Can Patients Participate in Designing Patients' Health Cards?

Claus Stark
Institute of Sociology
Technical University of Darmstadt
Darmstadt Germany
+49 201 825 2808
cs@computer.org

ABSTRACT

Since Summer 1995 a pilot project on patient's card has been running in Neuwied and Koblenz / Germany. On the basis of this project, we initiated another project on the role of the patient in designing this patient's card. With the help of this project, we wanted to activate the discourse among patients' groups about patient's cards. Another aim was to find out whether their participation in such card project could be possible. Despite high interests from patients' groups of our participation project, their participation was prevented due to several problems.

Keywords

Patient, Patient's Card, Participation, Patient Oriented Design, Smart Card Applications, Health Care

THE ROLE OF THE PATIENT IN DESIGNING PATIENT'S CARDS

"Where is the Patient in Patient-Centered and User-Oriented Design in Health Care Systems Development?" - this question was asked at the PDC'96 [1]. It was not possible to answer this question satisfactorily. This is also the key question of a research project at the Technical University of Darmstadt which focuses on patient's role in the development and assessment of the patient's card (a smart card with medical data used by the patient). The main aim of our project was to find out the patient's interests in evaluating and designing the patient's card, at the same time encouraging him to safeguard his or her interests in designing technology in the Health Care System.

It has been emphasized by the initiators of several patient's card projects that the main purpose of introducing medical card systems is for the benefit of the patients. But patient's view is not considered as an important research field (for exceptions e.g. refer to [2]). There is also no broad consent regarding the advantages of these cards in the society: Due to the introduction of the German Health Insurance Card in 1995, the Association of Alternative Patients' Offices in Germany is taking efforts to discuss not only the prospects and promises but also the social risks of this new technology [3].

Since 1995, a project on patient's card has been running in the small town of Neuwied / Koblenz in South-Western Germany [6]. It is initiated by the *Federal Association of Health General Practitioners*, the *Local Association of Health General Practitioners Koblenz* and the *Federal Association of German Pharmacists Associations*. Aim of this project is to define and design the patient's card from the professionals' point of view. From 1995 till 1997 we discussed with various patients' groups (e.g. *AIDS-Aid, Association of Rheumatic Patients, German Association of Haemophiliacs* and *some Diabetes Groups*) regarding their interests on the Patient's Card Koblenz/Neuwied explicitly from the patient's point of view [4], [7] - [12]. After one year of practical work with local patients' groups and members of the card project in Neuwied and Koblenz, we finished our work. The relationship between the card project initiators and our working group was very formal. A constructive teamwork between the patients' groups and the card project group could not take place.

SMART CARDS IN HEALTH CARE

Smart Card Technology

A smart card is a complete microprocessor-system, which is embedded in a plastic card (like a credit card). It is

called "smart", because this plastic card has its own "machine intelligence" on board: A microprocessor, various kinds of memory (e.g. ROM, RAM, EEPROM), a standardized input/output-interface, a card operating system and application software. The memory of a smart card is actually very restricted because of the restrictions on the very small physical dimensions of the chip (approx. $20mm^2$, actually < 20kB). A smart card has normally no direct user-interface with keyboard and monitor, but only one serial input/output-channel. The user has to use a smart card terminal to connect the computer (the smart card) with the user-interface (normally the user-interface is integrated in special application software). The combination smart card and user-interface is a complete personal computer. A smart card has normally a complete operating system with access control, memory management, file management, I/O-management etc. Some smart cards are able to use cryptographic algorithms for encryption- and digital signature-schemes. This option is very important for some "legally binding"- applications (e.g. electronic presecription, health professional card), and applications using public key cryptography (e.g. for encryption and digital signature).

A smart card is a very small, but complete computer system with own application software (e.g. database), which a user can bear in his / her wallet for several applications. One of such applications could be the patient's card. One card can be used for several applications (the multi card, e.g. banking card, credit card, social insurance card and patient's medical data card on one card).

Projects on Patient's Card

Since the introduction of the administrative Health Insurance Card in Germany in 1995, several projects on patient's cards have been planned (but only few were tested because of different political, social or financial problems of the initiators):

- *ACard* for Pharmacy Applications (with digital signature-functions). Medication Cards should help to prevent incorrect prescriptions and incompatibilities. No special target group, everyone can use this card.

- *Berlin Health Passport* for prevention of diseases. No special target group, everyone can use this card.

- *Vital Card* of the German Health Insurance Company *AOK*. Medical Insurance Cards should help to cultivate "healthy lifestyle" among the insured people.

- *DiabCard* for diabetes patients. This card contains a very specialized data set for the treatment of diabetes mellitus.

- *DefiCard* for heart patients. This card contains a very specialized data set for the treatment of patients with a implanted defibrillator.

- *OncoCard* for cancer patients. This card contains a very specialized data set for the treatment and rehabilitation of cancer patients (oncology).

- *Bayer Health Card* with several applications (e.g. monitoring in pregnancy, patients with heart-diseases, patients with diabetes).

- *XRayCard* for saving x-ray pictures and x-ray-exposition passport. No special target group, everyone can use this card.

- *DentalCard* for saving current dental status (e.g. alloy-passport). No special target group, everyone can use this card.

- *QuasiNiereCard* for kidney transplantation.

- *Medical Patient's Card Koblenz/Neuwied* for multi purpose medical applications, which is tested by the practitioners. No special target group, everyone can use this card.

These cards contain not only administrative data (e.g. name, address and insurance number) but also medical information e.g. diagnoses, therapies, allergies etc. There are also card applications for special patients' groups (like diabetes- and cancer- and other chronic patients) as well as for general purposes for the whole population (e.g. ACard).

The project on the "Health Professional Card" should provide administrative smart cards for employees in the Health Care and people in private practice.

PATIENTS AND PATIENT'S CARDS

In all German projects on patient's cards project information and participation of citizen and patients plays a secondary role. The local and supra-regional patients' groups were not considered. Our experience with card designers is that they avoid working directly with the patients' groups [9]. But the designers need not fear patients: Patients' groups are very interested in the technology of patient's cards and would like to contribute in designing [11].

Actors in Health Care

Who are the real designing actors? Who gives a first concrete form to the abstract object "patient's card"? Who possesses the "structuring power" in the health care? To answer these questions, we should focus on active groups in the Health Care [13]. With the help of policy field analysis, two categories of groups can be identified: Active "professional designers" and the majority of passive patients' groups.

There are several actors in the Health Care namely Medical Practitioners, Nursing Staff, Patients, Researchers, Pharmaceutic and IT-Companies, Health Ministry, Health Insurance Organizations, Legal Advisors, Economists, Medical Informatics Institutes etc.

These groups can be further classified into two categories: "Professional" and "Patient". The "Professionals" can be easily identified by their profession. They can represent their professional interests in well organized ways. The second category, however, "Patient" is enigmatic. Everybody is patient, but at the same time no one is patient from "profession". And this is so, although the majority of society is represented by this category, they have less influence in decision making in Health Care.

Professionals

There are several professional groups with different attitudes towards new technologies:

- General Practicitioners: The main German association of the settled practitioners, the *Federal Association of Health General Practitioners* in Cologne, currently coordinates several smart card projects. The physicians want to lead the designing process, i.e. it is not very attractive for them to leave this competence to the health insurance organizations. The *Federal Association of Health General Practitioners* want to improve the working conditions for the physicians and want to avoid medical controlling by Insurance Companies and Public Authorities.

- Health Insurance Organizations: Their basic interest is to reduce costs and to improve quality of medical treatment by rationalization of administrative and medical processes, control of costs, detection of misuse and bad quality in treatment process. Besides this, there is strong competition among the different companies.

- Other Professionals: The pharmacists are organized in their own Federal Association. The main task of this association is to strengthen the pharmacists' role in the pharmaceutical market. They developed their own card applications for medication (*ACard*) and for electronic prescription, among other things to defend the pharmaceutical competence against the drugstores. Nursing staff can represent their interests in their own organizations. They don't play that important role in developing patient's cards and health professional cards.

- Industry: IT-Companies want to sell their basic products and want to conquer new markets in time.

- Research: Medical Informatics Research focuses mainly on the technological and organizational aspects of card applications, however there is less research on technology assessment.

- Privacy: The German federal working group of the commissioners of privacy and data protection formulated some strict resolutions concerning medical smart card applications. They were invited for guidance in several projects.

Patients

The present work focuses on the main group involved in the Health Care System "the patients". They are the main target group for using patient's cards. Yet there are very different groups of "patients" indeed:

- Unorganized Patients: The main group of citizens and patiens. It is difficult to reach this group for participation.

- German Federal Working Association "Aid for Disabled People" (BAG HfB): The BAG HfB is the main national parent organization of patients and disabled persons groups in Germany, representing over 70 organizations.

- Different Patients' Organizations: There are different groups with their own aims and organizational forms. One possible categorization could be:

  - First Contact Groups (e.g. AIDS-Aid)

  - Talking Groups (e.g. Alcoholics Anonymous)

  - Therapy Groups (e.g. Society of Haemophiliacs)

  - Legal Assistance Groups (e.g.

General Patient Union)

These are the groups coping with special aspects of diseases and disabilities. These local patients' organizations are the main target groups for our participation project. But it was difficult to convince them to participate in our project, because partially they are only sensitive to questions of their immediate interest.

- "Health Stores" and Alternative Patient Offices: In the 80ies, people from the so called "alternative scene" wanted to initiate a new medicine paradigm on a more democratic basis - and founded health stores in several German cities. Their main working field at present is to do counselling of people with legal as well as medical problems. However, they also criticize the established medical business on a structural level and formulate alternatives in health policy. In 1994, they demanded open discourses on new technologies in the Health Care System, especially on medical smart cards. As they are resolutely against IT-technology, it is difficult to convince them to participate in our project. Their arguments (concerning social problems with technology) and their suggestions (concerning alternatives in aims and technologies) are very valuable.

In our participation project, we focused on the "organized patient" in a patients' group, because he is very interested in improvements of the health care system, he is engaged in acting as "patient", and it is relatively easy to reach him (via adress list from the local public health authority). It is very difficult to reach (more or less healthy) citizens in his role as patient (for that use representative methods can be used, e.g. via random selection).

Interests in Card Designing Process

In developing concrete aims for usage Information- and Communication Technology provides a broad scope for design. Technology is always embedded in a social context and that is why it cannot be evaluated without it. It is interesting to observe which problems in the Health Care have preferences. For that it is necessary to know the aims of the current projects - and ask : Can Patients be satisfied with these aims?

Aims of Card Projects ...
The main aim of many of the card projects is for the

"benefit of the patient", which is somehow a very abstract aim. But it seems this aim is less important than "cost limitations" and "customer bonds" (which are rather more concrete aims). This is illustrated in the following examples:

- ACard: This project has been running since 1995 by the Federal Association of German Pharmacists' Associations. Although the purpose of this project is to support the medical practitioners for better prescriptions of medicines, however in the actual practice they are not supposed to save medication data on this card. Besides this, another important aim is to compete with drugstores in the pharmaceutics market.

- AOK Vital Card: In 1995, all members of the AOK (a german health insurance organization) in the district of Leipzig (approx. 500.000 members) were supposed to get a medical smart card. This card was to support "healthy" lifestyle among the insuranced people. But this concept remainded undiscussed in time with the other actors in this area (e.g. the other health insurance companies, public health authorities, physicians, pharmacists, hospitals, privacy, patients' groups). Actually this card was designed only by the AOK in order to be more effective in competition with other medical insurance companies.

Both cards were to be useful for patients and citizens. But in its designing process patients interests were hardly considered - whereas commercial interests are dominant. This may be legitimate, but might lead to card solutions with less usefulness for patients.

... and Designing Options
What can patients contribute in designing the smart cards? What are their interests? This should be clarified in a discourse, which has not been realized till now. Many design solutions can be considered at different levels such as: Organizational and legal frameworks for card application are equally as important as with technical aspects of the card operating system and the access programs. Such cards can be designed in various aspects such as: Data security, privacy, personal autonomy, safe medical treatment and perpetuation of evidence for trials (e.g. concerning "professional blunder"). Some of these aspects are discussed below - It could be possible that other interests are more relevant.

- Definition of data: In general patients' groups are well informed about the relevant data. They can discuss with the professionals what kind of data structures are meaningful for different card applications.

- Who is allowed to read, write and delete the data? Should the patient read the card? Or should only the practitioner be able to read and write data?

- Access control: How can we protect data from unauthorized persons? Family members, other physicians, inspectors from government or insurance organizations can ask for access to the data on the "personal" patient's card. Is it possible that the patient protects different types of data (administrative data, emergency data, treatment data etc.) in different ways? Or can every practitioner have access to the entire data set?

- Can the medical data stored on the patient's card be confiscated by the public prosecutor? Acutally medical information stored on a smart card is not subject to professional secrecy. At present it could be a legal risk for patients to carry compromise information on a patient's card.

- It can be very important for a patient to have access to his/her own medical diagnosis and treatment data (in order to perpetuate evidence, e.g. for trials). Can the patient expect from his physician to save his medical record on the card - on demand?

- Name or pseudonym? The entire identity of the card bearer can be stored on the card (e.g. name, adress, insurance number) - or pseudonyms [5] could be used to reduce the risk of personal discrimination. The concept of pseudonym allows the card bearer to act quasi-anonym in different transactions (like medical treatment). The card bearer's personal identity can be uncovered only in a very controlled manner (e.g. if misusage of the card is evident).

- Can the patient determine the keys used for patient's card (e.g. the changing of PINs, keys and algorithms)? Exclusive determination of the keys by the patient (or via a trusted trust center) could be useful if he cannot trust the cryptographic keys anymore (this could have been broken or otherwise compromised). It

may also possible that his PIN can be spied out. So it is important that the changes in the access secrets (e.g. PIN) should only be done by the bearer of the card.

- Should it be possible that the patient can open or close data sets at the physician's computer system with his patient's card? This could be a very attractive option for a patient's card, because personal medical data is only available for the professionals, when the patient unlock it with his card. The pros and cons are not yet discussed.

- Patients can demand, that data can be stored on the card with their permission only.

- Patients can learn, what kind of information is important for them and how to manage it by themselves in the sense of "data autonomy". If data would be stored unintentionally on the patient's card without his permission and knowledge, this could mean his disqualification from a subject - with equal rights among the other actors in health care - to an passive object of these actors.

- The right of non-submission of the card could be demanded: It can be possible that the patient is forced by physicans to give the card, e.g. for anamnesis. Opinion of our working group was that submission of the card should be voluntarily, without any legal pressure.

- Training for the qualified use of the card for patients, practitioners and other health professionals. Often basic privacy rules are neglected unknowingly by the health professionals (e.g. "leakage" of private medical informations by the professionals in the practice during medical treatment of the patient). Training could be very important for sensibilization on privacy problems.

- Is use of the card for the patients compulsory or voluntary? Compulsory use is wished by different actors like physicians, with compulsory use of several structured data items (e.g. standardized emergency data set). The arguments of the physicians, leaded by their professional medical responsibility, that it is not possible to trust "any unsystematic and random data collection of medical data" (e.g. which are selected by the patient on his/her own criteria). Some patients' groups are resolutely against compulsory patient's

cards, because they fear lots of control over patients from the health care professionals.

Problems

In 1995, in Koblenz we conducted a "future workshop" among the members of the local patients' groups. In this workshop, we could find out some basis problems which make effective participation very difficult:

- Financial problems: Who should take over participation charges of the patients' groups? The groups are not able to finance their participation. **The initators of the card project refused to take over the charges. In our project, we financed the meetings of our working group from the funds of the Technical University of Darmstadt.**

- Schedule problems: Most of the groups are working on a honorary basis. As a result members have very little time for their activities which are not very close to their genuine work. Development of a patient's card is a very strange and unfamiliar theme for most of the members of patients' groups. Our participants from patients' groups were very often technical professionals like engineers (with active interest on technology). It was very difficult to interest the "non engineer"-patient for our project.

- Information problems: How can citizens and patients get current and adequate information about the projects, technologies and relevant social aspects? The direct participation of our representatives in the meetings of the card project initiators was refused by them. Aditionally we could not get direct and valid informations from the card initiators concerning aims, strategies and technologies (except published materials).

- Conflicts between actors: How can conflicts during the participation process be fairly solved? Without any predefined solving procedures on conflicting aims our working group did not believe on fair conflict solving. The only real option for patients' groups seemed to refuse cooperation with the other actors.

- Does participation makes the development of alternative solutions difficult? People who are working on patient's cards are not able to work simultaneously on card-alternatives due to

lack of time.

- Participation as alibi: Is it not that participation of patients' groups serves only the acceptance provision and the legitimation of patient's cards? Our working group expected active and serious participation in the development process, and they were not accepted only acceptance provision for the card project. They realized the risk, that their only task could be to agree the concepts of other actors, to give a acceptance certificate ("Card is examined and accepted by representatives of the patients") without own opinions in the development process.

- Is there actually the need of the patient's card? Perhaps smart cards are principally not suitable to solve the general problems in Health Care? The first question to be answered is that , what kind of real problems in the Health Care System exist. Answers to this question depends on the actor. Some members of our working group wanted a fundamental discussion on computerization in the society, before they solve technical details like user-friendly access control for patient's cards.

- Legitimation to speak for "The Patient": Organized patients from the patients' groups a very small minority group in the whole social group "patient". Are patients' groups as a minority legitimated to represent "The Patient"? Our working group in Koblenz/Neuwied was not elected in a democratic manner as a "patient's speaker" to represent patient's opinions and interests.

Further reasons preventing participation:

- Too many projects running simultaneously. To participate in all important projects is difficult for the members of the patients' groups due to their time and financial restrictions. On the ranking list of these projects a participation project on patient's card is possibly not very important for them.

- How is it possible to measure success of participation? Our working group did not believe that technology is so designable that patient's interests can really form technology. So PD must show to the interested potential participants what kind of designing options are really available for them.

- Necessity of representation: There are various

kinds of patients (in a sociological manner). Patients, who are organized in patients' groups are only a very small part of "the patient". PD should reach all these groups to get representativity.

– Suitable choice of participants and adequate methods difficult. PD must be organized professionally at the beginning of a technology project. Are representative methods (e.g. consensus conferences) more adaequate than methods with involving people concerned (e.g. future workshops)?

– No change of "ill" structures in the Health Care System through smart cards. According to the opinions of some members of our working group improvement of our Health Care System without discussions on its fundamental structures is not possible. Only after social consent on these fundaments, development of technology (which supports this "healthy" structures) makes sense.

– General thinking on privacy. It is difficult for patients to decide wheather smart card applications are dangerous concerning privacy, or if smart cards are one of the building stone of effective self-determined privacy. Privacy is a very important theme on patient's card applications.

PLAY YOUR CARDS, PATIENT !

Applications of smart cards are very important in many social working fields, e.g. in Health Care. Very often they are misused for marketing purposes and policy enforcement in certain professions.

In order to get useful applications of smart cards in the society it is necessary to implement the broad discourse among the different actors in the specific application fields. This should be achieved not only with the help of technical and medical experts but also with the affected groups and randomly selected citizens.

Since 1995 the German Federal Working Group on "Smart Cards in the Health Care System" has been dealing with planning, testing and introduction of card systems in the German and European Health Care System(s). This working group consists of several representatives from various fields (e.g. Medical Practitioners Associations, Medical Insurance Companies, Technical groups, IT-Companies, Card Companies, Politicians, Privacy Commissioners etc.) - but not from patients' organizations and employee unions. This working group can play

important role in balancing interests of all social groups in card designing. For that, the working group must also be open for critics, patient organizations and other important actors.

One of the answers to the question asked in the PDC'96 about the role of patients in the Health Care Systems development may be: Patients are not yet enough integrated in the designing process. In future, this need to be done in order to get socially compatible, democratic and healthy structures in the Health Care System.

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