

Patient Participation Accross the Digital Divide in Norway

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Abstract

The emergence of electronic healthcare records is an important step to allow patient participation in healthcare. Patient contribution improves the quality of healthcare information. Records, and other information, must be structured to allow this involvement. The information entered by patients may need some monitoring by professionals to ensure its quality. In Norway, the closest thing, yet, to electronic patient participation is the emerging "Individual Plan". We review experiences with patient participation. We discuss whether all access to the the plan should be electronic. Printing out the plan will be necessary. Professionals should only update the plan through the web to ensure consistency of the plan and keeping it current. Since patients (plan owners) may not have the same access to computers and the Web, they should be given some form of access as an alternative to electronic access. The simplest access method would be talking to a professional coordinator.

Keywords: Electronic health records; Personal health records; Patient participation; User Involvement; Individual plans

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1 Introduction

The development of electronic healthcare records (EHRs) and the widespread availability of the Internet may provide patients with a quick way to read their own records. Also, patients themselves may be allowed to enter information into the record, update it and correct errors. Trials with network patient participation in records have been conducted, and some systems are already in full scale use. In Norway, patient access to and input of healthcare information has been hampered by concerns over information security and privacy. However, there is an ongoing project that seeks to allow patients, healthcare providers and other public service providers to make an "Individual Plan" for the patient, or "plan owner". This project may be used as a learning example or "proof of concept" for full scale access to medical records. We claim that:

- Allowing patients to contribute to and correct their own electronic healthcare information will improve the quality of the information.
- Even patients without access to computer networks and computers might be able to participate to some degree.
- Patients/clients should be provided with an alternative to computer access.

This paper will try to show to what degree these claims have been substantiated, and how the situation could be improved.

The method we will use:

- We will search for and study relevant literature on the subject. To be selected for review, a reference has to fit within one of these categories:
 - The transition to EHRs in Norway, and state of the Norwegian healthcare system.
 - Patient participation.
 - Individual plans in Norway.
 - Example of technology that could support participation.
- We will describe the challenges in making information accessible for viewing and updating by patients with or without access to the Internet.
- We will propose solutions for those challenges. We may use the Norwegian electronic "Individual Plan" as a case example.

2 The EPR

In our preparation for looking at a development of the individual plan we conduct a short pre-study of the Electronic paper record, EPR. We look at the situation a few years ago, the situation today, make an short comparison of these two and the work that has been done and need to be done to transition from paper to electronic records.

2.1 The situation a few years ago

To get an overview on the development in the work on EPR we have looked on a report done in 1998 by NTNU students [NPAS98] for KITH [KIT03] in making a prototype of an EPR. At the time this report was written all records made by health personnel had to be stored as paper regardless if the information was stored electronically. None of the computer systems of that time stored all the information needed in a patient record. So the systems that were in use contained just part of information. The work on composing a standard had just begun with the KITH project "Mer helse for hver bIT" started in December 1997, see also [KIT03]. Because of the lack of standards the different projects of building EPR systems were roughly independent and varied in functionality and user interface. The lack of a standard also made communication between the systems at best difficult. The goals for EPR at time were to give a better information and decision basis for diagnostic, treatment, follow up, research and quality assurance. Other functionality goals were overview over treatment progress and other ways to sort documents.

2.2 The situation today

The most important difference today is the approval of EPR as the only form of documentation. The work on the EPR is currently more organized than some time ago, because of amongst others KITH, in regards to cooperation and standardization. The EPR is in use in every hospital and general practice, though most of them still have a paper record as well. The increasing use of electronic referral and discharges (epicrisis) is also an important difference. The possibility to communicate on a secure and standardized platform has lead to that electronic discharges can be sent by almost every hospital in the north, west and middle of Norway, and some in south and east. The same goes for the possibility to receive electronic discharges. There is a little more work remaining regarding sending/receiving referrals, this according to presentation made by KITH[HL03]. Having a electronic record has a lot of benefits, but there are also some expected benefits which aren't true. In his study [Lær02] done in 2002, Hallvard Lærum doctorate student at NTNU, comments on a few truth and lies regarding the EPR. Those are:

- The systems are standardized and structured compared to clinical practice.
Lie: They are document based sorted by Piene-distribution ("Norgesjournalen").
- The systems gives better access to information.
True: Even if downtime occurs the record is rarely "missing".
Lie: No hospitals has implemented mobile solutions in a bigger scale, and no hospitals has a PC in every patient room.
- Hospitals save money.
Lie: Initially the hospitals have invested a lot in infrastructure (PC, network, etc.) and education of personnel.
Lie: The real time and resource savings is not yet in place.

- The patient records are paperless.
Lie: Only one hospital have been given permission to destroy the paper records (Aust-Agder, Arendal), the rest has both paper and electronic records.
True: Main parts o the record is in digital form (primary record, discharges, lab reports)
- EPR is used by nurses
Lie: Nurses has just general functions and reading access to the systems.
- EPR is used by doctors
True: Is used for reading primary record and lab reports
Lie: Is nearly not used for anything else.
- EPR is spread amongst every hospital
True:67 of 70 hospitals has licensed for EPR, EPR are implemented for doctors in appr. 80% of bedposts
Lie: The systems are incomplete

2.3 What is done? What remains?

To get a brief overview over how work is done to make the old paper record exclusively electronic we have looked at work done at Agder sykehus, where the record system is exclusively electronic as the first hospital in Norway. First of all the old paper record is no longer updated, this implies that all new paper is being scanned. At the same time all old paper is being scanned in order to make all the old records available in digital form. This method has been proven to give some difficulties. Scanning of old paper record has stagnated due to the need of scanning new incoming paper (test results, referral etc.).The paper records are therefore not destroyed in a desired speed. Also, the scanned record, except from single test results referrals etc, is stored as a single file and searching in this is done manually by reading and scrolling. Another problem that have to be addressed is user interface; for the moment everybody uses the same user interface and this means that a lot of uninteresting functionality and information is displayed. There is also the problem in updating the record without the need to be in an office with an computer. All work that is done has as a goal to get time and resources used in a way that it benefits the patient.

3 Patient Participation

3.1 Experience with Participation

Studies have shown benefits from allowing patients to access and update their own medical information[TS01]. A Dutch study[LBM02] found that, during interviews, patients provided corrections and new information to their records. Most of the information patients give is correct, but may conflict with some standards.

Web-accessed systems will allow patients to do this at their leisure, from home or from work. Computer literate and interested patients find access to be valuable, making interaction with clinicians more effective [CPK02]. However, those not familiar with computers have some difficulty [KSP+03]. EHR systems have traditionally been made for clinicians, and this should be remembered when opening them up for patients [WL03].

3.2 Accessibility

In Norway, as in other countries, Internet access is less common in the households of the retired, older people and those with low income [Nor03, Table 1]. Thus, only allowing Web access to a system could potentially exclude some of the most important users. During design of new services, access methods for those without Internet access and computer experience must be designed as well.

4 Individual Plans

In Norway, Web accesses to electronic health records (EHRs) will not be possible for some time. The idea of making complete medical records available to Norwegian patients on-line has raised many security and confidentiality issues. Norwegian Law does not yet allow this to happen. The individual plan has been chosen as a project to precede a Web accessed record; this is because it is more light-weight application than an EHR; it may also meet less legal resistance.

4.1 What is an "Individual Plan"?

Many problems are caused by the lack of coordination of different healthcare, social and other services. Services might over-lap each other, they may interfere with each other, or important things may not be done because of confused responsibilities. Service users might describe this as being "tossed like a ball" between service providers.

To improve on this situation in Norway, a government regulation was passed [oHA01]. This regulation states that people who need long term coordinated care and assistance are entitled to an individual plan. The responsibility of creating and maintaining an individual plan is most often placed on one of the local municipal/town authorities (not county municipalities), who are responsible for primary healthcare, primary schools, nursing homes, psychiatric care and other local services that people need. If not handled by the municipalities, plans are handled by state funded hospitals or psychiatric institutions. [oHA99] explains Norwegian healthcare organisation anno 1999; the state has since taken over hospitals from county municipalities.

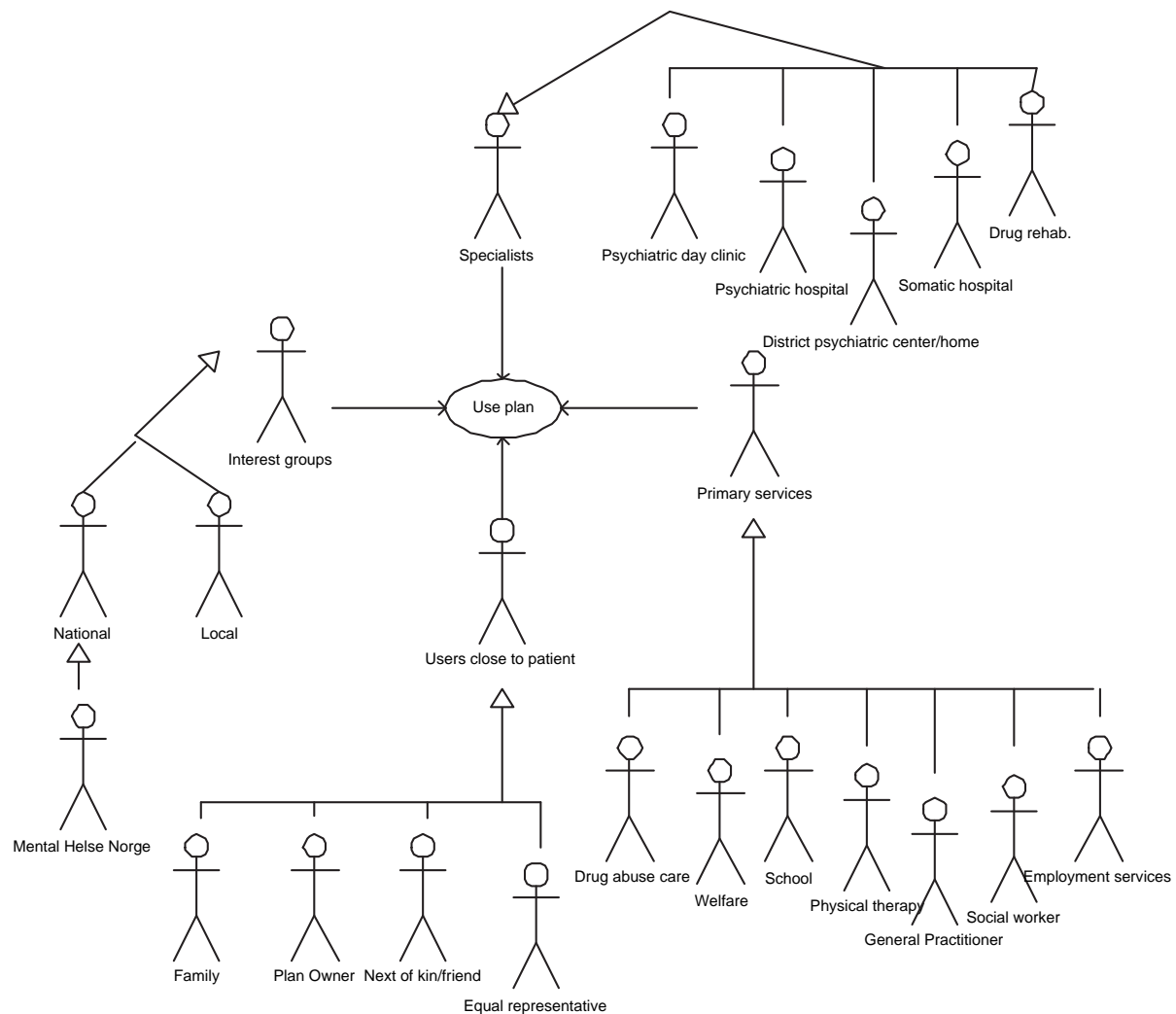


Figure 1: Users of individual plan.

The individual plan is cooperatively developed by the care and assistance providers, the "patient" and friends and family. The "patient" is usually called a "plan owner", because people who have an individual plan are not necessarily given healthcare services. Figure 1 (translated from from [RM03, Slide 46]), shows the roles that will be using the plan. The work is overseen by a coordinator. The professional with the most contact with the plan owner is usually selected as this person. The coordinator has to keep the plan up to date, and make sure that all the participants are reporting on their progress and evaluating the plan. Today this plan work is mostly done on paper, sometimes made on a single-user computer program with some file sharing capabilities.

Evaluation of existing solutions has shown that many municipalities struggle to shoulder the responsibility. The plans have a tendency to be forgotten, outdated and never evaluated [AAF⁺03, p. FS-4 - FS-5]. To alleviate this situation a project called Sam-Pro has been started [RM03, slide 39].

The individual plan is a good case for the study of patient participation, because it involves cooperation between people inside and outside the medical profession, including the patients (plan owners) themselves [RM03, Slides 13,18,40–46]. This application also has some potential users without access to or knowledge about using computers and computer networks. In addition, a web based system currently under development. This project, called SamPro, was started by the Norwegian Ministry of Health and Social Affairs, and co-funded by the Research Council of Norway. Even though the The SamPro project is smaller than a full EHR system, it has to stay in dialogue with governmental agencies about security [RM03, slides 8,39].

5 The hard copy dilemma

Having an alternative access method is necessary, but could cause problems.

5.1 Representing electronic information on paper

If stored electronically, it can despite be necessary to have information about, or from, the individual plan on paper. This can be the case, if one participant (e.g. the plan owner, a doctor without a computer) doesn't have access to a computer or Internet. In order to have the information present, this participant needs a printed copy of the information on paper. Printing out and posting all the info can take a lot of paper and time and hence money. And it is also an additional burden for the environment. If the electronic individual plan has support of a document archive, this archive could have stored video, animation or audio files. E.g. a practitioner could have made a video or audio record with the plan owner and added this record to the document archive. To print the information covered by these files would hardly be possible, and therefore this information could only be accessed with an computer. Another difficulty would be that the way to represent electronic information can be changed very easily. If there is a time line overview of tasks the plan owner has to perform, one can easily switch between monthly, weekly or daily view. And when clicking on a task, detailed information about it will be shown. This will hardly be possible on a paper copy. There one would have to make a list with all tasks, one after another, but one would lack the overview. Furthermore electronic data can be sorted or grouped e.g. after date, name, etc. Once printed out, information on paper will not change its view. Paper plans do not send out alerts and communications. This aspect will also be lost on paper. Another issue is the security problem. Making a lot of paper copies of some electronically stored information could easily lead to security problems. The people handling the papers could misplace them or treat them heedless in general. The slow speed of transaction is another disadvantage of paper, since electronic information can be sent much faster from one place to another. This may not be of great concern, because all the participants of the individual plan, who need information fast, usually have on-line access. After all, the biggest problem of not having electronic access to

the individual plan is updating or adding information. This is done rather easily with on-line access to the plan. But if a participant (e.g. the plan owner!) doesn't have this, they would need somebody else to do these updates and additions on their behalf; updates would also be needed to be mailed out. If the plan process is allowed to revert to paper, the plan will become inconsistent or be forgotten altogether.

5.2 Solutions

There is no discussion that there are disadvantages for a participant of an individual plan without on-line access to the plan. But nevertheless this may be necessary. So how can one make the disadvantages as small as possible? The biggest problem is adding or updating information on the individual plan. If the plan is stored on-line, a participant who wants to make updates needs on-line access. If he or she has no direct access, he/she needs indirect access, i.e. an intermediary.

5.2.1 Paper updates

To avoid inconsistency, all professional participants, in plan work and medical records, should be required to only change the electronic version. Printouts of "emergency plans" should be allowed. Patients/plan owners without the ability or access to the Web could be allowed to update the plan on paper. This could be read electronically, but involves investments in equipment and a question of who is going to make these. It's also a problem that it may be too formal in a way that the patient is not able to describe what he/she really intended. An other possibility is writing "essays", but this very time consuming for the patient, it also implies a problem in who is going to make (and how to) this information available electronic. Also, there is the problem of this information being too little formalized and difficult to interpret, so the benefits could vanish. The best way contributing in this case will be something between these two edges. Where the patient is to be given more specific task about what shall be written and how. For example a standardized form which can include some possibility of writing in own words. The most important issue here who is going to process this information so it becomes available in the record. Since every patient with an individual plan have their own coordinator this could be his/her responsibility to make sure that the patient has only one access point to his/her plan.

5.2.2 Telephone as a possibility

If there should be any need for a real time update on information there can be given a possibility of making a telephone call to the coordinator, or some sort of hotline similar to how banks operate with the telephone. For a medical record, this could be the front office of the General Practitioner. (A case scenario will be if you call up your personal hotline, after you have given in your social security number, you will be given the chance of give in test results, give in an update on your physical state, change

appointment. In the future you also might be able to have a mechanism who can make your speak message digital as you speak, as an example of this is [A/S03] who have made a dictation system which transform speak into writing.) The possibility to talk to a person when calling is in any case necessary because of the need for human-human interaction in some cases.

5.2.3 Other possibilities

- Plan owners could solicit the help of friends and family to access their plan. This could be a social and practical solution, but it may be hindered because some households have no Web access. Another serious problem is that some people are too modest to ask for help, even for serious problems.
- Plan activities could be conducted during appointments with or home visits from a care provider. This person could also be a voluntary helper aranged through the municipality.

6 Conclusions

Patient participation is a good method to increase the amount of data in healthcare records and other information carriers. The information should be supervised to maintain quality, and this could mean more work for professionals. Hopefully, this work will be somewhat offset by more efficient patient encounters and more relevant information. We believe that health care professionals and other professional participants in record and plan work should have access to computers and the Web at their work place. They should work with the individual plan on their computers. Emergency information printout should nevertheless be accessible.

Plan owners and other care receivers may not have access to a computer and therefore need a hard copy version of the individual plan. If they want to make updates/changes this should happen through a health care professional (plan coordinator would be best). They could arrange a meeting, and the professional updates the plan. Other possibilities are updates with paper forms or by telephone. Individual plans have less information and fewer updates during their execution, than an EHR would. Thus, it may be easier to find alternative methods for the plan than the record.

We recommend that the choice of updating method for the "dis-connected" plan owners should be taken only after hearing the plan owners themselves, and performing usability testing. The field of user interface design extends beyond the design of computer implemented interfaces, and can inform the choice of methods. Design of the Web service itself must also be informed by the nature of the users. It should be usability tested with elderly, young, blind, and other groups of potential users.

A Glossary

Electronic patient record(abbreviation : EPR)

The file that contains necessary medical and other healthcare related, information about a patient.

county municipality

Norway has 19 counties, "fylke". The county municipalities run some public services, like high schools. They used to run the hospitals

municipality

Norway had 434 local municipality areas, "kommune", as of 2002. The municipality runs local services.

regulation (government regulation)

An act of the Norwegian cabinet (regjeringen), based on law enacted by the Norwegian parliament (Stortinget).

Web

World Wide Web. Hypertext documents connected by hyperlinks, and accessed with Internet protocols. Does not include other Internet services like e-mail, although the edges are "blurred".

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