Empowering Patients: PD in the Healthcare Field

Finn Kensing, Dixi Louise Strand
The IT University of Copenhagen
Glentevej 67, DK- 2400 Copenhagen NV
Denmark
+45 3816 8888

{kensing, dixi }@itu.dk

Jørgen Bansler, Erling Havn
Technical University of Denmark
Building 371, DK-2800 Kgs. Lyngby
Denmark
+45 4587 1577

{bansler, havn }@ cti.dtu.dk

ABSTRACT

In this paper, we discuss PD issues and concerns in the context of a national initiative the purpose of which is to provide IT support for the communication and collaboration within a heterogeneous network of patients/citizens and health care professionals. We present the notion of patient empowerment as focus of ongoing research in the research program Health Care IT along with three empirical case studies under way. We conclude by highlighting the context-specific challenges development of new IT services in the health care sector poses and relate these challenges to existing PD concepts and approaches.

Keywords

Health care, health care information systems, patient empowerment, participatory design, information and communication technology, computer-mediated communication, CSCW.

1. INTRODUCTION

The healthcare sector is a crucial and constantly expanding component of contemporary societies. Although investments in information and communication technologies (ICT) generally lag behind other sectors, ICT applications for health care have the potential to improve cost-effectiveness, quality and accessibility of health care.

However, the healthcare sector poses important practical and theoretical challenges to information systems (IS) and participatory design (PD) research, because the institutional context is markedly different from the traditional contexts where IS and PD research is most often conducted (i.e. professionally managed business organizations in a free market context).

In this paper, we present a newly started research project on development of Collaborative Healthcare Information Systems (CHIS) and discuss how healthcare challenges theoretical assumptions embedded in current research on participatory design.

2. EMPOWERING PATIENTS

Researchers and policy makers have increasingly realized that effective communication and collaboration between healthcare professionals and patients – often referred to as patient empowerment – must form the cornerstone of healthcare in the future (8, 11). *Patient empowerment* is a healthcare philosophy that posits that optimal outcomes of healthcare interventions are achieved when patients become active participants in the healthcare process (4). According to this philosophy, cost-effective healthcare requires communication, consultation, and collaboration among healthcare professionals as well as with patients, their families, and community resources. Patient empowerment aims at transforming the healthcare professional/patient relationship and educating people to prevent disease (e.g. by changing their lifestyle) (3). Better outcomes, lower costs, and higher patient and provider satisfaction are likely to be the result.

In PDC-04 Proceedings of the Participatory Design Conference, Vol 2, Toronto, Canada, July 27-31, 2004, under a Creative Commons license. CPSR, P.O. Box 717, Palo Alto, CA 94302. http://www.cpsr.org ISBN 0-9667818-3-X

This shift towards patient empowerment provides new challenges for the development of health information systems (HIS) (9). Traditional HIS-initiatives focus on the computerization of patient records, providing order-entry and results-reporting functionality within the domain of individual institutions (2). However, given the growing complexity of contemporary healthcare (7), it is essential to recognize that institution-specific systems are no longer sufficient to meet the needs of patients, healthcare providers (hospitals, clinics, and general practitioners), national health systems, home care centers, and other stakeholders.

Patient empowerment requires that HIS designers look beyond traditional concepts of electronic patient records (EPR) and realize that healthcare work is highly interactive and communicative in nature. The challenge is to build collaborative health information systems (CHIS) that explicitly support the interdependent roles of patients and healthcare professionals in achieving healthcare goals (4). The development of such systems requires resolving not only technical and linguistic problems of communicating 'across boundaries,' but also the organizational and political issues related to information sharing in heterogeneous networks of institutions and 'communities.' The important questions to be addressed are: 'How can IT applications support communication between care providers and patients? 'How can IT applications support the interactive nature of healthcare work and enable the patient to take more control over his or her own health? 'How can IT applications support knowledge sharing among patients and provide tools for building patient communities?'

The Internet is already transforming the way various healthcare providers, public health authorities, patient associations and medicinal drug manufacturers communicate and interact with patients and the public at large. As a new, interactive medium of human communication, the Internet offers a range of new possibilities for supporting information retrieval, knowledge sharing, and collaboration across geographical, institutional, and professional boundaries. It is therefore not surprising that, in the view of the American Institute of Medicine (IOM), "the Internet will likely be the platform of choice for many if not most health applications because of the ready access it provides to both consumers and clinicians, as well as other financial and technical considerations." (6). However, at the present time, Internet-based applications supporting patient empowerment are best described as emergent, and our understanding of requirements, design principles and implementation issues related to such applications is quite limited. It is our expectation that collaborative HIS will strengthen the position of the patient, but it is extremely difficult to predict the long-term implications of this. Although the patient will get more ready access to information about his or her medical situation and clinical information, in order to be able to use this information the patient has, however, to become more knowledgeable about diseases, treatment options, lifestyle factors, etc. The result will be an even greater increase in demand for health information and medical consultation, which will put new demands on the healthcare information systems. Reliable and accessible health information will become increasingly important for the patient and make him or her better able to make informed choices and to have a say in the management of his own health, and the options for care and treatment.

In sum, while gains in medical knowledge and technologies have improved health outcomes, the effective use of information technology holds the potential of enhancing care further through better collaboration and communication between providers and patients. However, realizing this potential raises a host of sparsely investigated practical, conceptual, methodological, and technological issues. Interdisciplinary research is needed, not only to explore the technological requirements, but also to address the potential organizational barriers and consequences of creating collaborative healthcare information systems (CHIS).

3. THE HIT PROJECT

The Healthcare IT project (HIT) was set up and designed to investigate these issues within the context of the Danish national health sector. The main purpose of the project is to develop conceptual frameworks, design principles, prototypes, methods, and tools to support the design, implementation and use of collaborative HIS, based on evaluation of existing systems and empirical studies of development practices combined with interdisciplinary analysis and theory building.

The project has four objectives:

- To evaluate the design and use of existing collaborative HIS and examine how these systems change patterns of interaction and collaboration among patients and healthcare professionals.
- To examine and evaluate existing ISD methods and practices of CHIS design as well as strategies for organizational implementation and continuous development of collaborative HIS.
- To identify key organizational, cultural, and technical factors that facilitate or impede successful creation of CHIS.
- To develop prototypes of new, innovative CHIS applications and propose concepts, methods and tools to support the design, implementation, and continuous development of such systems.

The aim is to contribute to research and development, not only within the field of medical informatics, but also more broadly within the fields of IS and PD research.

The HIT project is a four-year initiative, carried out in collaboration among research groups from Roskilde University, the IT University of Copenhagen, and the Technical University of Denmark. The project is partly funded by the Danish Research Councils and involves nine senior researchers and four PhD students. It also involves a number of key actors from the Danish health care sector, including the city of Copenhagen, the Hospital of Amager, and the public national health portal on the Internet, *Sundhed.dk.*

Currently the researchers organize their activities around three empirical subprojects concerned with different aspects of collaborative health care information systems: mobile devices in home care, type 2 diabetes outpatient clinics, and a national health care portal. In the following the study of the development of web-services for shared care programs, initiated as part of the health care portal, is elaborated upon.

3.1 The public national health care portal

The national health care portal, *Sundhed.dk,* is intended to give patients and their relatives targeted access to the overall National Health Service in Denmark, affording users opportunities to gain an insight into their own possibilities and treatment at times when they have information and communication needs.

Moreover, the Health Portal is intended to facilitate communications between the parties involved in the National Health Service. In this connection, a crucial success criterion will be for the Health Portal to be seen as a tool capable of being integrated into clinical work in such a manner as to allow healthcare professional users to solve those tasks supported by the Portal in a quicker and/or improved manner.

Researchers from the HIT project will examine the design, organization, use and evolution of the Health Portal. In particular, the researchers will study the development of new services on the portal, e.g. services that support shared care[1] programs (in Danish, "sammenhængende patientforløb").

Sundhed.dk have, for example, initiated the development of a service for shared care during pregnancy. This development process is to serve as a pilot project where the sequence of events and activities of different health care professionals (e.g. physician, midwife, and obstetrician) is relatively standardized and delineated in time (9 months). The pilot project is to serve as a generic model for developing further services to support other patient groups such as asthmatics or diabetics. The case is an interesting starting point since pregnant women constitute a "patient group" particularly active in acquiring information on progress and options during pregnancy, and during pregnancy care is shared or 'handed over' between different health care professionals and domains.

---

[1] The aim of shared care programs is to improve cooperation in the health care system across the primary/secondary interface. Shared care is applied when the responsibility for the health care of the patient is shared between individuals or teams who are part of separate organizations, or where substantial organizational boundaries exist.

HIT researchers are currently studying this pilot project development process with focus on the very different actors and concerns involved in development process, challenges of integrating the new Internet service with existing information systems, and potentials for designing successfully for collaboration between the very heterogeneous professional practices involved. Furthermore, the perspective of the "patient" and questions of patient empowerment are explored through participant observation of pregnancy to understand how a pregnant woman and family/relatives currently experience contact with and the 'hand over' between health care professionals and how information and 'patient expertise' on pregnancy, risks and possible care options is acquired.

4. ISSUES AND CONCERNS

It is often assumed that it is possible (and desirable) to develop universal theories and methods of IS development. However, as Avgerou (1), among others, has recently pointed out, development and implementation of information and communication systems takes place in a diversity of organizational and institutional contexts, each characterized by its own structures, rationalities, issues and concerns, which influence the way systems are developed and implemented. As researchers, we need to take this diversity in account when we develop our theories and recommendations to practitioners.

We expect that the HIT project will highlight the variety of context-specific issues that emerge in settings different from that of the business organization. As already mentioned in the introduction, the healthcare field represents a strikingly different organizational and institutional context (10) compared with many of the sectors where IS and PD is typically conducted.

Healthcare constitutes an organizational field where economic rationality is confronted by other substantive rationalities, which have not received much attention in the IS and PD literature. At least three different rationalities influence the health care sector in modern societies (1). The first sees health care as a public service. Public accountability and a fair share of services to citizens are two of its driving principles. The second sees health care as the domain of medical and pharmacy science, where scientifically competent professionals exercise their judgements about the best medical treatments for the benefit of their patients. The third rationality is bases on the premise that health care is a service that can (and should) be efficiently delivered through market forces. The inherent limitations and contradictions of these three rationalities strongly impact the development and implementation of information systems in healthcare.

At a more concrete level, the healthcare sector is characterized by being both highly institutionalized – in terms of professional roles and regulatory structures – and operationally and technically complex (5). Unlike business organizations, most healthcare organizations (e.g. hospitals) have a dual administrative structure of medical personnel and administration. These institutional structures increase the complexity of developing and implementing information systems in the healthcare field. To complicate matters even more, most advanced health care information is not confined in one organization, although they may be hosted or sponsored by a specific organization, e.g. a government agency or a large hospital (1). They are inter-organizational systems that connect hospitals, pharmacies, general practitioners, national health institutions, and patients. Thus, the study of CHIS takes us beyond the microcosm of a particular organization with well-defined boundaries, managerial hierarchies and user groups.

Altogether, this presents an important challenge to IS research in general and PD research in particular. We expect that when we venture into the relatively foreign setting of healthcare, pre-existing PD ideas, frameworks, concepts, and guidelines need to be reconsidered and probably reshaped to deal with the unique aspects of the setting. For example, consider how traditional PD categories such as managers and users might fit the healthcare field. Hospital administrators are, of course, managers. But what about physicians, are they managers, professionals or users? Patients, are they users, or are they merely 'consumers' of health care services, similar to e-business customers? And if we decide that patients are users (which we do when we talk about patient empowerment and CHIS), how should we represent or involve them in the IS development process? How should we account for the – often conflicting and contradictory – relations among the institutional roles of different professional groups such as physicians, nurses, pharmacists, and administrators? It will in many cases be very difficult to identify whom the users are and even more difficult to figure out how to involve them in the development process – especially when one takes the highly politicized environment and the complicated web of power relations and information asymmetries among the different groups into consideration. It is therefore our claim that it will be necessary to move beyond general PD concepts and approaches in order to come up with feasible strategies for participatory design in the healthcare field.

5. ACKNOWLEDGMENTS

This research in progress is partly funded by the Danish Research Council (grant no. 2059-03-0029).

6. REFERENCES

[1] Avgerou, C. *Information Systems and Global Diversity.* Oxford University Press, Oxford, UK, 2002.

[2] Ball, M.J. 'Hospital information systems: perspective on problems and prospects, 1979 and 2002.' *International Journal of Medical Informatics* 69, pp. 83-89, 2003.

[3] Ball, M.J. and Lillis, J. 'E-health: transforming the physician/patient relationship.' *International Journal of Medical Informatics* 61, pp. 1-10, 2001.

[4] Brennan, P. and Safran, C. 'Report of conference track 3: patient empowerment.' *International Journal of Medical Informatics* 69, pp. 301-304, 2003.

[5] Chiasson, M.W. and Davidson, E. 'Pushing the contextual envelope: developing and diffusing IS theory for health information systems research.' *Information and Organization* (in press), 2004.

[6] Committee on Quality Healthcare in America. *Crossing the Quality Chasm: A New Health System for the 21st Century.* National Academy Press, Washington, DC, 2001.

[7] Gawande, A. *Complications: A Surgeon's Notes on an Imperfect Science.* Metropolitan Books, New York, N.Y., 2002.

[8] Kuhn, K.A., Giuse, D.A. and Talmon, J.L. 'The Heidelberg Conference: setting and agenda for the IMIA working group on health information systems.' *International Journal of Medical Informatics* 69, pp. 77-82, 2003.

[9] Rohm, B.W.T. 'A vision of the e-healthcare era.' *International Journal of Healthcare Technology and Management* 4 (1-2), pp. 87-92, 2002.

[10] Scott, W.R., *Institutions and Organizations.* Sage Publications, London, 2001.

[11] Segal, L. 'The importance of patient empowerment in health system reform.' *Health Policy* 44 (1), pp. 31-44, 1998.