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Shared care and the use of collaborative information systems: A new health reform and old pitfalls

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Abstract. The paper addresses the increasing need for collaboration in the Norwegian health sector, and how information infrastructures[3] can facilitate exchange and sharing of health information. An upcoming national health reform in 2009 will have focus on how the patient can get health services in, or closer to, their homes. The change in the cooperation processes between primary and specialized care will trigger the need for better collaboration platforms. ICT-systems that support collaboration have been available for more than 10 years, but they are still in limited use. Some indications of why this process has been so difficult are given as a basis for development of new systems that can support the health reform. The paper is based on a survey to the Norwegian hospitals in 2008, semi-structured interviews at hospitals and with GPs, participation in meetings with end users and available documentation.

1 Introduction

Information infrastructures offer a shared resource for delivering and using services in places where users interact. In a CSCW-context (Harrison 1996), place

[3] Information Infrastructures (Hanseth 2004) are defined as a shared, evolving, heterogeneous base of IT Inbased on open and standardized interfaces.

is defined as a cultural and communally-held understanding of the appropriateness of styles and behaviour and interaction, which can be organised around spatial features. ICT-systems that support shared care can be used in places where health workers from different organizations and patients interact. Shared care is cooperative healthcare across organizational- and often also geographical borders. Shared care will typically involve a diversity of health workers as General Practitioners (GPs), medical specialist, nurses, midwifes or physiotherapists. Design of collaborative systems for shared care is challenging, because it requires an understanding of the nature of the collaborative work processes and an ability to forsee how new collaborative tools can support existing or future work-processes.

ICT has been used as a tool to support the clinician's work-processes in Norway for more than two decades. The first Norwegian Electronic Health Record (EHR)-systems for GPs were in use as early as in 1984. 98% of the GPs have had these systems in daily use since 2001 and EHR-systems are also present at all Norwegian hospitals. These systems started as administrative tools, but have over time emerged to be systems that support daily clinical work-processes. The focus has also changed towards shared care that involves several caretakers in primary and specialized care. The electronic collaboration between the caretakers in different organizations has so far mainly been based on electronic messaging, but web-based solutions and access to shared core medical information are also coming up as new options. Deployment of electronic messaging has been much slower than initially expected. This has proven to be more related to organizational challenges than technical barriers (Heimly 2007).

2 Challenges and changes in the Norwegian health sector

The Norwegian health system has changed a lot since the first EHR-systems were developed. A major health reform in 2001 led to the organization of the 81 Norwegian hospitals under 5 health enterprises that are owned and operated by the government. All patients are assigned to **one** GP's patient list. All primary contacts with the health care system, except acute care, should be channeled through the GP. Most patients who are admitted to the hospital have been referred by their GP. When the patient has finished the treatment at the hospital, the normal procedure will be to return the patient to community care under the GP's responsibility.

The Norwegian health system has obvious challenges that also are visible in other European countries. The hospital administration wants to keep the patient stay as short as possible in order to reduce hospital costs, but patients who have finished the specialized care they need at the hospital but are waiting for transfer to nursing homes or are not well enough yet to move to their own homes, are filling up hospital beds. As people live longer and longer due to better health care, more and more patients will need care on their elderly days. Many people are also rescued from a sudden death as early newborns or in traffic accidents, but may need specialist care for a long period.

A new Norwegian health reform is expected in the autumn of 2009. The reform will have focus on how the patient can be provided with more health care in community care, closer to their homes, and reducing the need for expensive specialized care. This health reform is also likely to be followed by economic incentives, and resources will be transferred from the hospitals to the municipalities. The municipalities will have to pay the hospitals according to the number of patients they refer to specialized care, and there will also be a high cost to pay for patients who have finished their hospital stay, but have to wait for community care to be organized.

Orlikowski has had a focus on the need for better understanding for how technological systems interact with political actions and human choices (Orlikowski 1992, Orlikowski 2001). The implementation of the new health reform in Norway will need to be followed by both organization changes in the health sector and the development of improved ICT-solutions for shared care. These change processes should be coordinated.

3 Computer Supported Collaboration between caretakers in different health organizations

The coming health reform is likely to put an even higher pressure on the need for collaboration. Higher speed in the treatment line, and the possibility of rising costs for the municipalities due to delays and prolonged hospital stays will make the need for availability to the right information at the right time essential. It is likely that ICT-solutions for sharing of essential health information in core databases will become more common. It is also a trend towards web-based solution that are owned and operated by hospital or private actors where there is a strict control both on which input should be registered in the systems and which information should be shared.

3.1 The technical infrastructure is available

The motorway for information sharing and exchange in the Norwegian health sector in available to many actors. The Norwegian Health Net (NHN) is a closed secure high speed network that connects almost all hospitals and GPs. An increasing number of municipalities with nursing homes and home care offices are also connected to the net. One of the main uses of the health net is broadband communication between the hospitals, but more and more information is also exchanged between hospitals and primary care. The main challenge so far has been that a very limited number of services are available. The Norwegian health net is a technical infrastructure, but only to a limited degree an information infrastructure. Development of end user services has so far mainly been the communicating parties' responsibility. The new health reform will suggest that NHN shall be owned by the government and not the 4 Regional Health Authorities that operate the hospital as today. This intension is to emphasize that the health net is available for all actors in the health sector. The new NHN will also get an extended responsibility for adding new services to the net. This will probably also include collaborative systems as a national core EHR.

Existing services that are available in NHN are message exchange (discharge summaries, referrals, lab requisitions and results..), web-based solution for requisition of laboratory tests and different telemedicine solutions.

3.2 Some tools to support collaboration are present

In order to make the treatment chain between primary care and the hospital as efficient as possible, there is a need to register, communicate, and interpret the information that is exchanged by all the involved parties. The information can either be sent as a message, the receiver can actively get access to information that is stored by the other party, or the sender can actively register information in a system held by the cooperation partner. It might also be possible to share information in a system held by a third party. The selected technical solution can depend on national legislation, and agreements between the communicating actors.

In Norway the most commonly used alternative is messaging between GPs and hospitals (referrals and discharge letters..). A few hospitals use a web-based referral system where the GP registers the referral in the hospitals system. Core EHR-systems that includes the most essential information about medication and contact are at a pilot stage.

4 Lessons learnt

Obviously changing the cooperation process from paper to electronic should involve much more that just replacing the paper form with a corresponding electronic form that is sent electronically. Different alternatives will have implications on the involved health-worker's work-processes. How can I make sure that I get access to the right information when I need it? How can new possibilities for collaboration be used as a means to improve the quality of the information that is shared? How can I be aware that new information is present, at how can I make other parties that I have added new content that might be of interest? If the work-processes are changed, and the workload is shared between the health workers in new ways, how can we assure that the actors trust each other and support the new changes? A series of semi-structured interviews with users of existing systems used in shared care haves, a survey to the hospitals, participation in meetings with project managers and reading of reports and other documentation has provided some clues to factors that should be paid special attention when new systems should be designed and developed.

4.1 Awareness in collaborative health systems

4.1.1 To whome should I display my actions, and whose actions should I monitor?

Souza (Souza 2007) focuses the problem of "To whome should I display my actions, and whose actions should I monitor"? These questions are highly relevant in shared care because health workers need access to health information that is updated by many parties. Awareness of when new content is added is important, but should on the other hand not be to disturbing in the daily work-process. GPs that have been involved in a Norwegian core medical chart project (Heimly 2009) were very concerned that they should be disturbed in their daily work by flags of alarms that are popping up on their screen. They did not want be informed immediately when medication is prescribed for their patients by other doctors, but wanted to check this on a list at a daily basis.

4.1.2 Enough, but not too much information

Why would GPs want to send information as messages when information could have been shared? First of all: Legislation in many countries does not permit doctors at different levels in the treatment chain to share medical information. Information sharing requires the patient consent, and consent-based systems are not always practical in daily use. The legislation in Norway is changing very slowly, and is still quite restrictive. The introduction of a proposal for a law-change that will permit sharing of core-EHR information based on consent has led

to heated debates in the media. Patient seem to be very reluctant when it comes to how much information should be shared, and patient organizations seem to be more concerned with the possibility for sensitive information in the wrong hands than the possibility for better treatment if the clinicians have access to the right information at the right time.

But the most important factor is probably that the doctors only want to have access to the information they need, and not all the information that could possibly be available about the patient. A better structure of the medical record and better possibilities for filtering of information could have helped on this problem, but we not there yet. Most of the EHR-information is just a big lump of free text. Important information can be hidden in the hospitals EHR-information, and the GP does not want to have the responsibility for searching through all this information in search for something he or she does not even know is present. Instead of sharing all information, doctors seem to be more happy with getting the information they need transferred as an abstract, og getting access to some core information about the patient as current medication, diagnoses, allergies and updated demographic information.

4.1.3 The purpose of the information, documentation for you, me or the patient?

Documentation that can be present in shared care can be produced for use in one context, but can be used by other actors in a different context. When a specialist writes information into an EHR, the recorded documentation might be used in several contexts:

- Documentation as a part of the internal work-process that covers the treatment of the patient at the hospital. The hospital-stay should be as short as possible, but on the other hand, the patient should also be well enough to not be readmitted within a short period of time The patient will normally be treated by many doctors and nurses at different shifts, and accurate information about the patient's medical condition, medication and treatment plans needs to be available at a "need to know" basis.
- Another goal is to document the work he or she has done in order to satisfy the legislation Complaints from the patients about procedure failures and maltreatment is getting more and more common, and thus documentation of the actual treatment and procedures followed is getting more and more important.
- Documentation for the patient. The patient is getting closer and closer to a customer, and requests access to their own EHR. Many patients even have bedside access to their own EHR. This also means that the EHR-documentation must be written in a language that is understandable for non-experts.

- Documentation for the next level in the treatment chain. The GP would request EHR-documentation that is important for further treatment when the patient returns to primary care. The GP would typically not be interested in details regarding surgery or a cure that was given during the hospital stay. Information about current medication when the patient leaves the hospital is on the other hand important, and information about the outcome of the hospital stay, scheduled appointments with the specialist and expectations for further treatment in primary care.
- Documentation for reporting to national registers, eg a "patient register" with administrative information about hospital stays or quality assurance registers as the Norwegian Cancer Registry.
- Documentation for reimbursement. In Norway hospital get paid from the government according to have many patients and which diagnoses they treat on an annual basis.
- Documentation for research purposes.

The GPs are very concerned with the amount of time that is spent on documentation and the registration process has to be as efficient as possible.

His or hers income is likely to depend on the number of patients treated, and the time for each consultation is very limited. Documentation of the outcome of the consultation, suggested treatment plan, scheduled appointments and medication are examples of information that should be present in the GP's EHR. If the GP decides to refer the patient to a specialist, sufficient information for making the appointment should be provided.

4.2 Trust

Trust is important in collaborative work, but it is a challenge for health workers, as for most other people, to trust others recommendations. This can particularly seem difficult when you interact with people that you do not know very well. As an example, the waiting-list coordinator commented during an interview that a project where GPs could refer patients directly for hernia surgery at the hospital ward without passing through the outpatient clinic was terminated because there had been several cases where the hernia could not be found when the patient was admitted to the hospital. The specialists at the hospital meant that the GPs were not qualified for choosing patients for surgery. In interview with a representative from the hospital management later, it was on the other hand claimed that "missing hernia" would also often be the case even if the patient was admitted via the hospitals outpatient clinic, and that the problem was not necessarily related to the GPS competence.

The health-workers in different organizations seem to need to get a better understanding of the cooperating actor's work-processes. Norway has so far had positive experiences with practice consultants who are GPs that work in part-time positions at the hospital. This could typically be 2 days a month. Their mandate is to work with improvement of procedures that are related to collaboration between primary and specialized care. Some examples of activities are: revisions of procedures for referrals, templates for documents that are communicated, eg discharge summaries, referral og lab. reports. The practice consultant will also often be used as resource persons in projects where new ICT-solutions to support shared care are introduced. The practice consultants practice would often be used as a pilot site. According to the survey to the hospitals in 2008, 75% of them have practice consultants, and the hospital reported that they have good experiences with their effect on improvement on collaboration.

5 Results and recommendations

Information that is supposed to be shared need to be suited for the context in question. A common understanding of the needs of actors who are going to share the health information should be developed over time, and should also imply changes in both specifications of data, user interfaces and technical solutions over time.

"Me deciding requirements for You" is seldom a good solution. Collaborative systems need to develop over time and changes in user interfaces need to be easy to implement. The tension between doctors in primary and is likely to remain, and it is not evident that new technical solutions will be more used than the existing ones if they do not support the health-workers work-processes to a sufficient degree at all levels. Extended use of practice-consultants can be beneficial for a better understanding of other actors' needs.

New technical solutions will facilitate new possibilities for collaboration, but many of the existing organizational barriers will still remain, and should be carefully considered when designing new technical solutions. Use of qualitative research methods can be used to get a better understanding of how future collaborative support for shared care can be designed and used. Further use of semi-structured interviews (Kvale 2007, Holstein 1995) with future users and data analysis based on grounded theory (Clarke 2005) can be beneficial.

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