Project proposal: HealthcareIT - HIT

1. Empowering Patients

– IT-support for highly distributed and heterogeneous networks of people, organizations, and resources

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 (Kuhn et al., 2003; Segal, 1998). *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 (Brennan & Safran, 2003). 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) (Ball & Lillis, 2001). Better outcomes, lower costs, and higher patient and provider satisfaction are likely to be the result.

This shift towards patient empowerment provides new challenges for the development of health information systems (HIS) (Rohm, 2002). Traditional HIS-initiatives focus on the computerization of patient records, providing order-entry and results-reporting functionality within the domain of individual institutions (Ball, 2003). However, given the growing complexity of contemporary healthcare (Gawande, 2002), 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 (Brennan & Safran, 2003). 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." (Committee on Quality Healthcare in America, 2001). 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). In this project, we, therefore, focus on ways to improve the design, implementation and use of CHIS.

2. Research Objectives

The main purpose 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 main 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 significantly contribute to research and development, not only within the field of medical informatics, but also more broadly within the field of IT research. By focusing on collaborative HIS, we want to encourage attention to the many new challenges that confront IS designers involved in creating IT systems under modern conditions of flux and instability (Nardi et al., 2002 ; Truex et al., 1999). In the past, many system development projects took place in

relatively stable settings (often within a single organization) and user groups were usually well defined, relatively homogeneous, often collocated, and with clearly defined, stable roles. However, these conditions are rapidly becoming obsolete (Castells 1996). Today, we are witnessing massive increases in the uptake of advanced communication technologies and many organizations operate in an increasingly distributed manner. Organizations are also experimenting with new more 'virtual' organizations forms and the creation of electronic links to suppliers, partners, and customers. Understanding these trends and their implications is crucial to designing IT systems that meets users' needs in today's changing world.

In terms of the research areas described in the *Oplæg til IT-forskningsstrategi,* the project will contribute to research within three fields: *information systems; IT, media and communication;* and *systems development and use.*

3. Subprojects

The HIT project consists of three subprojects, each focusing on a specific aspect of CHIS. The first project focuses on the issue of *communicating* large volumes of intrinsically complex and dynamic healthcare information to patients. The second project aims at supporting *consultation* and the creation of patient communities, while the third project focuses on the *collaborative* aspects of CHIS.

Common to all three projects is that they, in various degree, deal with: (1) the design and implementation of new, innovative IT systems intended to support highly distributed and heterogeneous populations of users, and (2) contexts characterized by emergent organizational forms, fuzzy boundaries, fluid roles, and shifting configurations of communication partners and collaborators.

All three project will be carried out in close cooperation with public and private healthcare organizations, in the following referred to as the project's partners.

Communication of health information

The aim of this project is to improve the design and deployment of CHIS designed to disseminate health information to specific patient groups as well as the public at large. The project will study the technical, linguistic, and organizational challenges involved in creating such systems; evaluate existing systems; propose design principles, frameworks and methods to support the design process; and, together with the partners, develop prototypes that illustrate new, innovative design ideas, which allow for more interactivity and 'customized' information.

Four project partners – *Den fælles offentlige Sundhedsportal, Kræftens Bekæmpelse, Novo Nordisk IT,* and *AstraZeneca* – are already involved in the creation of web sites that offer access to knowledge about diseases and their treatment, as well as general and specific advice about health issues. The aim of these sites is either health promotion (encouraging behavioral change) or health education (helping the patient to better cope with a condition). Some of these sites have more than 60.000 visitors per week and they are prototypical examples of the state of the art for this type of health information systems. The content of these existing sites are, however, still relatively general, not targeted at the individual patient's problems and interests.

Consultation and patient communities

The aim of this project is to explore new types of more interactive CHIS that support patients' consultations with physicians and other healthcare professionals as well as the formation of

active communities of patients with similar conditions, e.g. diabetes or coronary diseases. These systems may help patients seek (and discuss), not only general health information, but also information related to their own special condition and needs. Furthermore, they may allow patients to actively participate in decisions surrounding their own care.

Interactive healthcare systems of this type are still in their infancy. However, one of the partners, *Den fælles offentlige Sundhedsportal,* is actively engaged in developing and implementing the first generation of such interactive and consultative CHIS applications. The development of the first applications and services is planned to begin in Spring 2004.

Home Care

The aim of this project is to study the use of mobile devices in home care and together with the partners develop and evaluate prototypes of new applications of such devices. In addition the project will explore how such applications may transform established work-based communication practices and support the empowerment of patients receiving home care. The development of applications for this type of mobile devices, which are characterized by small displays and limited (wireless) network capabilities, requires much attention to interaction design and the severe limitations of speed and security caused by the underlying wireless communication network.

One of the partners, *Sundhedsforvaltningen i Københavns Kommune,* has for some time used mobile devices to support coordination and collaboration in a more or less stable network of nurses, home care assistants, and administrators. In the near future, they plan to also include the municipality's residential homes ('plejehjem'), bringing the total number of potential users up to more than 10.000.

4. Research Approach

The approach adopted in this project is *analytical* in seeking to understand the complexities of contemporary healthcare work and the challenges involved in creating CHIS, and *constructive* in striving to develop prototypes of innovative applications as well as concepts, methods, and tools to support the design and deployment of CHIS.

This is to be achieved by combining action research with different types of field studies. 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 and applicability of the research, but also the validity and reliability of the results. The project explicitly addresses the methodological issues involved in interdisciplinary research and seeks to contribute to the ongoing discussion of how practice-based, interdisciplinary IT research should be conducted to guarantee academic quality.

Given the communicative and interactive nature of healthcare work and the social nature of the design and implementation processes that we want to improve, then it is necessary to augment computer science by drawing upon (and contributing to) a number of IT research disciplines that address technical as well as social, organizational and cultural issues. These include:

- Participatory Design (PD)
- Computer-Supported Cooperative Work (CSCW)
- Interaction Design
- Computer-Mediated Communication (CMC)

These IT research disciplines and related 'reference disciplines' like sociology, organizational studies, and media studies, constitute the project's theoretical foundation. However, to promote synergy and 'cross-fertilization' among the various disciplinary fields represented in the project group, all research activities will be carried out in interdisciplinary teams. Furthermore, we anticipate that practitioners (i.e. system designers and healthcare professionals from the participating public and private organizations) and patients will take part in many of the activities.

5. Project organization and plan

HIT is a sizable, multi-institutional project involving a number of researchers, which requires careful coordination. Finn Kensing, the IT University of Copenhagen, will act as *project manager*. The project manager, in collaboration with two senior researchers representing Roskilde University and The Technical University of Denmark, form a *management team* of the project. In coordinating the activities of HIT's researchers, the management team will consult periodically with an *advisory panel* composed of representatives from the private and public organizations taking part in the project in order to ensure the maximum transfer of knowledge.

HIT is designed to run for four years and is organized in two phases. During *phase one* (lasting 1.5 year), a number of ongoing initiatives in the partner organizations will be the focus of explorative case studies within each of the sub-projects described in section 3. The aim of these studies is to explore the CHIS applications as well as design practices and use patterns in order to identify key issues for subsequent focus studies in phase two. Each of the explorative studies will be documented in a report. In addition, they will provide feedback to the partners – supporting future development through an analysis of their applications and their use, their design work, and internal work organization. At the end of phase one we will produce a report summarizing the results from these explorative case studies. This report will compare and integrate results across the organizations within each sub-project, providing a foundation for establishing the focal topics for research in phase two.

During *phase two* (lasting 2.5 years) we will focus on selected themes in relation to CHIS, based on their relevance for deepening our theoretical understanding as well as their practical relevance for the partners. An important criterion for selecting the themes will be their ability to create commitment from the partners and the researchers to engage in experiments with the development of innovative prototypes and conceptual design of IT systems, communicative practices and organizational forms, as well as methods and conceptual frameworks.

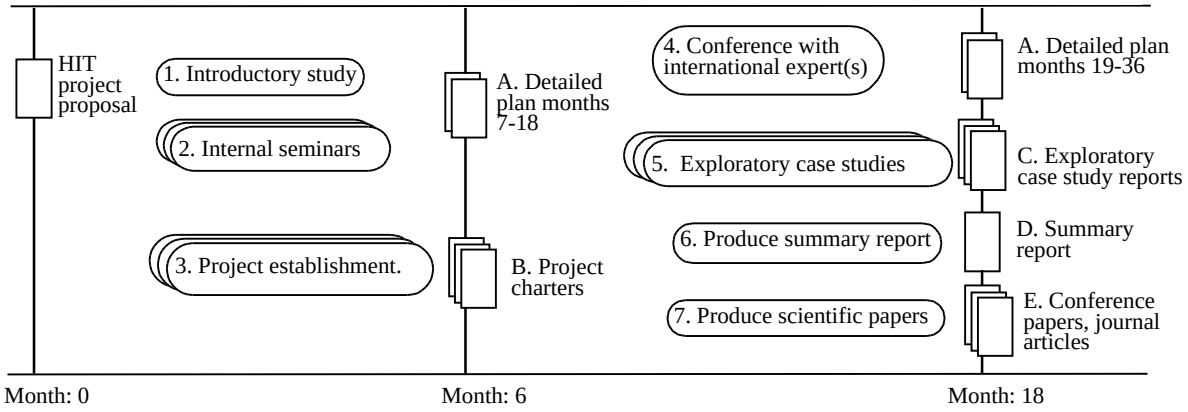
Organized in focus studies, the second phase will primarily consist of action research aiming at increasing knowledge through the participation in the phenomenon studied. In addition, verification studies will be carried out to establish the degree to which findings from focus studies can be generalized across organizational contexts. This research will again result in design, implementation, and evaluation of working prototypes of different kinds of CHIS as well as reports based on each of these as well as conference papers, journal articles, and a book. The book will give a comprehensive picture of the challenges met by the participating organizations, while providing further recommendations on how to harvest the potentials of CHIS applications in other settings. In conjunction with teaching and consultancy, the researchers will offer to participate in the organizations' implementation of improvements suggested via detailed study in phase two.

In both phases, we will arrange conferences or workshops featuring internationally acknowledged experts as well as researchers and professionals from participating organizations. The aim is to create synergy between the Danish and international research communities and between research and the Danish healthcare sector. An important part of these conferences/workshops will consist of developing scenarios for improving CHIS applications. Anchored in the concerns of the patients and partners involved, these scenarios will aim to be both innovative and realistic for future development. A baseline plan for both phases is presented in figure 1.

Activities (the numbers refer to figure 1):

1. Introductory study including survey of literature, establishing cooperation with other national and international research groups, and with participating companies/organizations.
2. Internal seminars for the HIT research group, for presenting and discussing the different research backgrounds represented by the group and finalizing a detailed research plan for the project.
3. Project establishment planning and negotiating HIT's cooperation with each participating partner to be documented in a project charter with each organization.
4. Conferences with internationally acknowledged experts and project participants from the partner organizations. Cross-organizational feedback will be provided via evaluation and comparison of results from the field studies.
5. Exploratory multidisciplinary case studies by HIT researchers in close cooperation with project team members from the partner organizations. These case studies map the organization's utilization of the potentials of relevant technologies. Following evaluation, an exploratory case study may lead to a focus study.
6. Produce summary report comparing and benchmarking exploratory case studies, and establishing the focal themes for subsequent activities.
7. Produce scientific papers for presentation at international conferences and publication in relevant international journals. Central papers and new research experience will be published as a book at the end of the project.
8. Multidisciplinary focus studies conducted by HIT researchers in close cooperation with project team members from the partner organizations. These studies will develop themes selected from exploratory studies. As action research, these studies will include experiments with the development of innovative prototypes and conceptual design of IT systems, communicative practices and organizational forms, and methods and conceptual frameworks contributing to the development of effective core competencies.
9. Researchers and practitioners from the partner organizations will develop prototypes and conduct "proof of concepts test" of potential new CHIS applications.
10. Verification studies by researchers in close cooperation with project team members from the partner organizations. These studies aim to verify results from the HIT project, investigating the generalizability of concepts, models and solutions derived from HIT's activities while seeking similarities and/or differences between situations analyzed and other implementation contexts.

HIT research plan, month 0-18. Baselines at project start and after 6 and 18 months.



HIT research plan, month 19-48. Baselines after 36 and 48 months.

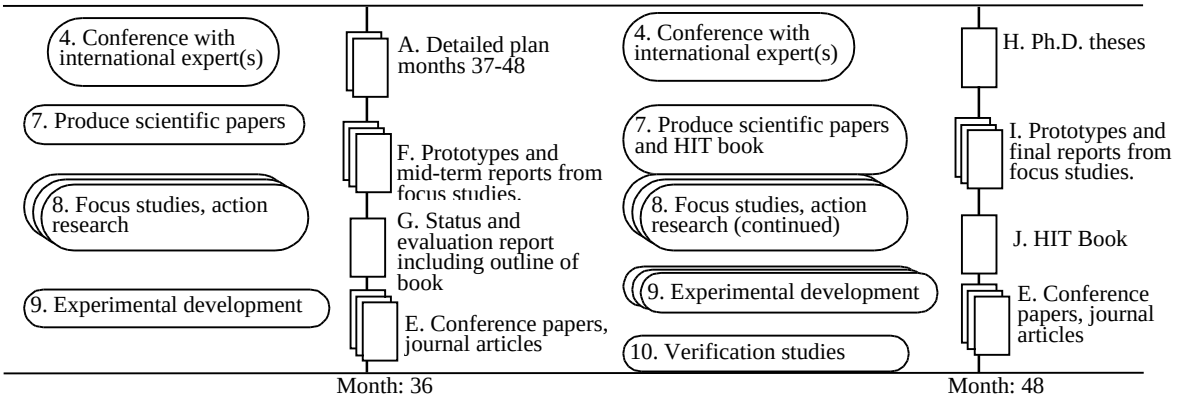


Figure 1. HIT baseline plan

Products:

A. Detailed plans for meeting the next baseline are produced before each major phase.
B. Project charters describing the cooperation with each partner to be included in HIT's activities.
C. Reports describing each exploratory case study which identify themes for focused studies and provide feedback to the partners.
D. Summary report from all exploratory case studies. This report compares and synthesizes the results from these studies and establishes a basis for developing benchmarks and choosing themes for subsequent focus studies.
E. Scientific papers and articles reporting findings from the HIT project for submission to international conferences and academic journals.
F. Prototypes and mid-term reports documenting status, preliminary results, and planned activities from the focus studies.
G. Status and evaluation report presenting results obtained by the HIT project to date with plans for the continuation of the project and an outline for the HIT book.
H. Ph.D. theses based on research carried out within the context of HIT.
I. Prototypes and final reports from focus studies, experimental development projects, and verification studies conducted in parallel with focus studies.
J. Book reporting findings from the HIT project. The book will offer descriptive case analyses of the challenges met by participating companies and organizations and insights for harvesting the potentials of relevant technologies.

6. Intended results and their dissemination

The project will respond to demands from the Danish society by its contribution in terms of a - in relation to its size - substantial amount of Ph.D. degrees in an area of great societal importance. Moreover, the project is explicitly designed to further sustained cooperation across public research institutions, private companies and public organizations in the health sector. The HIT project is designed to provide new and timely knowledge for both the research community and for the professional groups within the partner organizations and the health sector at large. More specifically, the intended results can be divided into six broad categories:

Empirical studies. The project will produce a number of detailed empirical case studies that examine the design and use of CHIS applications. These studies will focus on the applications, design practices and use patterns as well as how these activities are structured in organizational and cross-organizational contexts. They provide the empirical basis for the development of new theoretical frameworks as well as concepts, methods and tools for improving practice.

Theoretical frameworks. An important goal of the project is to create dialogue and synergy among the multiple theoretical perspectives and vantage points represented by the participating researchers. We aim at the development of theoretical frameworks for interdisciplinary IS research. While not attempting to integrate the different perspectives into one theory, we will focus, rather, on increasing the capacity of each to make appropriate and positive use of a diversity of perspectives on design, organization, communication and IT.

Prototypes, concepts, methods and tools to support practice. The project contributes to practice by development of innovative prototypes and conceptual design of IT systems, communicative practices and organizational forms, and methods and conceptual frameworks contributing to the development of effective core competencies. The aim is to guide organizations in (1) designing CHIS applications, (2) managing design and use processes, and (3) integrating CHIS applications in collaborative work processes in distributed organizational forms.

Postgraduate teaching. The project will contribute to the production of Ph.D. dissertations within its domain. Also, all involved researchers will ensure quick dissemination of the projects' intermediate and final results through their ongoing postgraduate teaching activities, especially master thesis supervision.

Laboratory for Innovative Design. The project will establish a Laboratory for Innovative Design in the new building of the IT University of Copenhagen. The purpose of the laboratory is to create a forum for studying and developing design competence. It is inspired by the work of D. Schön (1991**)** who at MIT pioneered an approach to "Educating the Reflective Practitioner" that involves highlighting the role design materials play in the development of design competence. The lab will be a physical space equipped with video recording, editing, and presentation tools as well as various tangible materials that allow for developing and conveying design ideas. The lab will be used by this project as well as by postgraduate students, and it will work as a showcase for courses focusing on the development of design competence. Further, private and public companies may be offered the opportunity to use the lab for experiments and reflections on design practices.

Wider dissemination of results. Dissemination of results from the project will therefore take a number of forms. First, the partner organizations will have direct access to information through their involvement in the research activities and their participation in internal workshops or conferences. Second, results will be disseminated through international conferences and research seminars attended by national and international research colleagues, as well as professionals from the participating organizations. Third, results will be published in various conference

papers and scientific journal articles along with a book presenting both the analytical and constructive results of the project. Fourth, selected information will be available to the public directly via a World Wide Web site, which will also be used to support internal communication. Finally, as mentioned above, all involved senior researchers will ensure that project results are communicated to postgraduate students through their teaching.

Relations to strategic plans.

The IT University has recently prioritized and organized the major part of its research in relation to three themes. The intent behind this application is to gather a group of researchers from the university - and from neighboring universities with whom they have successfully cooperated before - to start a new initiative within one of the themes: Software Production. At the Technical University of Denmark the project activities will contribute to the establishment of the Center for Information and Communication Technologies (CICT), a strategic initiative carried out in cooperation with Nokia, Siemens, Motorola, and other industrial partners.

7. Partners

HIT will cooperate with a number of private and public companies and organizations in Denmark. Through letters of intent the following partners have expressed their interest in being involved in the project: *Novo Nordisk IT, AstraZeneca, Kræftens Bekæmpelse, Sundhedsforvaltningen Københavns Kommune* and *Den fælles offentlige Sundhedsportal.*

Novo Nordisk IT and *AstraZeneca* are pharmaceutical companies. They have developed websites that provide company neutral information and pieces of advice about living with the diseases for which they produce medicine. The sites also allow for chats with other patients and an expert team answer questions.

Kræftens Bekæmpelse is a private association that conducts research about cancer, supports patients and their families, and provides information on how to prevent cancer. Among the association's initiatives is a web site oriented towards schools. The plan is to provide a common information space for school classes working on projects about cancer.

Sundhedsforvaltningen Københavns Kommune is in the process of introducing mobile devices to support the coordination and exchange of information in a network of nurses, home care assistants and administrators. They have plans for including residential homes into the network bringing the number of potential users up to more than 10,000.

Den fælles offentlige Sundhedsportal is a public initiative that is about to launch a web portal that gives citizens access to information about healthcare. In Spring 2004 the plan is to start a project that expands the services offered by supporting coordination and consultation among individual patients, general practitioners and hospital wards.

8. Applicants

The applicants form an interdisciplinary group of researchers representing three universities in the Copenhagen area. All senior applicants have worked together successfully in earlier projects. Their professional background encompasses computer science, sociology, and information systems. More specifically their current areas of interest include: participatory design (PD), computer supported cooperative work (CSCW), software engineering (SE); computer mediated communication (CMC), and human-computer interaction (HCI).

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