Appendix a – Project Proposal

IT Support for Shared Care

This project brings together healthcare professionals, system developers, and researchers for the purpose of exploring how IT systems can be designed and implemented to provide effective support of *shared care* programs. Such programs focus on increasing collaboration among healthcare professionals across sector boundaries and on improving communication between healthcare professionals and patients.

Background

The healthcare sector is one of the most critical components of modern, post-industrial economies. Healthcare spending accounts for a substantial – and increasing– portion of gross domestic product in all OECD countries (e.g. 13.0 % in the U.S., 9.7 % in Germany, and 8,5 % in Denmark). Despite the substantial resources that are allocated to healthcare, there is a general and growing dissatisfaction with the healthcare system. This dissatisfaction is, at least partly, rooted in a perceived lack of coordination, continuity and support in the care of individual patients, particularly in instances when treatment involves several healthcare providers such as hospital departments, outpatient clinics, home care assistants and general practitioners.

This is also the case in Denmark. A recent document from Amtsrådsforeningen (Danish Regions) depicts the situation as one riveted with chronic coordination problems [11]:

> The lack of continuity and coordination is one of the greatest problems facing the healthcare system. A large minority of patients experience their treatment as an orienteering race. (Translated from Danish)

Shared Care

Against this backdrop of growing critique of the current healthcare systems, politicians and healthcare providers alike are seeking to innovate and develop collaborative arrangements, often referred to as *shared care* (in Danish, *sammenhængende patientforløb*), to improve quality and efficiency of complex care services involving the combined effort of a variety of healthcare agencies and professionals. The development of such new inter-professional care arrangements can be observed not only in Denmark, but also in the UK, the Netherlands, Italy and other European countries. Shared care can be defined in the following way [9]:

> Shared care applies when the responsibility for the healthcare of the patient is shared between individuals or teams who are part of separate organizations, or where substantial organizational boundaries exist.

Shared care programs focus on improving co-ordination, collaboration and knowledge sharing among healthcare professionals across sector boundaries, as well as involving patients as active participants in the process. Research has shown that shared care significantly improves cooperation and quality of care [10], but also that the implementation of shared care programs is a long-term and difficult process [6, 8].

In Denmark, shared care models have primarily been introduced in relation to chronic illnesses, such as diabetes, asthma, and dementia [10].

IT Support for Shared Care

Establishing good communication across organizational and professional boundaries is perhaps the most crucial aspect to successful shared care programs. Shared care involves sharing information about patients at appropriate points in the care or treatment process. In most cases, this, however, is a highly distributed process, involving professionals in different locations (hospital departments, outpatient clinics, home care centers, general practitioners, etc.) that increases the need for electronic communication.

The challenge is to build collaborative health information systems (CHIS) that explicitly support the interdependent roles of patients and healthcare professionals [2]. The development of such systems requires that researchers and designers look beyond traditional concepts of electronic patient records (EPR) and realize that healthcare work is highly interactive and communicative in nature and that optimal outcomes are achieved when patients become active participants in the healthcare process [2].

While traditional EPR solutions focus on the computerization of patient records within the domain of individual institutions [1], the development of CHIS addresses the problem of supporting *cooperation across institutional and/or professional boundaries,* in highly heterogeneous networks of healthcare professionals, home care workers and patients. This is not a simple or straightforward task. Research on organizational communication has consistently shown that working *across* functional boundaries and sharing knowledge is problematic, because knowledge is localized, embedded and invested in practice [see e.g. 3, 4]. Thus, the development of effective CHIS involves resolving not only technical problems, but also organizational and cultural issues related to overcoming the "knowledge boundaries" that exist between different professions in the healthcare system [8].

Denmark is in a good position to develop IT solution that support shared care. The Danish healthcare system is technologically advanced and at the same time in front with regard to developing shared care programs [10]. In accordance with the National IT Strategy for the Healthcare System 2003-2007 [7] some important initiatives have already been taken. In this project, we focus on two important examples:

- Sundhed.dk (the Public National Healthcare Portal) has started the development of an electronic medical record (in Danish, *elektronisk vandrejournal*) to support shared care programs within obstetrics.
- H:S (Copenhagen Hospital Corporation) is working on the experimental development and implementation of a system (*DiabetesRASK*) to support communication between healthcare professionals and diabetes patients.

The long-term goal of these projects is to develop generic models of shared care systems, which eventually can be applied to the treatment of a whole range of different diseases.

Research Objectives

This project investigates how IT can best be used to support shared care and has three main objectives:

- To *identify and assess current approaches* to developing ICT support for shared care programs, in Denmark and internationally. The study will take a critical perspective on existing initiatives, raising key technological and organizational questions that emerge from a comparison of various current models and systems.

- To *identify and assess the necessary pre-conditions* for successful development and implementation of shared care programs, including the required ICT systems. The study will seek to systematically identify and classify the key technical, organizational, and cultural factors that facilitate or impede successful development.
- To *develop and evaluate generic models and prototypes of CHIS applications*, and to propose concepts, methods and tools to support the design, implementation, and continuous development of such systems

Research Approach

The approach adopted in this project is *analytical* and *constructive.* It is analytical in seeking to grasp the complexities of contemporary healthcare work and the technical, organizational, and cultural challenges involved in developing and implementing successful IT-support for shared care. It is constructive in striving to develop generic models and prototypes of CHIS designed to support shared care.

The research will combine theory building and in-depth case studies with action research, carried out in close collaboration with our partners in the healthcare sector. By combining a variety of qualitative research methods (e.g. participant observation, document analysis, and interviews), we seek to ensure not only the practical relevance of the research, but also the validity and reliability of the results.

Given the complex socio-technical nature of the object of study, it is necessary to draw on concepts and theories from a number of disciplines, including medical informatics, information systems, computer-supported cooperative work (CSCW), computer-mediated communication, and participatory design.

Project Plan and Activities

The project involves three main activities: (1) a study of "state of the art" with regard to shared care programs and IT, (2) case studies of IT and shared care projects in the Danish healthcare sector, and (3) development of generic models and prototypes as well as methods and tools to support the development process.

State of the Art. The study will consist of collecting practical experience with IT-support for shared care in other EU countries (primarily the UK and the Netherlands) combined with a systematic literature review focusing on key concepts, models and theories related to shared care. Because of the interdisciplinary nature of research in healthcare IT, an important goal will be to sum up and synthesize research across a variety of disciplines (e.g. health promotion, management in medicine, medical informatics, information systems, and CSCW).

Case Studies. A number of case studies will be carried out in close collaboration with healthcare providers, IT consultants and suppliers of hardware and software solutions. The case studies will concentrate on IT-support for shared care programs within the areas of obstetrics and diabetes. One set of case studies will focus on the development and use of the DiabetesRASK system, developed by H:S and in the process of being implemented at five diabetes clinics in Copenhagen. A second set of case studies will focus on the development and use of an electronic medical record (in Danish, *elektronisk vandrejournal*) designed to support obstetrics shared care. Sundhed.dk is responsible for the development of this system. The purpose of these case studies is to identify and investigate technological, organizational and cultural issues that impact the successful implementation of CHIS for shared care.

Development of generic models and prototypes. Based on the survey of the state of the art and a first round of 'exploratory' case studies, a number of generic models and prototypes of CHIS will be developed, tested and evaluated as to their measurable effects using quantitative as well as qualitative methods. This will take place in close collaboration between university researchers and practitioners from the healthcare system and the involved IT companies (in a second round of 'focused' case studies). In addition, we will propose concepts, methods and tools to support the design and implementation process. The overall aim is to develop innovative socio-technical solutions to the problem of integrating healthcare work across institutional and professional boundaries.

The project is expected to start January 1, 2005 and finish December 31, 2008. It is organized in three partly overlapping phases. During *phase one* (lasting approx. 1 year), the state of the art study will be finished and two exploratory case studies will be carried out in collaboration with Sundhed.dk and H:S. In *phase two* (also lasting approx. 1 year), we will focus on key issues identified in phase one and carry out a number of in-depth or 'focused' case studies, designed to further theory building and lay the ground for the development of generic models and prototypes in *phase three* (lasting approx. 2 years). During phase three, the intention is to test and evaluate selected models and prototypes in real-life situations. The research plan is detailed in appendix b.

Expected Results

The project is designed to further cooperation among universities, healthcare providers and private IT companies. The aim is to stimulate cross-fertilization of ideas from the different sectors and produce new knowledge of interest to both researchers and practitioners.

The project will contribute to *IT research* by advancing the emergent, multidisciplinary field of healthcare IT and providing new insights into the socio-technical problems of communicating and collaborating 'across boundaries,' in heterogeneous networks of organizations, people, and computers. The healthcare context is foreign to many IT researchers and healthcare poses significant challenges to existing theories about design and implementation of IT in organizations [5]. By taking on these challenges, the project can expand the general body of knowledge about IT in organizations as well as contribute to the more specific fields of CSCW and CMC.

The project will contribute to *healthcare practice* by providing healthcare providers with new perspectives and insights on how to design and implement effective and innovative CHIS solutions to support shared care. The in-depth case studies of how IT can play a role in the development of effective shared care programs will offer practical experience and lessons learned, which may prove highly valuable in connection with future efforts to stimulate the use of IT in healthcare.

Finally, the project will benefit *Danish IT industry* by developing and evaluating new generic models and prototypes of IT applications for shared care in close collaboration with the intended users. In this way, the project will help Danish IT companies establish relationships with customers and users within the healthcare sector and build a knowledge base, which may give them a sustained competitive advantage in the world market for shared care applications.

Partners

The project will be carried out by an established group of IT researchers from the IT University of Copenhagen, Roskilde University and the Technical University of Denmark

in close collaboration with Sundhed.dk (the Public National Healthcare Portal), H:S (Copenhagen Hospital Corporation) and the IT companies Acure and Rambøll Management.

The research group spans a number of relevant disciplines (information systems, CSCW, computer-mediated communication, and participatory design) and has extensive experience with this type of research collaboration with external partners. The partners from the healthcare sector and the IT industry are among the leaders in the field and together they muster considerable expertise with regard to systems design and the integration of IT in healthcare work. Details about the organization and management of the research collaboration may be found in appendix b.

References

1. Ball, M.J. (2003). 'Hospital information systems: perspective on problems and prospects, 1979 and 2002,' *International Journal of Medical Informatics* 69: 83-89.
2. Brennan, P. & Safran, C. (2003). 'Report of conference track 3: patient empowerment,' *International Journal of Medical Informatics* 69: 301-304.
3. Brown, J.S. and Duguid, P. (2001). 'Knowledge and organization: a social-practice perspective,' *Organization Science* 12 (2), pp. 198-211.
4. Carlile, P.R. (2002). 'A pragmatic view of knowledge and boundaries: boundary objects in new product development,' *Organization Science* 13 (4), pp. 442-455.
5. Chiasson, M.W. and Davidson, E. (2004). 'Pushing the contextual envelope: developing and diffusing IS theory for health information systems research,' *Information and Organization* (in press).
6. Hardy, B., Mur-Veeman, I., Steenbergen, M. and Wistow, G. (1999). 'Inter-agency services in England and the Netherlands, a comparative study of integrated care development and delivery,' *Health Policy* 48, pp. 87-105.
7. Indenrigs- og Sundhedsministeriet (2003). *National IT-strategi for sundhedsvæsenet 2003-2007* (in Danish), Indenrigs- og Sundhedsministeriet, Copenhagen, Denmark.
8. Mur-Veeman, I., Eijkelberg, I. and Spreeuwenberg, C. (2001). 'How to manage the implementation of shared care,' *Journal of Management in Medicine* 15 (2), pp. 142-155.
9. Pritchard, P., and Hughes, J. (1995). *Shared Care – The Future Imperative,* Royal Society of Medicine Press, London, UK.
10. Rubak, S.L.M., Mainz, J. and Rubak, J.M. (2002). '"Shared Care" – et integreret samarbejde om patientforløb på tværs af sektorgrænserne' (in Danish), *Ugeskrift for Læger* 164, pp. 5256-5261.
11. Sundhedsfagligt Forum (2004). *Sammenhæng i søgelyset* (in Danish). Amtsådsforeningen, Copenhagen, Denmark.