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# Making Sense of Medical Records in a Non-Medical Practice

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**Abstract**

The medical record is being redefined not only by medical practice but also by other practices. One example is the introduction of medical records as reliable or trustworthy components of public welfare. The paper reports on an ethnographic study of ICT in public welfare. The issue of ethics in relation to ICT becomes pertinent when medical documents move into a non-medical practice (public welfare) to support the assessment of what kind of job a client (unemployed citizen) can manage. The patient/client is proactively involved in this process at the intersection of several perspectives: the physician, caseworker, and patient/client. We draw on earlier work on 'situated ethics', and we illustrate how this framework may be extended with reference to *displacement* to emphasize the difficult double role of the patient/client when the medical record moves across contexts.

**Author Keywords**

Situated ethics; public welfare; vulnerable participants, collaborative information systems; cross-sectorial work; ethnographic studies.

**ACM Classification Keywords**

H.5.M Information interfaces and presentation (e.g. HCI): Miscellaneous.

### **Resource processes**

'Resource processes' were introduced "[...] *to retain as many as possible in the labor market – preferably in non-subsidized employment. The reform is intended to ensure that the future will see an increased emphasis on the resources of the individual and the development of his or her working ability. Therefore, rehabilitation teams have been established in all municipalities. Here, the employment-related, social and health-related resources and challenges of the individual will be clarified simultaneously, focusing on training, employment, and financial independence*" [7 p. 17].

### **Resource contents**

In the cases that we observed as part of the study reported here, 'resource processes' included suggestions regarding, e.g., physical training, piano therapy, treatment of different types of abuse, and advice sessions (mentoring).

### **Introduction**

Contemplating ethics in relation to information and communication technologies (ICT) is a difficult task; though, it is being taken up by more and more scholars in HCI, e.g. [1, 4, 5, 6]. The challenge is how to analyze specific ethical issues in relation to ICT; our aim, like others before us, is to openly explore this question. We do so in an ethnographic study of public welfare in Denmark and the practices of constructing medical records as reliable in this context. Medical records are essential in public welfare to document when a person is unable to take a job on normal conditions due to medical issues. For the record to become actionable the patient is turned into a client who proactively helps the 'rehabilitation team' caseworker in constructing the record so that it may pass as trustworthy in public welfare. The record (in principle) becomes reliable when various perspectives are aligned (patient, caseworker, and physician) and no longer contested by any of these actors.

Thus, ICT play a role in the emergence of new ethical considerations around the medical record as it moves across contexts (or is *displaced*) and it's role is redefined. Recently the Danish courts ruled that patient medical information is no longer private in the sense that it is considered the property of patient/clients. An employer had been given access by a municipality to patient/client medical information that until then was considered private because it had been produced in the context of GP services. However, the patient/client information was transported into the records of the municipality through an understanding that it would remain private.

The technical way of transporting information between a physician - usually the GP of the patient/client – and the municipality (responsible for public welfare) is through a medical information system. The purpose of this paper is to begin to address the ethics and design of ICT in relation to issues following from such *displacement*; The research question is: How is ethics considered in public welfare relying on ICT, and what role does the patient/client play in the process of constructing records? In particular, we examine the double role of the patient/client from the perspective of situated ethics [1], extending this perspective with reference to the *displacement* of medical records.

### **The Medical Information System**

ICT in public welfare is provided by a few main contractors in Denmark, who are also the main contractors providing ICT in relation to the primary health care sector. The medical information system [Mediconnect] supports the work of rehabilitation teams, e.g. exchange of documents across public welfare (98 municipalities) and primary- and secondary care (5 regions). Similar cross-organizational constructs are found in Sweden [2]. In Denmark ICT for supporting rehabilitation teams started out as a service of communication between medical specialists and the municipalities. The municipalities could request different types of medical statuses (templates).

The country-wide introduction of rehabilitation teams in 2013 introduced a new need for safe communication across different agencies: Caseworkers in the municipality social agency, health agency, employment agency, and in some cases the child and youth agency - and on the other hand the region (medical consultant). Municipalities were already using

### **Support by ICT**

A rehabilitation team relies on a shared medical information system. Files are released as the case progresses (e.g., with the medical consultant's approval of the clinical documentation in a particular patient/client case before the meeting of the rehabilitation team). The functionalities of the system are developed continuously, e.g., new roles are defined to support a clear distribution of responsibility whenever one of the formally defined steps in the case management is completed.

### **Coordination**

A secretariat has just recently been integrated into 'resource processes'; the secretariat is instrumental in making sure that all steps are completed in due time, and that the required documentation is in place before the meeting between the patient /client and the rehabilitation team takes place.

Mediconnect at the time, and it was decided to build on the existing system rather than develop a new system.

Today, the request of a medical status (fig. 1) takes place in a separate application. Medical documents are still central to the rehabilitation team practice: making sure that 'resource processes' (the public welfare scheme) are assigned to the right patient/client also means knowing the medical constraints. Nevertheless, 'resource processes' have often been subject of criticism as rehabilitation teams are said to disregard patient/client medical conditions [8].

### **Research Method**

We followed an iterative approach of collecting data and identifying themes that guided the next round of data collection [3]. The starting point of the study was the employment agency; later analyses brought us to focus on the rehabilitation team where the paradoxical presence of a medical information system in a non-medical practice guided the study. The paper presents findings from 7 months of ethnographic fieldwork in 2015 / 2016 (ongoing) with a rehabilitation team that administers the public welfare scheme 'resource processes'.

The rehabilitation team is a cross-organizational construct (across municipalities and regions), but it is located in the same building as the rest of the employment agency and relies on the same services, e.g. guards that check-in clients and provide support for those who are unstable, intoxicated or emotionally upset when they arrive.

The study counts approximately 89 hours of observations; *In situ* interviews were conducted with

caseworkers (4), a legal consultant and caseworker (1), IT specialist (1), Secretariat (3), other rehabilitation team members (4), lead consultant (1), management (3). Narrative ethics guided the selection of cases (see the last side bar of this paper). In the following section we briefly review how we encountered ethics and ICT, drawing in particular on the framework of situated ethics [1].

### **Situated Ethics**

So what do we mean by 'ethics' and how is it related to ICT? In essence we "[...] focus on sensitizing people to ethical tensions, and through this enable ethical action, [rather] than prescribing types of responses" ([1 p. 237-238] *referencing* Guillemin and Gillam 2004). This perspective implies a focus on an in-depth understanding of everyday conflicts of various types that potentially have ethical implications.

We analyze issues of ethics and ICT using the framework suggested by [1]. They explore e.g. how literacy for generic and trade names of drugs becomes important for system design, and they suggest a framework or catalogue of principles and issues, e.g.: 1) Intellectual property 2) Literacy 3) Standardization 4) Transparency 5) Work ethics, and 6) Allocation of resources.

We emphasize the role of patient/clients, and we analyse how their 'mindset' (that is the citizens *readiness*) plays a central role for the subsequent use of medical records. We show how the double role of the patient/client is essential in aligning different perspectives on assigning a 'resource process' under conditions of *displacement*.

### Steps in case management

*First*, a caseworker prepares a draft rehabilitation plan together with the citizen. Based on this meeting with the citizen, the caseworker makes a recommendation [ICT: request of documentation, filing]

*Second*, a central secretariat notifies the citizen about the meeting with the rehabilitation team and the various hearings [ICT: scheduling, request citizen comments, coordination]

*Third*, the recommendation is explored together with the citizen in the rehabilitation team, which then makes a second recommendation [ICT: request citizen comments, filing]

*Fourth*, a representative of the rehabilitation team makes a decision as to whether a 'resource process' is to be assigned to the citizen [ICT: statistics, communication]

*Fifth*, a new caseworker, together with the citizen, makes a final plan for the rehabilitation of the citizen

### Analysis: Situated Ethics in Public Welfare

Making judgments on people's mindset is essential for caseworkers' practice throughout the employment agency. Mindset is an informal criterion by which caseworkers assess patients/clients' readiness to engage in a resource process. A legal consultant and caseworker explains: "*The Consolidation Act on Legal Protection prescribes that the client has a right to be involved in the management of their case. Translated into practice it means that a client's mindset is essential for what measures we should initiate*" (*In situ* interview with caseworker 08 01 2016).

Applying for a 'resource process' is a rather bureaucratic exercise. The 'personal coordinative caseworker' (PCC) first makes the call as to whether a patient/client is motivated for a 'resource process'. The application raises three possibilities: 1) reimbursed flexi-job 2) 'resource processes' and 3) disability pension. Roughly five steps follow the PCC's formal application for a 'resource process' (listed in the side bar to the left).

The following narrative focuses on this first step of case management based on ethnographic studies in the rehabilitation team. What the citizens in the study had in common is that they typically struggle with both personal and health-related challenges. This was also the case with 'Fatima' (all data were anonymized) whose story we unfold.

#### *The double role of the patient/client*

Fatima is age 45. She first arrived in Denmark with her husband and children 15 years ago. However, Fatima was living in a violent relationship and at some point she decided to leave her husband. At first Fatima got a job in the local senior citizen facility with the help of a

neighbor. Having held that job for almost 7 years, she started having personal problems when her mother died. At that time Fatima had not been in her home country for years and she started experiencing anxiety that became worse and worse. At some point she was fired from her job in the senior citizen facility because of absenteeism. She was enrolled in different activities by the local employment agency: a hairdresser course, a cooking course etc., but her anxiety did not wear off. Later she started seeing a psychiatrist; her physical health was also becoming a problem. At this point Fatima's PCC recommended that Fatima apply for a 'resource process'.

A social worker from the municipal social authorities participated in the meeting to support Fatima. Fatima speaks poor Danish and the social worker on several occasions speaks on her behalf. The caseworker carefully explains that no decisions can be made in this meeting. The purpose of the meeting, says the caseworker, is to "[...] *make sure that it is actually the citizen that responded to the letter that was sent from the employment agency as part of the application process*" (*In situ* interview with caseworker 05 05 2015). So, did Fatima in fact fill out the template herself, and does she really want to apply for a 'resource process'?

The meeting begins and the caseworker asks Fatima if she takes the medication that her psychiatrist has prescribed, which Fatima confirms. She also asks if Fatima is suffering from any other medical conditions and notes down Fatima's response. Fatima at first seems confused and starts looking in her handbag; then she takes out a pile of business cards, some of them very old, and starts reading out some of the names, including private specialists and specialists in

## The role of electronic templates

In the first step of case management, a medical status is requested from the patient/client's GP. The request takes into account the patient/client's own information on his or her medical conditions; the GP's status is guided by this information – as well as by a physical examination of the patient/client.

The image shows a screenshot of a Danish electronic form titled "LÆ 265 Lægeattest til rehabiliteringsteam". The form is divided into several sections. At the top, there are two boxes for patient information: "1.1 Allevens adresse" and "1.2 Tidligere sygdomme". Below these is a section for a declaration of consent, with the text: "Jeg bekræfter hermed, at jeg har læst og forstået indholdet af denne lægeattest og at jeg har givet min samtykke til at min læge kan udlevere de nødvendige oplysninger til rehabiliteringsteamet." There is a checkbox for "Jeg har læst og forstået indholdet af denne lægeattest og at jeg har givet min samtykke til at min læge kan udlevere de nødvendige oplysninger til rehabiliteringsteamet." and a checkbox for "Jeg har læst og forstået indholdet af denne lægeattest og at jeg har givet min samtykke til at min læge kan udlevere de nødvendige oplysninger til rehabiliteringsteamet." Below this is a section for the patient's health status, with the text: "2.2 Patientens helbredsforhold". The form is filled out with some text, but it is mostly illegible due to the resolution.

Figure 1: The electronic template [LÆ265] that the GP uses for returning medical information to the rehabilitation team.

hospitals. The caseworker takes notes and at the same time tries to crosscheck the names listed in the electronic template in front of her that Fatima had filled in before the meeting. It is essential that the information Fatima provides in the meeting is as complete as possible because the case will be desk-rejected if the rehabilitation team later finds that relevant medical records were not collected.

To be able to recommend a 'resource process' for Fatima, the caseworker needs her to sign an agreement that allows the caseworker to request copies of her medical records. Also, Fatima has to make an appointment with her GP, the caseworker explains, to document her general state of health. Fatima looks exhausted at this point, half an hour into the meeting, and the social worker explains to her that she will help Fatima get it done. Fatima has a lawyer, the social worker explains, that advised her not to sign anything that he has not seen. The caseworker stops and explains that they cannot proceed with the application without the consent. After a few minutes they agree that the social worker takes a picture with her smartphone and send to the lawyer so that Fatima's application can proceed.

As the meeting continues it becomes clear that Fatima's anxiety is her biggest problem. However, it is only at the end of the meeting, when the caseworker wants to make sure that Fatima understands her rights that they get back to this problem. The caseworker explains Fatima that she is entitled to 5 weeks of vacation like any other Danish citizen. While it seemed a formality that the caseworker mentioned Fatima's rights on this point, it was important in motivating Fatima to believe in more options for help to recover. It would take at least some weeks before all medical records had been

retrieved and the rehabilitation team could proceed with the administration of Fatima's case.

### *The Displacement of Medical Records*

A patient/client may always refuse to give his/her consent (referred to by caseworkers as a restricted consent), which means that the caseworker preparing a recommendation for the rehabilitation team cannot request copies of various medical records. A restricted consent may be interpreted as 'process damage' so that the caseworker may simply desk-reject a case for lack of information. However, in all cases we observed, the patient/client actively helped in constructing the relevant medical records.

In Fatima's case intellectual property does not become an issue in the administrative process as such. Intellectual property, instead, is a legal matter: When documents are transported into the municipalities' records, a different set of rules in terms of their 'visibility' comes to apply.

The intellectual property changes from the medical specialists who produced the records to the employment agency. The lawyer of the patient/client is bypassed here to avoid waiting time that could make Fatima's anxiety worse.

In the end, the caseworker and Fatima manage to collaboratively explore the reasons why Fatima is suffering from anxiety and to come up with alternatives (travelling to her home country) that depend neither on medical treatment nor on the municipality handling of her case.

### **Final Remarks**

Situated ethics, it has been suggested, is essential because "[...] given the many opportunities information

### **Ethical clearance**

An obligation of professional secrecy applies to all researchers affiliated with the research project and the University of Copenhagen generally. In addition, a contract of professional secrecy was signed by the field researchers with the employment agency, of which the rehabilitation team is an organizational and legal part. An application regarding research ethics was approved by the Danish Data Protection Agency. All citizens involved were asked permission whenever researchers observed their meetings with caseworkers.

### **Ethical conduct**

Narrative ethics [1] played a central role in the specific study reported here. In practice this meant that particularly sensitive cases are not reported in order to give vulnerable citizens the benefit of the doubt in terms of their permission and consent, e.g., in cases of controversial diagnoses.

*and communication technologies offer, it is vital to take account of the need for privacy, respecting people's right to maintain boundaries, but also to preserve privacy, autonomy, confidentiality, and solitude. Other ethical issues connected to ICT are transparency – awareness of and the ability to understand IT systems and their implications – and literacy” [1 p. 240].* Although [1] study situated ethics in relation to e.g. professionals making use of medical dispensers we find that the framework is promising for the analysis of ethics and ICT more generally.

The present study explored the patient/client role in making records reliable and actionable in public welfare when records are translated outside the medical domain in which they were originally produced. The medical information system, the case illustrates, provides a free-text space. In this space the caseworker lists, e.g. that the patient/client has been informed about her rights as a checklist and information to the secretariat (next step in the case management).

The immediate response to Fatima's situation and the communication of her rights that may help stabilizing her situation is thus only a side-effect of this free-text space that reminds the caseworker of e.g. informing patients/clients about their rights. Nevertheless, stabilizing the situation and mindset of a patient/client may be essential not only for the patient/client but for the rehabilitation team also to prevent that the case is prolonged if the situation changes and new documentation is required.

Important questions remain for future research and systems design, e.g.: how can we tell if ICT makes a difference for how medical information moves into

public welfare with the help of patient/clients, including their roles as reliable sources as well as participants in the process.

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