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Participation and Representation - a Discussion Based upon a Case Study in the Danish Healthcare Sector

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Abstract. The Scandinavian approach and the Participatory Design community has come a long way in terms of raising attention to include future users in the design and development of new technologies and in relation to making PD approaches applicable in real life projects. Based upon a case study of a - in many ways - successful project in the Danish healthcare sector we discuss issues in relation to participation and representation in projects with diversified user groups.

Introduction

Over the past two decades the Scandinavian Approach and Participatory Design has come a long way in making participatory approaches applicable in practice, i.e. in real life projects in for example business settings. There is, of course, still a viable debate in relation to dealing with problems in the design and use of information technology as witnessed for example by Dan Shapiro's call for Participatory Design to "consider claiming an engagement in the development of large scale systems, and more particularly an engagement with the procurement and development of systems in the public sector...." (Shapiro, 2005, p. 32).

In this paper we want to discuss issues in relation to participation and representation based upon findings from a case study of a project in the Danish healthcare sector. The healthcare domain has emerged as an important area for

Scandinavian IS researchers and for PD - from our point of view due to the relevance of issues involved in designing it support for communication and interaction among actors crossing professional, organizational and institutional boundaries.

Chronic diseases, like diabetes, are affecting growing numbers of patients in western countries. When treatment involves several providers - such as hospital departments, outpatient clinics, general practitioners and homecare providers - issues like continuity of care and coordination become central. In many ways the project on it-support for diabetes treatment in a Danish region is a successful one. It is well integrated with related activities at the organizational and institutional level (Bassett et al, 2006), and the system is technically quite well designed. However, the uptake and use of the system by the primary healthcare providers is at odds with the intentions. In this short paper we will discuss this issue in terms of how to engage with practitioners from this domain in a project based in the secondary sector.

SharedDiabetes

As part of a long-term research effort in relation to it-support of diabetes treatment (Bødker, 2006; Danholt&Bødker, 2005; Danholt et al., 2004), we have followed the implementation of a system for supporting shared care of diabetes (Granlien&Simonsen, 2007). The system - SharedDiabetes¹ - was developed and implemented in the central part of one of the five Danish regions and is now being spread to the rest of the region.

In order to understand the project, a simple introduction to diabetes treatment is needed: When a suspicion for diabetes with a patient is discovered - in a hospital or the general practitioner's practice - the patient is referred to the diabetes outpatient clinic to have the diabetes diagnosed properly. Here the patient upon diagnosis receives initial treatment with the goal of becoming *well regulated*, i.e. achieve a stable situation by a combination of medication, a changed diet and physical exercise. In the outpatient clinic the patient is treated by a multi-disciplinary group of specialists: diabetes doctors and nurses, dieticians, ophthalmologists (eye specialists), and podiatrists (feet specialists). When the patient is well regulated, typically within less than a year, the patient is discharged to his/her general practitioner (GP).

This is the workflow for type II diabetes - by far the most widespread (type I patients are treated in the hospitals). Upon discharge, type II patients are seen by their GP on a regular basis, every three months and a more thorough control every 12 months. In relation to the yearly control, the GP refers the patient to see an eye specialist and a foot clinic. Late complications of diabetes (of which some are

¹ a pseudonym.

related to sensibility in feet and changes to the eyes, hence the yearly checks at the eye specialist and the foot clinic) are serious to the individual patient and costly to deal with for the healthcare system. Effective care and the patient's active participation are central to reduce the late complications, and thereby improve the quality of life for the patients and lower the costs for society.

The Case Study, its Methods and Initial Findings

The empirical investigation took place throughout 2005/06 and comprised a series of interviews, observations and document analyses, see table 1. Interviews were semi-structured and lasted 45-75 minutes. They were recorded and later transcribed (later in this paper referred to as GP1, etc.). Observations at an outpatient clinic were carried out over three days - in total approximately 15 hours of observation documented by field notes. Interview transcripts and field notes from the observations were analyzed using a coding process inspired by the theoretic sampling technique known from grounded theory (Glaser&Strauss, 1967).

Table 1. Empirical activities in Region A

	Interview	Observation	Training session	Documents
General practitioners	3	-	3	*
Outpatient clinics	2	3	-	
System developers	2	-	1	*
Region	1	-	1	-

SharedDiabetes was developed in response to an action plan for diabetes from the Danish National Board of Health in 1994 (Bassett et al, 2006). Establishing a regional diabetes committee was the first result of the action plan. A variety of initiatives such as restructuring the diabetes outpatient clinics to reflect a team oriented care, hiring a diabetes nurse and diabetes practice coordinators at the regional level to improve the communication between the various care providers, and establishing schools for newly diagnosed diabetics were later launched to fulfill the action plan. After a number of the initiatives had been carried out, a need for an it system that could help monitor and support the treatment as well as provide a means for quality assurance was identified.

The project involved representatives from the various stakeholder groups, e.g. diabetes doctors and nurses from the outpatient clinics and the diabetes practice coordinators, i.e. general practitioners with a special interest in diabetes. Compromises had to be made in many areas during the design of the system. The

specialists at the outpatient clinics requested extensive data versus the general practitioners' wish for simplicity, ease of use and a minimal use of time. As part of the implementation the general practitioners were given three hours of training before getting a password to the system. In return of an additional remuneration they are expected to use the system for reporting the yearly status.

SharedDiabetes is used by all outpatient clinics, a substantial part of the GPs, and has recently been made accessible to patients in the region through the Danish National Public Healthcare Portal. SharedDiabetes is a web-based system for registration of data relevant for the treatment of patients with diabetes such as: HbA1c, blood pressure, weight, medication, status for eye and heart etc. The system is being promoted as a system for supporting shared care. SharedDiabetes can be accessed through an Internet browser and requires a manual login, or it can be setup to be accessed via the general practitioners patient administration system/electronic patient record (EPR) system through an integrated link. The system is integrated with the hospitals' laboratory system, which means that results of the patients' tests occur in the system automatically. The integration with the general practitioners' electronic patient record systems is done by text messages (edifact) from SharedDiabetes. At the time of our investigation the outpatient clinics did not have an electronic patient record and used SharedDiabetes as their main system for diabetic patients together with the hospital patient administration system. For that reason we do not know about the integration, or the planned integration, with a potential full EPR system.

The system is designed for use *during* the consultation to facilitate involvement of the patient (to help the patient become active in his/her own treatment) and with a fine-grained level of data. This is how we observed the system being used at the outpatient clinics. The general practitioners we interviewed never used the system during a consultation, but preferred to consult the system before the consultation and register data afterwards. Most of them preferred to use their own system, and others said they hardly ever used any system during consultation. They prefer to be "present" and not hiding behind the screen during the consultation.

"I would rather use the time – and I might sound a little self-righteous now – but I prefer using my time with the patient and then use the computer either before or after [the consultation]. That's what I do generally" (GP2).

"I won't sit with my back to the patient [facing the computer]. I believe that's rude ... it is not the job of a physician to sit and act like a computer nerd" (GP1).

Many of the general practitioners in our study did not feel the need for shared care – especially not if shared means shared between the general practitioner and the outpatient clinics. Less than 5 % of their consultations regard diabetes (Vedsted et al., 2004), which means that they typically have 50 patients or less with diabetes and only one fourth of them is also being treated by the outpatient clinic. Even if the patients are shared with the outpatient clinic, the general practitioners do not feel the need for a shared record or a shared treatment.

"Either I take care of my diabetes patients or the outpatient clinic does. [Most often] I manage them myself and then there are some cases where they are hard to manage. They are then referred to the outpatient clinic and they will take care of the extended yearly control" (GP2).

When the patients are being treated by the outpatient clinic the general practitioner does not interfere with the treatment and vice versa. The general practitioners would gladly share and exchange data with the outpatient clinics, but they all preferred to use their own system and then have some kind of data transfer module.

"I was quite insisting on this matter, but it was technically not possible to do this at this point in time. I am of the opinion that a [shared care system] should have been developed where the application should be within our computers" (GP3).

"If it [shared care system] was on my computer then it could get most of the data [from my electronic patient record system]. But there should be a little piece of code that did this [automatically]" (GP3).

The general practitioners would prefer a solution with a system much more integrated with their own record systems. The general practitioners were all very positive about their own system, they all found an opportunity to show us the excellence of *their* system.

Discussion

The project was well integrated with the regional activities of diabetes treatment, as evidenced by (Bassett et al, 2006) and our interviews; the system is actually quite well designed; and a leading medical doctor from the regional University Hospital has claimed remarkable results in terms of significantly less late complications from diabetes to the shared care initiatives. However, findings from the study also point to a number of challenges for it supported shared care, especially related to GPs' use of SharedDiabetes. Some of these challenges are related to structural issues, and some are related to the insufficient involvement of key actors.

Structural problems and lack of attention to general practitioners' practice

A large part of the structural problems comes down to the fact that GPs as well as other care providers in the primary healthcare sector are private businesses, while diabetes outpatient clinics are part of public hospitals. In Denmark virtually all GPs have electronic patient records, and there are more than 20 different EPR systems in use in GP's clinics. Currently the Danish regions owning the public hospitals are developing and implementing full-scale hospital EPR systems, but when the SharedDiabetes project started, and when the system was first implemented in the region, there was no EPR system at the region's hospitals. For

that reason SharedDiabetes was designed for use as the main system for diabetes patients.

The GPs, however, have their own EPR system as their main system. This means that the use of SharedDiabetes in GP's clinics is on top of their EPR system involving extra work and overhead. When seeing a diabetes patient the GP has to log into SharedDiabetes by opening a browser window, check data from previous consultations, register the relevant data from the current consultation, and then return to the EPR system. This extra work was actually acknowledged as part of the project: the services to be performed by GPs were regulated and included in the financial agreements between the GPs and the region. However, in the daily use the lacking integration causes frustrations, as illustrated by the quotes above, for example "I was quite insisting on this matter, but it was technically not possible to do this at this point in time. I am of the opinion that a [shared care system] should have been developed where the application should be within our computers" (GP3). As noted by the GP, achieving a tight, or *seamless*, integration between SharedDiabetes and his EPR system requires a vast amount of resources. Given the project's software architecture decisions this would involve all the 20+ providers of EPR systems for GPs.

In general the GPs find that SharedDiabetes does not support their way of working. The GPs we interviewed never used the system during a consultation, but preferred to consult the system before and register the data after the consultation.

Due to the fact that the information input to SharedDiabetes is not integrated with the GPs' electronic records, and the fine level of granularity of data requested by the doctors at the outpatient clinics, using the system becomes tedious extra work in the GP clinic. This is reinforced by the low frequency of diabetes patients in general practice. Less than 5% of a GP's consultations regard diabetes (Vedsted et al., 2005), which means that s/he typically has 50 patients or less with diabetes to be seen once every three months, or three patients weekly. This means that using the system never becomes routine, the GP always has to use extra attention - for example to locate a specific field.

Participation of diversified user groups

Our findings resemble experience from other studies of the uptake of clinical information systems, for example Short et al. (2005). The implication of the findings is that by not attending to the GPs' professional practice regarding use of computers in their consultations, risks are high that GPs will only use a shared care system to an extent fulfilling the minimal requirements in agreements between the region and GPs. From this, one could hypothesize that a small number of GPs would use the system as intended. We have not been able to test this hypothesis, as we have only been able to obtain data on the number of GPs having

followed a course on SharedDiabetes and hence obtained a password to the system (more than 50% of GP clinics six month after launch (Bassett et al., 2006)).

How can we end in a situation like this in a project with all the best intentions? It is our claim that for a variety of reasons, the project operated with a *specialist mindframe*. The situation was seen from the regional diabetes committee's point of view. Here we have the experts (doctors and nurses from the outpatient clinics), and actors from this domain are the dominating actors in the project. They work full time with diabetes, and they are allocated to the project as part of their job. The GPs involved in the project were primarily the diabetes practice consultants, who are only paid a few hours monthly. This means that general practice is represented by physicians with a special interest in diabetes who work part time for the region with improving the collaboration between diabetes outpatient clinics and general practice. Hereby they can easily "get carried away" by their joint interest in diabetes treatment, and thus become less representative of GP clinics and clinical practice.

And what does representation of GP clinics mean, anyway? This is actually quite a tricky question. GPs and other care providers are private businesses without any organizational structure, for example a trade organization, from which individuals can represent all GPs. In the matters of contract negotiations between the GPs and the regional and national healthcare organization, a formal structure has been established. However, this only covers the contractual and financial agreements, not questions about the design of it systems to be used in the GPs' clinics. The question of representation is strongly linked to time and economic issues. Whereas the people from the regional outpatient clinics are allocated to the project as part of their full time job, GPs who take part only do it out of their personal interest and with a limited amount of paid hours.

So where PD approaches in 'stable' or classic organizational settings have elaborated guidelines for user participation and representation, for example to include users with knowledge of the work domains in question, who enjoy professional respect from their colleagues, and who have time available for the project (NN et al., 2004), PD needs to develop guidelines for participation and representation in projects with more diversified user groups.

Relating to Gärtner and Wagner's classic distinction between three arenas for PD (Gärtner&Wagner, 1996) - the individual project, the company and the national level - we see that the complexities of this project in part can be attributed to an increased structural complexity at the "company" level. We do not only have a strong power base with the actors at the regional level, also actors from the primary healthcare sector do not have a structure of representation enabling the involved actors to speak on behalf of their colleagues, while still others actors are not involved at all.

Conclusion

From a case study of the implementation of a shared care system for diabetes treatment in the Danish healthcare system, we have identified challenges for the PD community to address issues of participation and representation of user groups in projects with diversified user groups. These groups are not weak in the classic sense, actually they are quite outspoken, however, the challenge is to create opportunities and room for the involvement of actors with different institutional and economical orientations than a project's dominating actors.

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