discussed repeatedly for each screen shot)
Selection mode for desired data/access interface Type of presentation (graphical, tabular, etc) Quantity of data presented, time frame (day, week, etc) One data set at a time, or two or more sets in parallel Naming of graphs, data points etc. Size and type of letters and numbers Use of colours Identification of upper and lower bounds/limits Simplicity/complexity of overall presentation Etc.
<b>Outlook:</b>
Feedback, next steps, etc. Thank you!

**Fig. 2.** Excerpts from a focus group discussion guideline

The results of these meetings were recorded in short written notes and annotations (in native language) based on the numbering of the discussion guideline and amended/complemented with new headings/key words as new topics arose from the discussions which were deemed relevant to the assessment.

Unfortunately, at the present stage of development, concrete user trials and specific task analyses could not yet be performed. However, in case further resources should allow progress to the stage of a simple prototype application to be demonstrated to patients, it is expected that these methods will be indispensable to further develop universal access criteria for patient access to their EHR.

#### **4. Discussion**

As indicated above, research based on these methodologies is of a preliminary, rather exploratory nature, and the sample of patients involved is both small in numbers and concerns a very specific group. As a consequence, findings cannot be generalised in any quantitative sense; rather, they should be regarded as a first indication of the variety and breadth of issues to be taken into account when seriously considering access for patients to their EHR. Key generic results of the participatory methodology used to elicit Universal Usability recommendations relate to general conclusions, access devices, and presentation of EHR contents.

Generally only those data of particular importance for most patients, which they can understand, interpret in their relevance and assess with regard to their implications for lifestyle, behaviour and medication, should be pre-selectable for access by the patient. In other words, as a first important step, only a (flexible) subset needs to be easily accessible in a different non-physician/care provider mode by the patient. This patient subsystem should be flexible with respect to the data to be selected for inclusion, the set available for viewing by patients, the range of access devices used for viewing the data, and the modes of presenting the data and adjusting their presentation.

Generally patients must have access rights to their whole medical history, i.e., to all data any doctor has about them on file. However, adequate presentation of any and all of this data can only be accomplished in the longer term. A priori, it must be taken into account that even for a very specific, chronic situation affecting several patients at the same time, patient access and viewing must be adjustable to their individual situation. As already mentioned above, even those patients are very different with respect to their computer literacy (or illiteracy) and experience of the Internet and various access devices, their individual interests and preferences in accessing their own data, their personal involvement in handling their disease and motivation to take an active part in this, and also in the socio-economic environment and education/income situation.

To initiate the concept of patient access to their EHR and support its diffusion, those modes of access and access devices which patients are familiar with should be used, and where the probability that it is available in their household or can easily be implemented is high:

- Paper:** Most patients state as first priority a presentation of their weekly or monthly data on a piece of paper. This is a mode they are used to, and which sometimes already today can be accessed, albeit cumbersome, by asking their physician for a print-out during a visit or by postal mail. 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. So far, 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 elderly people are getting more and more into using them, also for accessing the Internet and its Web services. One of our patients, who is almost 80 years old, turned out to be very computer literate, and, not surprisingly, his preferred access medium is his PC. And with younger patients having relevant experience at the workplace, this will become more and more familiar.
- 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% of older people are used to accessing information via teletext, it is not surprising that they would, in principle, very much favour such an access device (except for those used to a computer). Indeed, it is to be expected that this would be the preferred means of access if the technology to achieve this were available. In this sense, the TV screen and technologies adapted from the ones people are used to when accessing different TV programmes, and Teletext would be the most “universal” ones from the point of view of the majority of patients.

Other access devices such as mobile telephones are not favoured; those who have some experience with them regarded them as too complex and difficult to use, and the screen is simply too small at present (similar considerations would apply to using PDAs - but children probably would favour such devices). Mobile access beyond the home is also no issue because these high-risk patients do not travel much and have to be close to some sort of storage for their dialysate fluid several times a day. Whether mobile Web pads used within the home would be an interesting alternative remained unclear; people are not yet familiar with this technology.

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 carry out amongst other tasks, the following:

- 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

Since patients have very heterogeneous preferences, some prefer to see only one data set at a time (more is too complex for them), others insist on at least two in parallel to get a “feeling” for the correlation between these vital data. Depending on their subjective health status or changes in it, they want to look at the data immediately rather than in a more usual weekly or even bi-weekly rhythm. And although a graphical presentation of time series data is clearly the preferred mode, one patient would rather look at the more familiar tabular form in which he was used to seeing similar data.



**Graph 1:** weight measures for one month

Graph 1, a graphical presentation of the daily weight of the patient, identifies a presentation format approved by all. This basic type of graphical presentation of time series data by a line connecting the daily values, and thereby allowing easy identification of changes in the value, was favoured also for all other relevant patient vital data. However, some detailed suggestions for improvement were made for easier comprehension by patients:

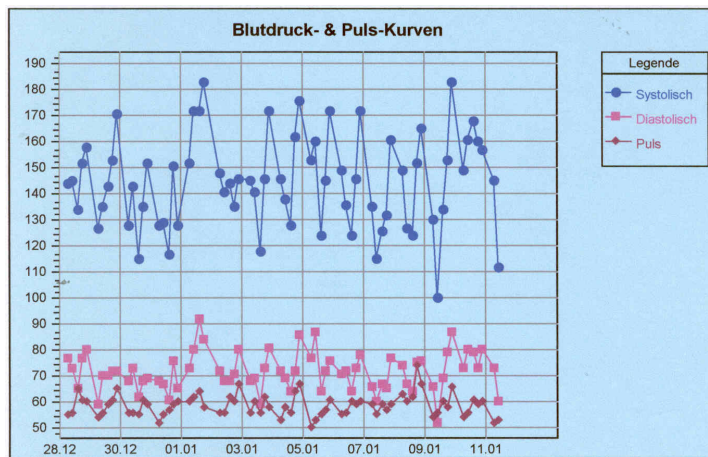
- Larger type of letters for heading of the graph, numbers on the axes, and legend.
- Clearer identification and naming of axes
- more contrasting colours and a thicker line to identify the upper and lower bounds of the values pre-set for the patient’s weight by the nephrologist
- more prominent identification of values lying outside of the pre-set boundaries (e.g., by a red flag, a flashing signal or similar).

In addition, patients very clearly voted for an option to have these data presented for different lengths of time periods and for earlier time periods.



**Graph 2:** Combination of blood pressure, pulse and weight chart on one screen

The same basic considerations apply to Graph 2, although here the heading of the graph is much more prominent and readable. Integrating the value for “pulse” into the upper graph was not regarded as useful, and this line should be deleted. Whereas some patients preferred the simplicity of to the more complex combined presentation of several vital data in, others voiced a very strong preference for having these data presented in tandem. This assessment strongly correlates with the age and activity level of the respective patient and his self-assessment as to whether he can use these data for himself to adjust behaviour, diet and even medication to return the measured data to the optimal level prescribed by the physician.



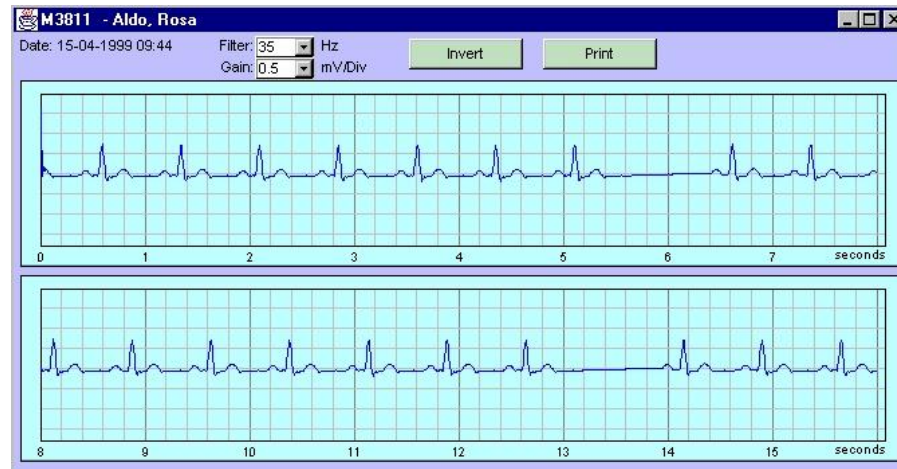
**Graph 3:** Blood pressure and pulse values, measured four times a day for two weeks

Graph 3 presents four daily measurement values for blood pressure and pulse. Again, the value for pulse was regarded as disturbing rather than supporting comprehension of these vital data. An option to stretch or draw out the values for the same time period over a greater width would be useful, and an option to somehow “relate” the respective systolic to the diastolic value was identified as perhaps useful to better understand the meaning of these data. Again, whereas some patients assessed this graph as very helpful, others were overwhelmed by its complexity and preferred the presentation of only the daily mean values as in the two preceding graphs.

**Table 6.** Blood pressure and pulse values, measured four times a day for two weeks

Trends für						
Telefon:		Alter: 56 Jahre		Pat.-Nr.: Dias 1		
Datum	Gewicht		Sys/Dia(Mitt)		Puls	
22.07.2001	95.8 kg	10:56	161 / 92 ( 150 )	00:44	75	00:44
			170 / 97 ( 155 )	10:58	66	10:58
			159 / 90 ( 136 )	13:44	69	13:44
			156 / 93 ( 131 )	18:27	66	18:27
21.07.2001	95.8 kg	10:45	148 / 88 ( 119 )	00:55	78	00:55
			155 / 92 ( 138 )	10:46	68	10:46
			155 / 87 ( 107 )	12:36	73	12:36
			156 / 84 ( 132 )	16:52	72	16:52
20.07.2001	95.20 kg	10:47	165 / 92 ( 144 )	20:56	69	20:56
			163 / 92 ( 147 )	00:44	72	00:44
			152 / 96 ( 129 )	10:49	72	10:49
			156 / 87 ( 126 )	13:16	72	13:16
19.07.2001	94.87 kg	10:13	146 / 85 ( 118 )	21:15	80	21:15
			159 / 91 ( 130 )	00:51	76	00:51
			150 / 92 ( 137 )	10:16	68	10:16
			151 / 91 ( 134 )	13:04	66	13:04
18.07.2001	94.33 kg	10:14	156 / 89 ( 137 )	17:16	68	17:16
			154 / 88 ( 136 )	21:45	69	21:45
			160 / 94 ( 131 )	00:59	72	00:59
			156 / 95 ( 134 )	10:17	70	10:17
17.07.2001	95.20 kg	11:08	145 / 92 ( 124 )	13:58	65	13:58
			153 / 90 ( 132 )	19:11	66	19:11
			184 / 98 ( 143 )	11:10	67	11:10
			145 / 90 ( 120 )	13:16	69	13:16
			152 / 90 ( 121 )	17:37	68	17:37
			152 / 87 ( 127 )	21:37	75	21:37

Although PD patients are used to seeing their data in tabular form, Table 6 was heavily criticised. The following recommendations were made: a better separation of the daily blocks of values (e.g., by a horizontal line or a gap); a clear identification of the meaning of each value (time is not identified as such); no abbreviations; deletion of the mean blood pressure value (which patients cannot put a meaning to); data measured at the same point in time should be on the same line. Data for a longer time period and mean daily values would also be helpful. But as mentioned earlier, most patients prefer a graphical presentation to such tabular presentations because it allows them to more easily and quickly identify trends over time which would indicate that some change in behaviour or medication is needed, and which identify critical values in an easy manner.



**Graph 4:** 16 second rhythm strip (one-lead ECG)

Graph 4 was rejected by all patients as not useful for them. This is the type of data they cannot make sense of, and experts were afraid that small irregularities like the one seen in this graph, but which - according to physicians - does not signal a real problem, would only unnecessarily disturb patients and even lead to bothersome phone calls to the physician.

## 5. Concluding Remarks

Having access to their EHR and being able to see selected vital data in such an improved form was highly welcomed by all patients. Although some preferred access in paper form, e.g., via a fax machine at home, others would welcome access via a standard computer and an easy to use, but flexible interface they are already used to, or on a TV screen with an easy to handle, very simple remote control<sup>1</sup>. Amongst the patients interviewed, there was none for whom this would not be a realistic option as long as the interface is easy to handle, uses large buttons and large characters etc. as outlined above. But of course, for severely disabled persons such as blind patients, this access mode would break down and a different interface had to be used.

<sup>1</sup> Already in the early 90s pilot applications showed that even very frail old (90) ladies can operate such a system, see Stroetmann and Erkert (1999).

**Appendix – Excerpt from the Patient Questionnaire**

Dear patient,

Your opinion is important to us and will help to improve our tele-monitoring devices and the presentation of your vital data on a computer or TV screen or paper, and to design them to your needs. We will visit you in person / call you to discuss the following questions / issues with you. We expect that this will take about 20 – 30 minutes of your time.

Thank you !

Study-No.: \_\_\_\_\_ installation date: \_\_\_\_\_

Investigator: \_\_\_\_\_ current date: \_\_\_\_\_

**Was the installation made punctually according to your appointment ?**

Yes       No      greater than:       15 min.       30 min.       60 min.  
 delay

**Are you satisfied in the way devices have been installed and explained to you ?**

Installation:                       Yes       No      if No:

Explanation:                       Yes       No      if No:

**Are the user-manuals and descriptions of the devices easy to understand ?**

not read       Yes       No      if No:

**Are you satisfied with the in-home placement/mobility of the devices ?**

Weighing:                       Yes       No      if No:

Home Hub:                       Yes       No      if No:

Blood Pressure-Unit:               Yes       No      if No:

Heart Rhythm-Unit:               Yes       No      if No:

**Do you feel comfortable using the Blood Pressure-cuff and Heart Rhythm-Unit-wrist bands ?**

Blood Pressure-cuff:               Yes       No      if No:

wrist bands:                       Yes       No      if No:

Are you satisfied with the way measurements are displayed and/or announced ?

**Weighing:**

Display:  Yes  No if No:

announcement:  Yes  No if No:

**Blood Pressure-Unit:**

Display:  Yes  No if No:

**Heart Rhythm-Unit:**

Light & Sound  Yes  No if No:

According to your experience, how easy are the devices to use ?

Weighing:  very easy  easy  not easy  difficult because:

Blood Pressure-Unit:  very easy  easy  not easy  difficult because:

Heart Rhythm-Unit:  very easy  easy  not easy  difficult because:

Overall, are you satisfied with the Home-Telemonitoring-Devices and how would you rate your satisfaction ?

Weighing:  very good  good  average  below average  worse

Blood Pressure-Unit:  very good  good  average  below average  worse

Heart Rhythm-Unit:  very good  good  average  below average  worse

overall impression:  very good  good  average  below average  worse

Would you like to have access personally to your data (chart and/or diagram) ?

Yes  sometimes  No

Remarks:

.....

**Note for the interviewer: As required, you may repeat some or all of the following questions for each chart/mock-up:**

With respect to having access to your own data, please have a look at the following graph/table/... (read the name/heading of the graph/table/... to the patient). We would like to have your opinion and discuss with you the following points:

which type of presentation do you prefer, which one is more readable for you?

.....  
.....

What about the overall quantity of data presented in this graph (or table)?

.....  
.....

Would you prefer to have these data only for a day, or rather for a week, or for a month, or ...?

- 1 day      1 week      1 month      other, specify:

.....  
.....

Do you want data on each of your relevant vital data at a time, or do you think, for yourself it would be more helpful to have two or more sets of data shown in parallel?

.....  
.....

What about the naming of the graph, of the data points etc. - would this be ok for you, or what would you suggest to be changed/improved?

.....  
.....

May we also ask you how you assess the size and type of letters used in this chart?

.....  
.....

And what about the use of colours to highlight some of the data or information?

.....  
.....

Is it easy for you to identify the upper and lower bounds/limits set by your doctor for your vital data in the chart? Is it helpful for you?

.....  
.....

How would you rate the overall presentation of data in the chart, is the overall presentation easy to understand, does it help you to guide yourself in better dealing with your chronic disease?

.....  
.....

Are there any other comments, suggestions for improvement you could make?

.....  
.....  
.....

*After having discussed all charts with the patient:*

To sum up our discussion of accessing your own health data, let me ask you three more questions:

If you could chose how to obtain your data, would you prefer the data on paper (e.g., via a fax machine), on your TV screen, via a computer screen, a mobile phone, or ...???

- Paper (by mail) \_\_\_\_\_
- Paper (by fax) \_\_\_\_\_
- TV screen \_\_\_\_\_
- Computer screen \_\_\_\_\_
- Mobile phone \_\_\_\_\_
- Other \_\_\_\_\_

Would you prefer to receive them daily, weekly, or in a different interval? Or would you rather chose yourself?

- daily
- weekly
- different interval
- chose myself

If different interval, please specify: \_\_\_\_\_

Would you like to make any other suggestions or remarks helpful for you to better look after yourself?

.....  
.....

Last but not least: Do you have further comments not covered by the questions, or any remark you would like to mention here?

.....  
.....



In your household, do you personally access/use regularly:

<b>TV</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Yes	sometimes	No
<b><i>If yes, do you use teletext?</i></b>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Yes	sometimes	No
<b><i>Fax machine</i></b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Yes	sometimes	No
<b><i>Mobile phone</i></b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Yes	sometimes	No
<b><i>Computer (PC, laptop or similar)</i></b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Yes	sometimes	No

Please provide us with some information on your personal situation:

Your age: \_\_\_ years      Gender:      Male       Female

Primary (chronic) disease:

.....

Any secondary disease: .....

.....

New technologies can be complex and demand perfect vision or nimble fingers. What has your experience been? First, ...

..on some machines you have to touch on a screen. Do you find using touch-screens easy, somewhat difficult or very difficult - or have you not tried?

easy                      somewhat difficult                      very difficult                      Has not tried / no experience

What about using your fingers to use a credit or similar card, when using a cash point, making a phone call, or paying for goods?

easy                      somewhat difficult                      very difficult                      Has not tried / no experience

...and typing, say, your name, on a keyboard?

easy                      somewhat difficult                      very difficult                      Has not tried / no experience

Thank you very much for your co-operation!