

The patients' health informatics tool - Exploring the possibilities A Web 2.0 application for men with prostate cancer

Af Charlotte D. Bjørnes

V-CHI – Virtuelt Center for Sundhedsinformatik Aalborg Universitet, oktober 2011





















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The patients' health informatics tool - Exploring the possibilities A Web 2.0 application for men with prostate cancer

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Aalborg, Oktober 2011

Forord

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Nærværende rapportserie, udgivet af Virtuelt Center for Sundhedsinformatik, formidler resultater og erfaringer fra forsknings- og udviklingsprojekter i sundhedsinformatik. Det er hensigten, at rapporterne primært skal præsentere materialet på et tidligt tidspunkt i forsknings- og udviklingsprocessen og dermed give mulighed for fagligt feed-back til forfatterne. Rapporterne kan således indgå som et væsentligt element på vejen fra forsknings- og udviklingsside til publikation i internationalt peer-reviewed tidsskrift. Rapportseriens redaktionskomite antager derfor også manuskripter, der ikke præsenterer afsluttede færdige arbejder. Man ser på manuskriptets egnethed som indlæg i en faglig diskussion og opfordrer læserne til at kommentere og kritisere rapporterne, enten direkte til forfatterne eller gennem redaktionskomiteen. V-CHI kan, hvis redaktionskomiteen finder det relevant, udgive supplement til og reviderede versioner af allerede udsendte rapporter. Status for en given rapport og dens efterfølgende "tråde" vil være tilgængelig på www.v-chi.dk. Kun ved åben konstruktiv kollegial kritik kan vi opnå den nødvendige kvalitet i vores arbejde.

Specifikt om nærværende rapport

Projekt "Online patientbog" er gennemført i samarbejde mellem Aalborg Sygehus og Aalborg Universitet som et centralt element i det ph.d.-projekt, der er dokumenteret med ph.d.-afhandlingen: The patients' health informatics tool - Exploring the possibilities. A Web 2.0 application for men with prostate cancer. Ph.d.-studiet er gennemført af sygeplejerske, cand.cur., ph.d. Charlotte D. Bjørnes med vejledning af professor Christian Nøhr fra Aalborg Universitet, Institut for Planlægning og Virtuelt Center for Sundhedsinformatik, og med projektvejledning fra Aalborg Sygehus, Århus Universitetshospital: Sygeplejerske, cand.cur., ph.d. Charlotte Delmar og sygeplejerske, cand.cur., ph.d. Birgitte S. Laursen.

Patienter og sundhedsprofessionelle har været inddraget i design og udvikling af det nye Internetbaseret informations- og kommunikationsredskab Online patientbog med afsæt i spørgsmålet: Hvad har patienten behov for, for at være tryg i sit patientforløb? Svarene herpå er omsat til indhold og funktioner i redskabet, der er udviklet i et tæt samarbejde med it-eksperter og eksperter i klinisk praksis. Dermed har fokus været at imødekomme patienternes behov for information og kommunikation i deres behandlingsforløb.

Online patientbog blev implementeret i klinisk praksis på Aalborg Sygehus september 2009. Ved at kunne tilbyde mænd med prostatacancer adgang til en personlig Online patientbog får sundhedsprofessionelle i klinisk praksis et konkret arbejdsredskab i kontakten til patienterne. Redskabet giver den enkelte patient adgang til generel information, individuel monologbaseret information og dialogbaseret online kontakt med identificerbare og kendte sundhedsprofessionelle og medpatienter.

Evaluering af Online patientbog, efter det første års drift, viser, at redskabet har stor værdi for patienterne. Det Internetbaserede informations- og kommunikationsredskab gør det muligt at være den aktive patient, fordi redskabet bidrager til tryghed, frihed, indsigt og overblik.

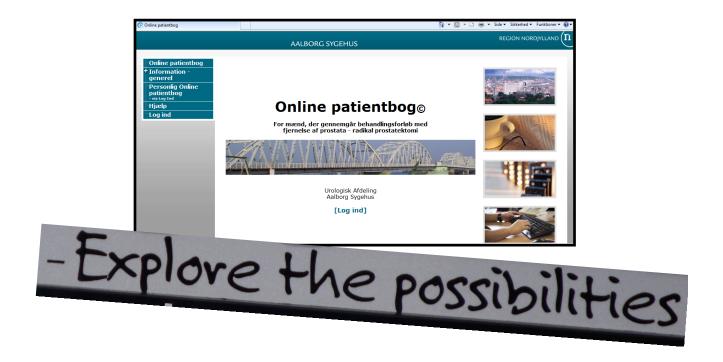
Med brugerinvolvering som et centralt element igennem hele projektet skylder vi stor tak til patienter, der har deltaget i interview, test af redskabet eller har evalueret deres oplevelser som brugere af Online patientbog. Ligeledes en stor tak til de mange eksperter fra klinisk praksis, der dækker forskellige faggrupper, og systemudviklere og programmører fra Region Nordjyllands IT udviklingsafdeling.

Charlotte D. Bjørnes Virtuelt Center for Sundhedsinformatik Institut for Planlægning Aalborg Universitet Oktober 2011

PhD Thesis

The patients' health informatics tool - Exploring the possibilities

A Web 2.0 application for men with prostate cancer



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Abstract

A considerable focus in the PhD project was to explore the qualitative effects of a new health informatics tool. The tool was designed, developed, and implemented as a part of the research process. Using Web 2.0 technologies, the health informatics tool aimed to meet the information and support needs of a group of patients, specifically men with prostate cancer undergo-Book® radical prostatectomy Thus. the Online Patient ing surgery. (www.onlinepatientbog.dk) was designed as an example of a patients' health informatics tool. The evaluation generates insights in the tool's ability to meet the patients' needs during their course of treatment and care. This substantiation of the qualitative effects contributes to an understanding about the potential of such health informatics tools.

To explore the possibilities of health informatics tools became the central part of the PhD project. However the primary focus was to get an insight in how men with prostate cancer experience a course of treatment based on short stays at the hospital. The number of men diagnosed with prostate cancer has increased by more than 51 percent from 2000 to 2009. Previously, these men were hospitalized up to 19-20 days in relation to the surgery. Today the stays in hospital are less than three days, and the time still decreases towards planned discharge the day after surgery. In addition, the men have to visit the outpatient clinic numerous times both before and after the surgery. The short contacts reduce the patients' time for information and support. To explore consequences experienced by the patients the existing literature was searched through and secondary an interview study was completed. The literature survey and the interview study substantiated the relevance in designing a new health informatics tool as the men experienced lack of information, support, and dialogues with the healthcare professionals in their course of treatment and care. These two studies also depicted how a new health informatics tool could be design to meet the needs of these men.

Based on innovative thinking and using a bottom-up design the patients as well as the health-care professionals were involved throughout the designing and developing of the Online Patient Book[©], by applying various participatory methods, such as interviews and design workshops. Subsequently, the health informatics tool was implemented as a part of the standard care in a specified clinical practice. Patients' experiences, as users of the resource tool, were generated by Internet-based interviews.

This research project substantiates:

• Qualitative effects of health informatics tools, which are designed using a bottom-up approach, developed, and implemented to meet the needs of a specific group of patients in a specific context

- ► That men older than 50 years are active Internet users, when healthcare professionals invite the men to use a Internet application, which combines Web 1.0 and Web 2.0 technologies
- ► That men experience accessibility of the healthcare professionals via the asynchronous environment Web 2.0 technologies offer
- ► That the patients' need for general and individualized information can be accommodated by adding a Web 1.0 and Web 2.0 application as a part of the standard care
- ► The potential of integrating Internet technologies in the future patient information and communication
- The potential of health informatics tools that integrate the patients needs in the design. This thesis illustrates how working with and in a dialectical connection between theory and practice throughout the research project develop nursing practice in a specific clinical setting. At the same time the dialectical connection generated knowledge which has applicability to go beyond the immediate setting, in relation to insight in:
 - ▶ How men with prostate cancer experience their contacts to the healthcare professionals in a course of treatment and care based on short stays at the hospital. For example the importance of both general and individualized information and support
 - How men as patients experience and use a health informatics tool as their tool in their course of treatment. The tool empowers the men, as it assists the patients in being active participants in their own care with the freedom to use the tool as and when needed. These health informatics tools can enhance the continuity of care, through the patients' increased ability to stay in control, which reduce the dependence on the healthcare professionals
 - ▶ How it is important that future health informatics systems incorporate the needs of the patients, during the design phase. A primary focus on the patients could support a health informatics design that compasses the patients' needs and thereby enable the patients to continue their normal day of life
 - ▶ How patients and healthcare professionals can participate in both the designing and developing phase via various participatory methods based on a bottom-up design and guided by the hermeneutic philosophy, which emphasizes the importance of dialogues in generating new knowledge.

Abstract in Danish

Patienternes sundheds-it redskab – en udforskning af mulighederne.

En Web 2.0 applikation for mænd med prostata cancer.

Et væsentligt fokus i ph.d.-projektet var at undersøge mulige kvalitative effekter ved et nyt sundheds-it redskab, der blev designet, udviklet og implementeret som en del af forsknings-processen. Online patientbog[©] (www.onlinepatientbog.dk) blev udviklet som et eksempel på patienternes sundheds-it redskab. Ved at anvende Web 2.0 teknologi var hensigten at imøde-komme behov for information og støtte hos mænd med prostata cancer, der gennemgår kirurgisk behandling i form af radikal prostatektomi. En kvalitativ evaluering af redskabets anvendelse i klinisk praksis bidrog til en indsigt i og forståelse for potentialet i sundheds-it redskaber, der specifikt udvikles til at imødekomme patienternes behov i deres behandlingsforløb.

Forskningsprojektet blev indledt med en undersøgelse af, hvordan mænd med prostata cancer oplever kontakten med sundhedsprofessionelle i kirurgiske behandlingsforløb, der består af en kort indlæggelse med ambulante konsultationer før og efter operationen. Antallet af mænd, der diagnosticeres med prostata cancer har været stigende. Fra 2000 til 2009 steg antallet med mere end 51 %. Mænd der behandles med kirurgisk fjernelse af prostata var tidligere indlagt i op til 19-20 dage. I dag er indlæggelsen i forbindelse med operationen mindre end tre dage, med fortsat reduktion hen mod planlagt udskrivelse dagen efter operation. Et litteraturstudie og efterfølgende et interview studie blev gennemført for at afdække mulige konsekvenser af den dermed reducerede tid for information og støtte fra sundhedsprofessionelle. I studierne afdækkes det, at patienterne savner individuel information, støtte fra og dialog med sundhedsprofessionelle. Fundene understøttede relevansen af og gav samtidig ideer til, hvordan et nyt Internetbaseret informations- og kommunikationsredskab kunne designes for at imødekomme patienternes behov.

Inspireret af innovativ tænkning og med afsæt i et bottom-up design blev patientbrugere og sundhedsprofessionel brugere inddraget i design og udvikling af Online patientbog[©]. Brugerinddragelsen skete via interviews og workshops.

Efter implementering i klinisk praksis gennemførtes en evaluering. Patienternes oplevelse som brugere af sundheds-it redskabet blev undersøgt via Internet-baseret interviews.

Evalueringen viser at:

Sundheds-it redskaber har kvalitative effekter, når der i design og udvikling tages afsæt i og er fokus på patienternes behov, og redskabet herefter implementeres i kli-

- nisk praksis med henblik på at imødekomme behov hos en konkret gruppe af patienter i en konkret kontekst
- ▶ Mænd over 50 år har interesse i og er aktive brugere af Web 1.0 og Web 2.0 applikationer, der tilbydes af sundhedsprofessionelle som informations- og kommunikationsredskab i mandens behandlingsforløb
- ► Mænd oplever at det er nemt og fordelagtigt at få kontakt med sundhedsprofessionelle via det fleksible miljø som Web 2.0 teknologier tilbyder
- ▶ Patienters behov for generel og individuel information kan imødekommes ved at tilbyde Web 1.0 kombineret med Web 2.0 applikationer som en del af standard pleje planen
- ▶ Internet teknologier er et potentiale i den fremtidige patient information og kommunikation
- Sundheds-it redskaber, der inddrager patienternes behov i design udgør et potentiale. Afhandlingen viser, hvordan en forskningsproces kan udvikle den konkrete kliniske praksis, når der arbejdes med og i dialektikken mellem teori og praksis igennem hele processen. Denne dialektik genererer samtidig viden, der kan have betydning ud over den konkrete kontekst ved indsigt i:
 - ▶ Hvordan mænd med prostata cancer oplever deres kontakt med sundhedsprofessionelle i behandlingsforløb, der bygger på korte kontakter. Generel såvel som individuel information er for eksempel væsentlig
 - ▶ Hvordan mænd oplever og benytter sundheds-it systemet som deres redskab. Et redskab som de kan bruge igennem hele deres behandlingsforløb til at indgå som aktive partnere og som understøtter deres frihed, idet de kan benytte redskabet når de har behov og tid. Mænd oplever derved en kontrol i eget forløb, hvilket reducerer oplevelsen af at være afhængig af sundhedsprofessionelle og kan bidrage til oplevelse af sammenhæng i forløbet
 - ▶ Hvordan det er essentielt, at patienternes behov inddrages i design. Et primært fokus på patienterne og deres udtrykte behov giver mulighed for at udvikle sundheds-it redskaber, der imødekommer patienternes behov og derved understøtter patienternes mulighed for at fortsætte deres normale liv og hverdag
 - ▶ Hvordan en hermeneutisk tilgang kan inspirere til brugerinddragelse i design og udvikling af sundheds-it redskaber. Den hermeneutiske dialog kombineret med et bottom-up design kan involvere patienter og sundhedsprofessionelle i udvikling af redskabet og generere ny viden.

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List of papers

The thesis is based on the following four papers, which are submitted and accepted for peer review in international scientific journals. In addition, the thesis refers to a fifth paper: The supplementing paper which documents an interdisciplinary process analysis of parts of the current research process. The researcher is second author to this paper, which is published. The papers will be referred to throughout the thesis by their Roman numerals.

Paper I:

Men with prostate cancer and the accessibility to information – a literature survey.

Bjørnes, C.D., Nøhr, C., Delmar, C., Laursen, B.S.

Accepted for publication Open Journal of Nursing, 2011, August.

Paper II:

Designing health informatics tools to accommodate the needs of men with prostate cancer.

Bjørnes, C.D., Nøhr, C., Delmar, C., Laursen, B.S.

Submitted to Research and Theory for Nursing Practice, 2011. March 20.

Paper III:

A Health 2.0 application designed and implemented to meet patients' individual needs: The impact on continuity of care.

Bjørnes, C.D., Laursen, B.S., Delmar, C., Cummings, E., Nøhr, C.

Submitted to International Journal of Telemedicine and Applications. 2011, May 26.

Paper IV:

Web 2.0 applications enhance personalized access to healthcare professionals.

Bjørnes, C.D., Laursen, B.S., Delmar, C., Cummings, E., Nøhr, C.

Accepted if revised BMC Medical Informatics and Decision Making. 2011, April 21.

Paper V: Supplementing Paper: Second author

Communication Challenges in System Development: Involvement of System Developers in small-scale IT Projects.

Petersen, L.S., Bjørnes, C.D., Bertelsen, P.

Information Technology in Health Care: Socio-Technical Approaches. 2010.

List of appendix

Appendix A: Interview guide utilized in the interview study. Danish version only.

Appendix B: A sketch from the interview study which the researcher draws during the process of interviews, for the researcher's use only to recall the study later on. The researcher experienced how the dialogues in the interview study generated new understandings for both the individual man, who was interviewed, and the interviewer (researcher) herself. Danish version only.

Appendix C: Examples on visualising the design in the developing phase of the Online Patient Book[©]. Commented screenshots, colour codes, and so on were used to communicate the design between the system developers and the project manager (the researcher).

Appendix D: User guide for the Online Patient Book[©] to healthcare professionals. A paper version was placed in the specific departments, who used the Online Patient Book[©]. The user guide in full length was attach at the first web page for healthcare professionals and related parts of the user guide were attach at each web page to be opened with a click on the Help Icon.

Appendix E: Action plan for healthcare professionals. The action plan was placed at write boards in the healthcare professionals working area. The write boards listed the actual patients in the department and the plan for the particular days work practice.

Appendix F: Screenshots from the Online Patient Book[©] which illustrate features and functions within the health informatics system. Patients' ID numbers and names on the screenshots are fictitious.

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Preface

The front page of the PhD thesis illustrates a screenshot from the website: The Online Patient Book[©] (www.onlinepatientbog.dk).

The screenshot is supplemented with a short quote:

Explore the possibilities

- This quote is shown on some of the license plates in Tasmania. As a part of the PhD study, I explored University of Tasmania and parts of the fantastic culture and nature of Tasmania.

Exploring is what a PhD study is all about (Ordbogen.com, 2011):

If you **explore** a place, you travel around it to find out what it is like.

If you explore an idea or suggestion, you think about it or comment on it in detail, in order to assess it carefully.

If you explore something with your hands or fingers, you touch it to find out what it feels like.

If people explore an area for a substance..., they study the area and do tests on the land to see whether they can find it.

The philosophical position hermeneutics is a non-naturalistic approach to human existence, which **explores** the various media of cultural formation and meaning generation in both individual and collective perspective. Philosophical Hermeneutics reflects the fact that what it means to be a person (or group of persons, an institution, a nation,...) depends on one's understanding of being that particular person... It is the plurality of the discourses of our understanding, which constitutes the human way of being... Philosophical hermeneutics delivers a pivotal contribution to our understanding of modern society. It provides an insight of the cultural and historical mechanisms which constitute our modern self understanding and thus our reality (PHH Aarhus University, 2011).

The aim of this thesis is to **explore** health informatics by travelling around it and think about and comment on it in detail, in order to assess it carefully, and by exploring it in both an individual and collective perspective.

Maybe health informatics has the possibilities (Ordbogen.com, 2011)?

If you say there is a **possibility** that something is the case or that something will happen, you mean that it might be the case or it might happen.

Acknowledgement

So many people helped me to **explore** - to travel this journey. I could not have done it without you! Thank you to every one of you – no one mentioned, no one forgotten. Thanks!

Many men offered their time to be a part of the study by contributing with their knowledge and their own experiences of going through a course of treatment and care for prostate cancer or by evaluating and describing their experiences of being users of the Online Patient Book[©]. Thank you.

Six nurses were involved in the developing and implementation of the Online Patient Book[©] being the primary collaborators. They all offered their knowledge as clinical experts, time, and interest. Thank you to RN Gitte Uldal, RN Anette Ringkjær, RN Birgitte Badstue, RN Benthe Nørkjær, RN Rikke Vingaard, RN Helle V. Lund.

Many other healthcare professionals and administrators at the Aalborg Hospital, Aarhus University Hospital, Denmark contributed with their expertises as well. Thank you.

Thank you to Head nurse Elsebeth Yde Laursen, who facilitated the developing and implementation of the Online Patient Book[©] in the Department of Urology, supported by the staff in general.

The IT Department, The North Denmark Region was partner in the developing and implementation of the Online Patient Book[©]. Two system developers were the primary collaborators. Thank you to Benny N. Bentsen and Christian B.M. Hauberg.

The group of supervisors reflects the interdisciplinary field in which the PhD project was completed. Thank you to Birgitte, Charlotte, and Christian for an exiting and inspiring process which helped me in exploring the possibilities. Also thank you to Liz Cummings, University of Tasmania for a rewarding counselling at the end of the PhD study and for inviting me to explore Tasmania.

My partner Jette was the invisible collaborator and much more than that throughout the whole process. Thank you, Jette, for supporting me in exploring the possibilities.

The PhD project has achieved external funds from: The Novo Nordisk Foundation, DOF Det Obelske Familiefond, Danish Nursing Research Society, Harboefonden. The funding source had no involvement in the study.



In respectful memory of my mother Doris Jensen and mother-in-law, RN Bengta Bjørnes.

Definition of terms

This pre-section contributes to a summary of core terms utilized throughout the thesis as well as in Paper I-IV. The definitions of the terms are primarily based on The large online dictionary in Denmark (Ordbogen.com, 2011) and in the perspective of the current research process.

Contact: Contacts are situations or conditions where persons are able to exchange information, attitudes, feelings and so on. This means that both availability (of the persons) and exchange-ability (the ability and opportunity to exchange) is central.

Short stays: Related terms are: Short stay surgery and short stay patients. Means planned discharge within a few days. Specified to men with prostate cancer treated with prostatectomy surgery, with a length of stay less than five days (in 2007).

Prostatectomy surgery: A prostatectomy (radical prostatectomy) is an invasive surgery to remove the whole prostate gland including the tumour, when men are diagnosed with prostate cancer. Radical prostatectomy is most often done when the cancer has not spread beyond the prostate gland. The aim of the operation is to cure the cancer.

The surgical procedures includes: Radical retropubic prostatectomy (traditional open surgery); Laparoscopic radical prostatectomy; Robotic-assisted laparoscopic prostatectomy.

Prostatectomy is associated with side effects such as urinary incontinence and impotence. Other treatment options for prostate cancer are: radiation therapy; hormone therapy; active surveillance.

Disempowerment is reduced amount of control that someone has over a situation or over their life. The feelings of powerlessness or helplessness.

The terms uncertainty and insecurity were used in operationalizing the term disempowerment.

Uncertainty is primarily attributed to the sensation of feeling unsure about the best action or choice in a given situation.

Insecurity is to feel unsafe, uncertain; a state of doubt about the future or about what is the right thing to do.

Certainty is the state of being definite or of having no doubts at all about something. To feel comfortable, confident, calm.

Security is to feel safe. A feeling of security is a feeling of being safe and free from worry.

Empowerment is the process of giving somebody power and status in a particular situation. To give somebody more control over their own life or the situation they are in.

If someone is empowered to do something, they have the authority or power to do it.

Continuity of Care: Healthcare provided on a continuing basis from the initial contact, following the patient through all phases of treatment and care.

Healthcare System: The complete network of agencies, facilities, and all providers of health care in a specified geographic area.

Highlight is used as synonym to: important, significant, or if something is said, point at, or emphasized by several.

Web 2.0 technologies: Web 2.0 technologies establish dynamic websites, which allow the users to do more than just retrieve information, as on Web 1.0 sites. Thereby Web 2.0 websites differ from the static web pages established on Web 1.0 technologies where the users are limited to passive viewing. A Web 2.0 website allows users to interact and collaborate with each other in a dialogue. Users can provide and control the data on a Web 2.0 site. The contents are user-generated and the users are interactive and able to communicate with each other.

Health informatics systems vs. the patients' health informatics tools: The objective of health informatics systems is to support and document safe and effective delivery of treatment and care to the particular patient and to the healthcare system in general: To solve problems around ineffectiveness and mistakes, e.g. in relation to medication, lack of communication between sections and between healthcare professionals. As such health informatics primarily serve as information and communication tools for the providers of healthcare and the network of agencies and facilities around; the healthcare system. These health informatics

systems are primarily open for and used by healthcare professionals and administrators within the healthcare systems.

Categorized under health informatics systems, the term patient informatics use information technologies to inform, teach, and empower patients to participate meaningfully in their healthcare. Hence, the new health informatics system named the Online Patient Book[©] is a patient informatics system. However, the purpose is primarily to meet the patients' need in their course of treatment and care. Therefore the term: **The patients' health informatics tool** is more precise.

The researcher: For consistency this term is utilized throughout the thesis, as synonymously to the author of the thesis, meaning the PhD Student during the research process, the interviewer in the phases of qualitative interviewing, and the project manager in relation to the Online Patient Book[©].

List of figures

This pre-section summarises the figure included in the thesis.

The figures included in the Paper I-IV are not listed in this pre-section, as these figures are attach and listed in connection with the separate papers.

Figure 1: The four phases of the research process and the relations to the research papers.

Figure 2: A flowchart of a standard plan for men with prostate cancer treated with prostatectomy surgery.

Figure 3: The research process as a spiral.

Figure 4: Findings in the survey of the literature: A negative process of disempowerment.

Figure 5: Findings in the survey of the literature: A positive process of empowerment.

Figure 6: Re-contextualized data in relation to the two head sections in the Online Patient Book[©].

Figure 7: Re-contextualized data in relation to some of the subsections in the Online Patient Book[©].

Figure 8: A cartoon from one of the men, who participated in the interview study.

Figure 9: The web application: The Online Patient Book[©] from the patient users' perspective.

Figure 10: The individual patient's opportunity to use the Online Patient Book[©] during his course of treatment.

Figure 11: The four phases of the research process, in combination with years, and the different phases of the Online Patient Book[©].

Figure 12: The patients' health informatics tools can be the key to enhanced continuity of care, by way of the individual patient's reduced dependency on the healthcare professionals.

1. Introduction

The thesis documents the results of a PhD project. Four papers are submitted and accepted for peer review in international scientific journals. These manuscripts are attached as a part of this document and will be referred to in the text by their Roman numerals.

The thesis must be seen as summarizing the research project. The thesis presents and connects the papers by illustrating how they document various processes in and the results of the four phases of the research process, as depicted in Figure 1.

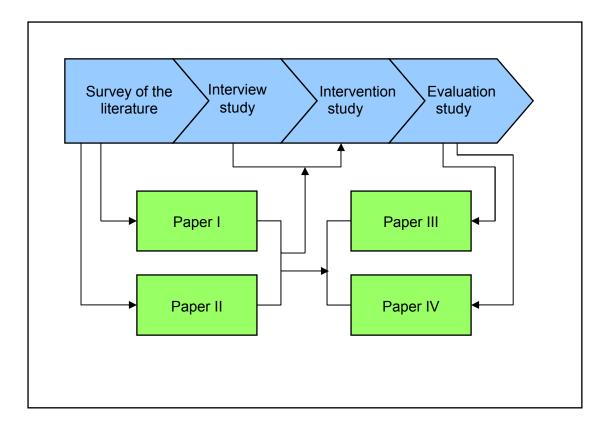


Figure 1: The four phases of the research process and the relations to the research papers.

The thesis is structured as follows:

Section 2 describes the background to the whole research process.

Section 3 defines the aims of the research, which are outlined as research questions, which again are operationalized in relation to the four phases of the research project.

Section 4 introduces the methodology and explains how the four phases are linked to each other in this perspective and how the methodology guided the various use of methods during the whole research process and the four phases. The methodology is operationalized in the

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methods. Preconceptions including theoretical preconceptions and ethical consideration are presented.

Section 5-8 document the four phases of the research process in separated sections. The operationalized research questions are attached to each phase. The four sections various in length, according to the documentation of the individual phases in the attach paper manuscripts. Findings are summarized in relation to each phase. At the end of each section the particular phase is link to the whole research process:

Section 5 documents the literature survey.

Section 6 documents the interview study.

Section 7 documents the intervention and differs from the other three depictions, as the results of this process are a product; the technology itself.

Section 8 documents the evaluation study.

Section 9 combines the whole research process by means of reflections on the limitations in the methods used in the project, the findings, and to the technology itself.

Section 10 contains the conclusion as it report the results of the whole research process in the light of the research questions.

Section 11 suggests implications for the future.

2. Background

The problem explored in this research process is born in nursing practice: The Department of Urology, Aalborg Hospital, Aarhus University Hospital, Denmark. A growing number of the patients, in urology departments in general, are men with prostate cancer, as the number of men diagnosed with prostate cancer has increased with over 51 percent from 2000 to 2009. In 2009 prostate cancer ranked as the most frequent cancer among men in Denmark (National Board of Health, 2010). Men with prostate cancer are going through very different course of treatments from watchful waiting regime to active treatment as surgery, medication, or radiation therapy. Therefore, men with prostate cancer are characterized as a diverse group, with different needs in relation to their course of treatment and care. This underpins the relevance in focusing on one of these groups.

In the particular urology department the number of men with prostate cancer treated with surgery Radical prostatectomy has increased. At the same time the individual patient's time at hospital decreases. Previously, these men were hospitalized up to 19-20 days in relation to the surgery (Litwin et al., 1997). In 2007, at the time the current research process was initiated, the short stays in hospital, for men treated with prostatectomy surgery, were defined as three to five days with admission the day before surgery. Today, in 2010-11, the men's stays in hospital are less than three days, with planned admission the day of surgery and planned discharge the day after surgery.

Figure 2 illustrates the normal flow of formal contacts between the individual man with prostate cancer and the healthcare professionals in a course of surgical treatment and care, according to the particular Department of Urology. As depicted the individual patient will experience a course of 14-16 short formal contacts in outpatient clinics and one admission from the day of surgery and discharge the day or two days postoperative. These contacts are even strictly planned and specified according to the standard care plan.

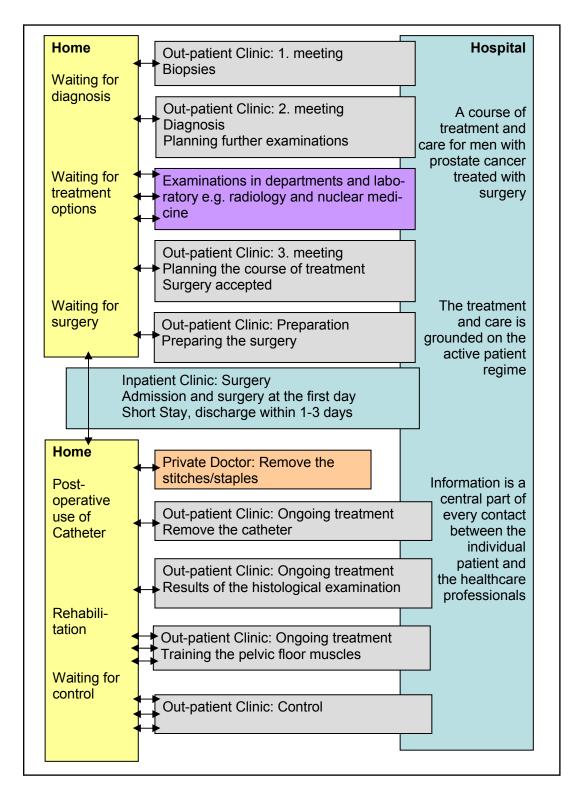


Figure 2: A flowchart of a standard plan for men with prostate cancer treated with prostatectomy surgery.

Men with prostate cancer, undergoing a course of surgical treatment and care raise a general issue based on the ongoing structural changes in the healthcare system. All around the hospital systems, an increasing number of patients are short stay patients, which means planned

discharge within a few days, and the time of hospitalization per patients still decrease (Larsen et al., 2008; The Ministry of the Interior and Health, 2006).

In general the patients are satisfied with shorter stays in hospital (Husted et al., 2006; Kehlet, 2001; Marx et al., 2006). Discharge within one day is efficient and it confirms the quality of the treatment. The patient is presumed cured and without having complications. However, the patients' have to learn to live with, and in, this new and unknown life situation. In relation to men with prostate cancer treated with prostatectomy surgery, the men are for example faced with and need to learn: how to handle the urinary catheter the first weeks at home after the surgery; early recovery after a large operation; the risk for long-term side effects such as urinary incontinence and impotence; and the risk for recurrence of the cancer. The healthcare professionals often play a significant role in this process of learning, but due to the reduced admission time at the hospital the patients have to learn quickly. This will be elaborated in the following.

The short stay regime is organized around and depends on seeing the patient as an active partner in his own course of treatment and care. In the particular context The North Denmark Region (2006), it is described as:

The accelerated course.... which we call: The active patient course. The definition points to our position to support the patients to be active partners in their course of treatment, with a focus on health in stead of disease. Thus, we recognize the patient as healthy, however with a dysfunction, which can be cured. The patients should be co-responsible in their own treatment and the way they live already before the surgery.

This illustrates how the patients need information and support to be active partners, and to learn, what to do, in their own course of treatment. The healthcare professionals play a significant role in this process (Danish Regions, 2006; Vinge, 2010; Wagner et al., 2005; Cahill, 1998; Gallant et al., 2002; Grum, 2008). However, the short contacts reduce the patients' time for information and support, as contacts are defined as situations or conditions where persons are able to exchange information, attitudes, feelings and so on (Ordbogen.com, 2011). Delmar (1999) describes how the nurses experienced that the short, quick contacts limited their opportunity to think and act in their relation to the patients.

The patients and the healthcare professionals both rely on the opportunity to exchange information. However, to exchange information is not enough, as human beings need to understand and learn the information, to act upon the information. The patients generally want to learn and to gain understanding for example on the diagnosis and consequences of treatment

(Grum, 2008; Rasmussen et al., 2009)(Paper I and II). Understanding the consequences is an important step for the patients to act upon the consequences. At the same time, healthcare professionals need to learn about the individual patient, to target their care activities. Thus, the patient needs to inform the healthcare professionals and the healthcare professionals need to obtain and understand these information to know which questions, experiences, and resources this individual patient brings into this unique and situated relation. In other words, contacts open for dialogues, which are important, as human beings learn about each other within dialogues; learn about feelings, experiences, hope, and so on (Hansen, 2005; Taylor, 2002; Gadamer, 2006). Accordingly, the dialogue is a process of learning to develop insight and a kind of shared understanding for both patients and the healthcare professionals (Hopen, 2003). Essentially, the contacts between the individual patient and the healthcare professionals must include dialogues.

The Danish nursing philosopher M. Scheel is one of several nursing philosophers, who describe the importance of dialogues within nursing. The current research process is, however in particular inspired by Scheel's theoretical understanding, which will be elaborated in section 4 of the PhD thesis. Scheel (Scheel et al., 2008) is inspired by several philosophers and develops what is characterized as a practice-theory called: Interactional nursing. In Scheel's perspective dialogues are actions and nursing practice is described as communicative and dialogue-based actions. In dialogues the individuals involve with each other and the world, trying to understand and thereby recognizing each other. Scheel characterizes caring practice as rational cognitive activities, which are of great importance for people's lives, health, and well-being. Hence, nurses need the dialogues to recognize, interpretive, and understand, to get an insight in what is important for the individual patient, for example what the individual needs to learn about in this particular course of treatment.

Thus, the short contacts reduce the time for these significant dialogues, whereby the patients need to learn quickly in the short stay settings. This again, increases the demands on the healthcare professionals' qualities and skills in relation to these communicative and dialogue-based actions (Vinge, 2010). Wagner et al (2005) describe how nursing practice has shifted from somatic care to more counselling and guidance. Burt et al (2005) explain how shortened hospital stays have the effect that the patients' concerns and information needs must be focused and timely.

In the beginning of the current research process, the researcher experienced how the community of nurses in the particular urology department expresses among each other, how they would like to have more flexibility in their caring for these men. These descriptions at infor-

mal meetings were elaborated during the research process at formal meetings through the workshops. The nurses experience a contradiction between: the time for formal and specified face-to-face contacts with the individual patient; the amount of information and guidance in relation to the patient according to the standard care plan; and the individual patient's need for information and support.

To comply with the organisational changes future information and communication tools must be designed in the light of possible consequences of the reduction in time of the formal face-to-face contacts. At the same time, the nurses and the healthcare professionals in general encounter a growing number of patients, who are searching for information and support for example by use of the Internet (Rasmussen et al., 2009; Rasmussen & Clemensen, 2009; Statistics Denmark, 2011)(Paper I and II). Therefore, it is relevant to consider and explore the present information and communication tools, too. At the same time, the rapid development in the area of health informatics could be a possible way to support the important dialogues between the patients and the healthcare professionals. New technologies as Web 2.0 technologies allow the users to be active, as well as open for dialogue-based contacts. These opportunities seem to comply with the demand for active patients and the need for dialogue-based contacts between the individual patient and the healthcare professionals. Therefore the current research project explores the possibilities of Web 2.0 technologies which demand an insight in how men with prostate cancer experience their contact with the healthcare professional in general and in particular an online contact.

In the following section of the thesis these aims are specified in the research questions and operationalized to be answered in four phases using diverse methods.

3. Aims – research questions – operational questions

This section defines the aims of the research project. The aims are illuminated by means of research questions, which again are operationalized in relation to the four phases of the research project.

The patient group in focus is men with prostate cancer treated with prostatectomy surgery. Specifically men undergoing a course of treatment with a length of hospital stay less than five days, according to the status in 2007, at the beginning of the research process.

3.1. Research questions

The research questions were:

- How do men with prostate cancer, treated with prostatectomy surgery, experience their contact with the healthcare professionals in clinical practice based on short stays?
- How can an online contact contribute in the contact between men with prostate cancer and the healthcare professionals?

3.2. Operational questions

The research questions were answered using different methods during the research process.

A literature survey was carried out to summarize the state of knowledge on how men with prostate cancer experience their contact with the healthcare professionals and what these men need and do to feel empowered. How the concept empowered is operationalized to feel secure and certain is explained in section 4 of the current thesis. The specific operational questions in the literature survey were:

- ➤ How do men with prostate cancer, treated with prostatectomy surgery, experience their contact with the healthcare professionals in clinical practice based on short stays?
- * What do patients need to feel secure and certain?
- **What is the role of the Internet?**

Secondary, the findings from the literature survey were used to explore how new information and communication tools must be designed to accommodate the needs of men with prostate cancer treated with prostatectomy surgery, in the light of existing literature on the subject. The questions asked in this process of analysing the data from the literature survey were:

➤ How should a new health informatics tool be designed to accommodate the needs of the patients?

- ➤ How do the present information and communication systems oblige the change towards short contacts?
- * How do men with prostate cancer treated with prostatectomy surgery utilize the Internet?

In the second phase of the whole research process an interview study was carried out to contextualize the research questions in the specific culture and society; Denmark.

- How do men with prostate cancer, treated with prostatectomy surgery, experience their contact with the healthcare professionals in clinical practice based on short stays?
- * What do patients need to feel secure and certain?
- * How do men with prostate cancer treated with prostatectomy surgery utilize the Internet?
- How should a new health informatics tool be designed to accommodate the needs of the patients?

Based on the findings in the first phase of the research process, and nuanced via the second phase, an intervention study was carried out in the third phase of the research project.

In this third phase, the intervention study, a Web 2.0 application, the Online Patient Book[©], was designed, developed, and implemented in clinical practice. Therefore, this phase does not contributed to answering the research questions directly. Still, the operational questions were utilized during the phase for example in the design workshops:

- * What do patients need to feel secure and certain during their course of treatment and care?
- * What do patients need to enhance empowerment during their course of treatment and care?

The intervention study was followed by an evaluation of the effects of the intervention for the patients, as a fourth phase in the research process. The aim of the evaluation was to generate insights in the tool's ability to meet the patients' need in their course of treatment and care. This contributes to an understanding about the potential of such health informatics tools, particularly in the area of supporting continuity of care and the importance of dialogues. The specific operational questions were:

- * How can an online contact contribute in the contact between men with prostate cancer and healthcare professionals?
- ➤ How can an Online Patient Book, as an example of the patients' health informatics tool, enhance the patients' continuity of care?

- ★ How can dialogue based web applications, as part of an Online Patient Book[©], improve quality in the contact between male cancer patients and healthcare professionals?
- * How can dialogue based web applications facilitate contacts between male cancer patients?

The answering of the research questions, meaning the operationalized questions, is explored in an interdisciplinary field of nursing and health informatics, and therefore also influenced by both nursing research and health informatics research.

However, the problem was born in nursing practice thus the approach and design were primarily inspired by nursing research. According to the presentation of the practice-theory Interactional nursing by Scheel in section 2 of the current thesis, the research process was inspired by Scheel's perspective. Scheel states that if the researcher wants to learn something about nursing it is important to learn something about people, about persons (Scheel et al., 2008). A hermeneutic approach compels the healthcare professionals, as well as the researchers, to recognize that each individual has a unique reality constructed by culture, language, and tradition (Rodgers, 2005). Hence, the approach and design in the current research project are primarily inspired by hermeneutic philosophy. As the hermeneutic perspective recognizes that people have different experiences, perceptions, and viewpoints, the hermeneutic perspective generates insights and understandings, for example in relation to the individuals' contacts with one another, or using Scheel's conceptualization interaction with one another. Therefore, all four phases in the current research project were guided by hermeneutic philosophy, which is elaborated and specified in the next section of the thesis.

4. Methodology

In line with the former section the aims in this research project were to learn something about how men with prostate cancer experience their contacts with healthcare professionals in general and specifically online contacts. Given that this research explores the qualitative effects of the health informatics tool, which is designed and implemented during the research process, it is important to focus on the attitudes, understandings, and experiences of those individuals involved. Therefore, it is relevant to conduct the research within the hermeneutic philosophy, which will be clarified in the current section of the thesis.

The four phases in the present research project were all guided by hermeneutic philosophy inspired by the philosopher H.G. Gadamer (1900-2002). Gadamer made an important contribution to hermeneutics in the twentieth century, primarily through his book Truth and Method (2006). A central aspect in Gadamer's work was to explore the nature of human understanding. Gadamer generated his philosophy on the hermeneutic tradition. Though, Gadamer contributed to an ontological shift, as he saw the hermeneutic circle as a way of being and living. Gadamer clearly states that hermeneutic is a way of thinking – a philosophy. From that point of view interpretation is something that happens to the individual human being, as questioning, understanding, and cognition is a way of being and living. To interpret means to enter into a dialogue, direct one's questions in the dialogue, and allow oneself to be questioned back, and continuing this back-and-forth process towards a new understanding. Human beings participate in this dialogical search for knowledge. In other words, hermeneutic philosophy rests upon a dialogical foundation.

The inspiration from Gadamer in the current research process must therefore be recognized as a contribution to the methods on the philosophical level. 'To go hermeneutic' is an art, not a method. An art of questioning that for example the researcher needs to learn. The researcher needs to act as a questioner by being in the art of questioning and testing, for example by utilizing different types of dialogues during the research process.

From the hermeneutic perspective to ask a question means to bring into the open. The openness of what is in the question, and consists in the fact that the answer is not settled. Gadamer (2006) talks about: The knowledge of not knowing. However, the not knowing, which are expressed via the question, places what is questioned in a particular perspective, as for example the research questions in this research process. These questions direct and thematise the following dialogical process. In order to be able to ask, one must want to know, which means

knowing that one does not know. Gadamer (2006) explains how the subject matter is broken open by the question and by that unfolded in a dialogue.

The dialogue is a process, an action, through which the individual comes to understanding. This illustrates how dialogues are a kind of intervention in itself. The dialogue has an impact on those who are partners in it, as they develop and reach a new understanding together. According to this perspective, by Gadamer (2006), knowledge is dialectical and dialogues generate new knowledge.

To understand what nursing is and what it means to be a nurse, the dialogues are significant, both among nurses, interdisciplinary, and in relation to the ongoing society. The nursing philosopher, which was presented already in the beginning of the current thesis (section 2), Scheel (Scheel et al., 2008) emphasize the importance of dialogues in nursing by describing that nurses needs dialogues. Scheel recognizes dialogues as actions, and nursing practice is described as communicative and dialogue-based actions. Scheel also emphasizes the dialogue between theory and practice. She points to the ongoing dialogue there has to be between practice and theory, meaning there must be a dialectical connection between theory and practice. Theory forms practice and practice forms theory.

The current research project is inspired by Scheel's practice-theory Interactional nursing (1995; Scheel et al., 2008), which is developed in the Danish context. M. Scheel (1929-2007) has made important contributions to nursing theory in the Danish context. However, Scheel is inspired by several philosophers from other European countries as well as from USA and Canada. Scheel herself describes how she is inspired by the long philosophical discussion in relation to the dialectic between practise and theory. Scheel is for example inspired by the philosopher C. Taylor. Taylor (Michelsen, 2008; Scheel et al., 2008) is one among several philosophers who discuss the understanding of dialectic, which the philosopher Hegel represents. Hegel is the first philosopher, who emphasizes the unity instead of the dualism between practice and theory. Taylor, as well as Scheel, recognise this viewpoint. Scheel describes how theory and practice both informs and inspires each other. There is a synergy between theory and practice. Scheel emphasizes how practice-theory as Interactional nursing must go beyond the tradition in nursing, and instead challenge and question theory, practice, norms, and values and thereby hold on to an ongoing changeable and developing process of learning.

In the international nursing perspective Scheel draws some lines between her own practicetheory Interactional nursing to the work of the nursing theorist P. Benner. Scheel as well as Benner are inspired by Taylor according to the importance of the dialectic between theory and practice. Both Scheel and Benner describe how theory shapes practice, and practice shapes theory. Scheel herself relates close to Benner according to this perspective by citing Benner's description that (Scheel, 1995): In the best of worlds, practice and theory set up a dialogue that creates new possibilities (Scheel, 1995; Scheel et al., 2008).

The inspiration from the practice-theory Interactional nursing in the current research process may thereby be seen in the light of these significant correspondences outside the Danish context.

In summary, the current research process is primarily initiated by the nursing philosopher M. Scheel, as the practice-theory Interactional nursing emphasizes the importance of the dialectic between theory and practice and the importance of dialogues. The reason for choosing this particular theoretical nursing perspective is though also driven by other core aspects in Scheel's theoretical understanding, which will be illuminated in the following.

Providing that the purpose of research is to generate new knowledge, which has applicability beyond the immediate setting, the dialectical synergy between theory and practice may also be a key point in relation to nursing science (Gerrish & Lacey, 2006). Hence, dialogues are also important in nursing research. If nursing researchers want to go beyond the description of nursing care to also develop nursing, the researcher needs the dialogue in practice, with the practitioner. To have an impact on clinical practice, the nursing researcher, being the theoretician, may intervene in clinical practice using dialogues. However, already by intervening in practice by dialogues, the researcher is a partner in the action, the dialogue actions. This again illustrates the dialectic between theory and practice (Scheel, 2004). To know is closely related to understanding and doing.

To Scheel (1995) the subject matter within nursing is human existence in health and sickness, and the nurse's role in this connection. Thus, nursing research needs to generate knowledge about the human beings, and their opportunities and possibilities in relation to health, illness, environment, and society. Scheel (1995; Scheel et al., 2008) also states that the basic to the nursing profession is peoples' interaction with one another. Interactions between people are central in Interactional nursing practice-theory, as human existence is seen as co-existence with other people. Human existence and autonomy depend on and develop through the dependence on the other people. Thereby, nursing research also needs to generate knowledge about human interactions, which is the aim in the current study, as the focus is on the contact between men with prostate cancer and the healthcare professionals.

To generate knowledge about interactions or as in the current research project about contacts, the nursing researchers, being theoreticians, need the dialogue with the patients as well as the healthcare professionals. A hermeneutic approach within nursing research, using questioning and thereby generate dialogues as a method, enables a deeper and stronger awareness and understanding of individuals' perceptions, and thereby of the individuals' attitudes, understandings, and experiences (Rodgers, 2005).

Therefore different types of dialogues were generated throughout the present research process to generate new understandings. All dialogues were based on the research questions according to the operationalized questions. The combination of different types of dialogues is illuminated in the next subsection of the thesis, by illustrating how the hermeneutic philosophy inspired the approach to the process and in the phases.

4.1. Methods

According to the research questions the aims in this research project is to explore qualities, which means to understand and document the qualitative aspects of the specified core themes and the qualitative effects of the technology under investigation. Therefore a hermeneutic approach was valuable, which will be further elaborated in this subsection.

The approach in the current research process is initiated by the research questions. A core theme in the research questions is contact. In this context the term contact relates to the patients contacts in their course of treatment and care. Contacts are situations or conditions where persons are able to exchange information, attitudes, feelings and so on (Ordbogen.com, 2011). Thus, contacts relate to: information, support, and dialogues. A core aim of the current research process is therefore to understand how a specified group of patients experienced information, support, and dialogues in their contacts. The hermeneutic approach by utilizing dialogues contributes to understand these experiences of contacts.

Additionally, the research questions depict that the current research process aimed to make the contacts technological by establishing opportunities for online contacts. An innovative approach initiated this process of developing and implementing a new technology (Jørgensen et al., 2009).

Thus, the core themes in the research questions depict the significant inspiration from diverse perspectives to the approach. The hermeneutic philosophy inspires the back-and-forth process by means of dialogues, which generated the new understandings. The innovative approach inspired the continually movement away from the starting point, which generated the new

tool. Thus, core aspects in the hermeneutic philosophy as well as in the innovative thinking guided the research process.

The core aspects in the hermeneutic philosophy that guided the research process were:

- * Recognition of the primacy of the questions. The research questions direct the answering in the current research. These directions are described and pointed out by the operationalized questions, which makes the particular perspective explicit
- ➤ Emphasizing the role of the preconceptions, and by that illuminate it prior and implicate it during the process
- ➤ Working with and in the dialectical connection between theory and practice: Theory forms practice and practice forms theory
- ➤ Utilizing the circularity of dialogues to generate new understandings. Human being participates in a dialogical search for knowledge for example by being partners in a continuous back-and-forth process between understanding the whole of the subject under investigation and considering parts of it
- **★** Combining the understandings with actions. The understanding of, and insight in, the meanings, are utilized and combined with the implication
- ➤ Considering the researcher as a part of the researched area, as the researcher being the questioner also always are a part of the dialogues in which the new understandings are generated.

The different types of dialogues that were established in the four phases of the present research process, as depicted in Figure 1 (section 1), to generate new understandings, were as follows:

- Literature survey in which the dialogical search for knowledge was conducted by means of dialogue with findings in earlier study relevant for the question; how men with prostate cancer experienced their contact with healthcare professionals
- * Interview study in which the dialogical search for knowledge was conducted as qualitative interviewing supplemented with Internet-based interviewing
- ➤ Intervention study in which the dialogical search for knowledge was conducted as workshops
- ➤ Evaluation study in which the dialogical search for knowledge was conducted as Internet-based interviewing.

The four phases depict that the primary focus of the research process was to get an insight in how men with prostate cancer experience their contact with the healthcare professionals in a course of treatment based on short stays at the hospital. However, the four phases also depict that the possibilities of health informatics tools became a central focus of the current research project.

Combining the diverse stages of the research process illustrates how the ongoing dialectic game between theory and practice, generated new understandings throughout the process. A problem experienced in clinical practice was explored in and substantiated by the survey of the literature. Already at this early stage of the process, new understandings were generated. During this learning process a new theoretical idea came up, to develop a health informatics tool for these men. This theoretical idea was then specified and implemented as a new tool in clinical practice. The values of the new tool in clinical practice were subsequently understood in the light of the researcher's theoretical preconceptions (see subsection 4.5).

Thus, the current research evolved to an innovative process meaning (Jørgensen et al., 2009):

From an idea to possible value

And become an intervention study meaning (Bygholm et al., 2009; Holloway, 1997; Polit et al., 2001; Lorensen et al., 2003):

From an experienced and substantiated problem to use and evaluate the effects of a tool in clinical practice.

This illustrates how the research, though already early in the process, became inspired by innovative thinking, according to the continuous generation of new knowledge, and thereby grew into an innovative, intervention process.

According to the present research project the innovative intervention thinking does not make a large distinction from the hermeneutic thinking. This is for example sustained by the emphasizing of the ongoing dialectic between theory and practice in both perspectives, as depicted above. Still, it is relevant to discuss two of the core elements in the hermeneutic thinking in a process oriented perspective.

First it is relevant to discuss the term parts. In hermeneutic the whole may be understood in the perspective of the parts. In a process oriented perspective as in an innovative, intervention study the term phases are more adequate. The terms innovation and intervention relate to processes, as innovation also means a process of change, and intervention means a process of actions. A process is defined as a course, whereby something happens, either naturally or due to a line of actions, so that something is changed or developed (Ordbogen.com, 2011). Summarizing, an innovative intervention study is a process of actions and changes.

Therefore, the current research is a process and the diverse stages of the process may be understood as phases and not as parts, which was more relevant according to the hermeneutic thinking. Though, Gadamer (2006) himself actually refers to the term process, as he characterizes the individual dialogue as a process of coming to an understanding. Every understanding, meaning dialogical search for knowledge, is a process of actions and changes.

As such the research process consists of phases, and each phase consists of processes by means of dialogues. From a hermeneutic perspective every understanding is itself a hermeneutical process, a specified process which must be understood in relation to the whole research process.

Secondly it is relevant to discuss the circularity in the hermeneutic thinking. In the perspective of Gadamer the hermeneutic circle does symbolise development, as the dialogical search for knowledge, which are depicted according to the circularity, is always a search for new understandings. From the perspective of Gadamer (2006), the circle symbolizes the continually search for new knowledge. A circle, we live in and do not step out of, but develop in. However, the circle can be understood as just moving around in the same circle without any progress or development. Therefore the hermeneutic circle is sometimes replaced by a spiral, which symbols a progress by the continually movement away from the starting point (Kjørup, 1997). From an innovative perspective this distinguishing feature is important, as the spiral covers the process of developing, creating, or formatting something new (Jørgensen et al., 2009).

By combining the hermeneutic philosophy with the process oriented perspective, the progress of understanding and doing all through the current research process can be depicted as a spiral. The spiral relates to the process thinking, as the spiral signals a process, in which one phase depends on the former phases and at the same time relates to the next phase. The understanding and action were generated in a back-and-forth process between theory and practice by means of diverse dialogues. Seen as a process of designing and developing a product each repetition in the process is an iteration, where the result of one iteration is used as a source for the next iteration (Jørgensen et al., 2009; Ordbogen.com, 2011). At the same time, these iterations associate with the hermeneutic philosophy, as one phase must be understood in an ongoing dialogue with the other phases and the whole research process. The research process is thereby an iterative process where each phase of the process provides new knowledge by which the understandings, and thereby preconceptions of the persons involved, continuously move. Therefore the current research pictures the circularity using a spiral, as illustrated in Figure 3.

However, this emphasizing on progress by means of actions does not conflict with the perspective of Gadamer (2006). In the perspective of Gadamer understandings are always also

actions, as to understand is to do. In other words the understandings are movements. Gadamer actually points to a sort of spiral himself, by describing that the understanding is always a movement in the circle, and moreover this circle is continuously expanding, since the concept of the whole is relative, and being integrated in even larger contexts always affects the understanding of the individual phase. Introducing the spiral is therefore not a redraw from the hermeneutic philosophy of Gadamer (2006). Instead the spiral illustrates how the approach in the current research process combined the hermeneutic philosophy with the innovative thinking.

The depiction of the research process as a spiral is corresponding to the perspective of Scheel, as she emphasizes the synergy between theory and practice. Nursing research must go beyond the tradition in nursing, and instead challenge and question theory, practice, norms, and values and thereby hold on to an ongoing changeable and developing process of learning.

Figure 3 illustrates a spiral, which gives a picture of the innovative process in combination with the hermeneutic perspective on understanding. Understandings and actions are generated in a back-and-forth process between theory and practice by means of diverse dialogues.

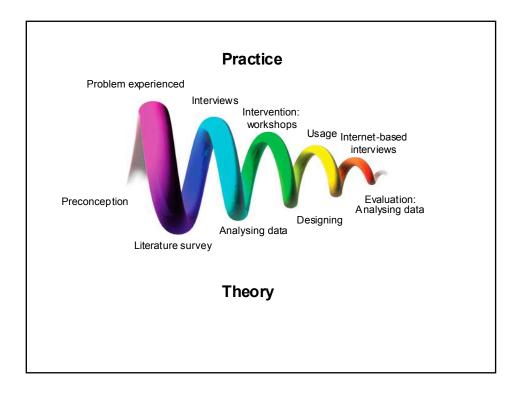


Figure 3: The research process as a spiral.

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PhD Thesis. The patients' health informatics tool - exploring the possibilities.

Thus, Figure 3 reports the four phases in the current research project. As mentioned earlier in this subsection of the thesis, the four phases were:

- **★** A survey of the literature
- **✗** Interview study
- **✗** Intervention study: Developing and implementing
- **Evaluation study**

Combining the four phases the suggestion was to:

- **★** Utilize the dialectic between theory and practice to shape both
- Utilize diverse dialogues to generate new knowledge, which at the same time is used by further actions
- ➤ Utilize the single phase to support the spiral meaning the progress and thereby the continuously movement away from the starting point. The movement in the innovative perspective is the developing of a product based on the idea of it.

The dialogical search for knowledge can then be sustained across the phases of the research process. In addition, the dialogical search for knowledge was also implicit in the individual phases.

In the sections 5-8 of this thesis, the four phases will be illuminated one by one. In each section the focus will be on how the search for new understandings was supported by different methods by description of the processes in each phase. In every one of the four sections the new understandings are summarized according to the findings. The connection between the phases will also be made explicit.

According to the survey of the literature and the evaluation study the illumination will mainly be summaries as these phases are described in depth in Paper I-IV.

The interview study is not presented in full in any of the four papers hence it is described in more detail in section 6.

The intervention study differs as the results of this process is a product; the technology itself. Therefore, the process of the intervention study is clarified in section 7. The other three phases result in empirical data, which were analysed and the findings are summarized in relation to each phase.

4.2. Qualitative interviewing

As described in the prior subsection the dialogical search for knowledge was also implicit in

the individual phases of the research process. The different dialogues conducted implicit in the individual phases were also listed in the subsection above. This list illustrates that qualitative interviewing was used in the evaluation study in addition to in the interview study. In the interview study the qualitative interviews were primarily face-to-face interviews. These interviews were supplemented with Internet-based interviewing. In the evaluation study all interviews were conducted using Internet-based interviewing.

The face-to-face interviews as well as the Internet-based interviews were grounded on the hermeneutic philosophy. According to the hermeneutic stance, knowledge is generated during the interviews and affects both partners, meaning that both partners gain new understandings. This is already pointed to earlier in the thesis. In addition, it is emphasized that the generation of new knowledge is directed by the preconceptions of the dialogue partners. In research this means that the answering in the individual interview is directed by the operationalized research questions, which are generated upon the researcher's preconceptions. This aspect is elaborated among other aspects according to qualitative interviewing in the following.

The hermeneutic inspiration was operationalized through the usage of the book Interviews by S. Kvale. The English version, second edition, has a second author S. Brinkmann (Kvale & Brinkmann, 2009). In all aspects of the interview processes the researcher reflected upon the detailed description of being an interviewer and doing interviews by Kvale and Brinkmann (2009). An example of that is the dimension of having men as the study population. The descriptions by Kvale and Brinkmann inspired the researcher to reflect on this aspect, and subsequently to utilize earlier studies to make specified decisions in the interview processes. This is elaborated in subsection 4.5., which is one of the following subsections.

Kvale and Brinkmann (2009) connect to the generation of knowledge in dialogues by their recognition of an interview as an inter-change of views between the participants. The knowledge is constructed in the interaction between the interviewer and the participants. This interdependence of interactions and the generation of knowledge correspond with Gadamer's philosophy. Like Gadamer, Kvale and Brinkmann (2009) define the specified interview, meaning the dialogue, as a process. They describe that interviewing is an active process where the participants through their relationship produce knowledge, as such the partners in the interview dialogue involves as co-constructors of knowledge, which again points to actions and possible changes for both partners.

As illustrated in the beginning of section 4, the hermeneutic circle is not a method according to Gadamer's hermeneutic philosophy. The circularity depict that understanding is a way of

being. However, when the hermeneutic understanding and thereby dialogues are utilized in research, the specified dialogue have a specified aim and a structure. The purpose of most qualitative interviewing is to understand the meaning of the participants' experiences according to a specific research agenda. Thereby qualitative interviewing is a kind of guided dialogue, in which the researcher needs to act as a questioner by being in the art of questioning and testing.

To guide the face-to-face dialogue the researchers often use an interview guide. In the current research process it was relevant to use a semi-structured interview guide, according to the aim of understanding how men experience their contact with the healthcare professionals. As described by Kvale and Brinkmann (2009) a semi-structured interview, with a focus of the participants' experience of a specific phenomenon still allows the participants to describe the topic using their own words and in their own time, as often these interviews start with an open invitation to describe a situation in which the specified phenomenon were present or enacted. In the individual interview, the following questions are then generated upon the participants' answers, whereby the participants have the opportunity to report on their own thoughts and feelings. Utilizing a semi-structured interview guide the researchers do not ask the questions in the same way and form to each participant. Kvale and Brinkmann (2009) illustrates how an interview guide may support a generation of questions based on a thematically dimension in combination with a dynamically dimension. They describe how a good interview question can contribute thematically to the generation of knowledge, and the dynamically dimension can promote a good interaction between the participant and the interviewer (Gubrium & Holstein, 2001; Hansen, 2005; Holloway, 1997; Kvale & Brinkmann, 2009; Laursen, 2004).

In the current research process every interview was conducted upon the understanding of human existence as co-existence with other people, which is a core aspect in the Interactional nursing practice-theory by Scheel (1995), as pointed to earlier in this thesis. Human existence and autonomy depend on and develop through the dependence on the other people. This illustrates the importance of the researcher being respectful and professional in presence in every interview context. The researcher's positions as the interviewer and often with a professional background do influence the structure of power in the specific interview. The interviewer must consider this in the specified context as well as when analysing the data. Laursen (2004) describes the relevance in awareness to the choosing of the research contexts. The structure of power and the specific research topic which can be very personal to talk about must be taken into account when planning the interviews. This is further considered according to the

description of having men as the study population in one of the following subsections (subsection 4.5.).

The specified processes of interviews in the current research are elaborated in the two sections where the interview study, section 6, and the evaluation study, section 8, are described. These detailed descriptions include reflections and decisions generated upon the illumination in this current subsection.

4.3. Data analysis

As depicted in the subsection above, knowledge is generated during the interviews and affects the partners in the dialogue, meaning that they retrieve new understandings during the dialogue. However, the dialogical search for knowledge is double in relation to qualitative interviewing. Firstly, the dialogues generate data. Secondly, dialogues are needed to interpret the meaning of these data 'texts'. These second dialogues represent the data analysis. Data analysis inspired by the hermeneutic approach can be described as (Ezzy, 2002): The researcher 'dialogues' with the terms to be understood, asking what it means to those who created it, and attempt to integrate that with its meaning.

In relation to the analysing of the data generated in the different phases of qualitative interviewing in the current research process, the inspiration by Gadamer's philosophy was operationalized by using hermeneutical interpretation of meaning (Kvale & Brinkmann, 2009). The dialogues with the data 'texts' were directed according to the operational questions related to the particular phase in which the data were generated. The data 'texts' were seen as answers to these questions and the new understandings were identified and understood by a continuous back-and-forth process both implicit in the specified phase and in relation to the whole research process.

The data analysis generated core themes, which emerge according to a re-contextualising of the data. This re-contextualising must be recognized in relation to the context of the current research, and thereby in the light of the innovative process with a focus of actions. The recontextualising points to future actions based on the new understandings, as for example in relation to the designing and developing of a new health informatics tool. According to the hermeneutic philosophy new knowledge is first gained by the use of it in the present context (Gadamer, 2006).

These aspects of data analysis are as well operationalized and thereby illuminated according to the two sections where the interview study, section 6, and the evaluation study, section 8, are described.

4.4. Preconceptions

In line with the hermeneutic emphasizing of the preconception, this subsection seeks to explicate the researcher's background.

The researcher's preconceptions are grounded in nursing and nursing theory. These have been achieved by working in clinical practice, by teaching nurses and nursing students in clinical practice, and by studying nursing theory at university level.

In relation to the patient group in focus, the researcher has been working in the operating theatres and thereby involved in the patients' course of treatment in a very short and often stressful time for these men just before their operation.

In relation to the field of health informatics the researcher has been utilising the Internet technologies in an earlier study by focusing on the qualitative effects of Web 2.0 based contacts to support healthcare professionals' opportunity for professional reflections (Bjørnes, 2007).

During the PhD study new areas were explored by involvement in nursing researchers' networking and networks of health informatics researchers, nationally as well as internationally. The Paper V (the Supplementing Paper) and the reference list reflect these perspectives.

According to the professional background as a nurse, the researcher did not carry any professional IT background into the study. In other words, the researcher stepped into a new field during the research process, that of health informatics. Therefore theories, practice, and research in the area of health informatics contributed to new perspectives throughout the study process, which are discussed in the section 9 of the thesis.

Theoretically, the researcher's main interests are around communication, interaction, the patient role, the healthcare professionals' role, education, and reflection. The theoretical issues that were relevant to the current research are elaborated in the next subsection.

4.5. Theoretical preconceptions

As a part of explicating the preconceptions, it is relevant to describe some of the theoretical pre-understandings in details, as these influenced various elements and choices during the research process.

As illustrated in the earlier sections of the thesis, the research process was first of all theoretically grounded on the hermeneutic philosophy, inspired by the perspective of Gadamer, and the nursing theory Interactional nursing by Scheel.

4.5.1. Men as patients

Though every single patient is an individual, there are indications of differences men versus women as patients. Studies and theories with a focus on gender in relation to men as patients and men as the study population were utilized in the qualitative interviewing and while designing the new health informatics tool.

Previous studies, with focus particularly on men as patients, state that male patients want to stay in control and retain autonomy. Men like to act (Sharpley & Christie, 2007; Agger & Ølgod, 2001; Agger, 2002; Joergensen, 1999; Johnsen, 2006; Olsen et al., 2007; Ølgod, 1999; Simonsen, 2006). Dickerson et al (2010) describe how men focus on problem solving, determine effects, treatments, and symptom management in a functional way. Male cancer patients actively organize information, monitor for reoccurrence, prepare, facilitate, and validate ahead of their contacts with healthcare professionals. Therefore information, advice, and tools that support actions, are important in their course of treatment. These aspects were particularly utilized in the design phase.

4.5.2. Men as the study population

In relation to men as the study population it is recognized that it is relevant to be aware of certain aspects for example while organising and completing interview studies. In an article by Sommer (2006), Madsen states, based on his research in gender, that men will probably talk about their feelings, though the likeliness depends to a great extent on the context and how the researcher or the healthcare professionals meet the male participants.

The importance of the context when interviewing men is supported by international studies (Pateman, 2000; Yong, 2001; White & Johnson, 1998). Aspects emphasized are for example:

- * Allowing the men the time and space to initiate the conversation, which for example can be supported by a relaxed and informal style and by spending time on informal talking about general social issues
- * Allowing the men time and space to settle in, as men often start with brief statements that everything went fine, though when the conversation develops the men often goes beyond these statements and share their experiences
- * Allowing the men to determine what is meaningful for them to talk about and what they give priorities to in relation to their experiences by utilizing the interview guide flexibly. In other words, utilize the dynamically dimension of the interview guide, according to the inspiration from Kvale and Brinkmann
- * Allowing the men to be interviewed in an environment that is familiar for them, for example the man's own home or his workplace.

Pateman (2000) describes how he experienced the involvement of the men's female partners, when interviewing, as an important way to enrich the data. He describe how the presence of the wife made a large difference, as the women gave lengthy detailed accounts and introduced new issues into the conversation.

When interviewing on personal topics related to experiences of uncertainty and vulnerability for example due to the cancer diagnosis and possible complications as urinary and sexual dysfunctions, Yong (2001) explains how the interviewer can utilize the professional background, for example as a nurse, to make the interview context more familiar to the men.

During the interview process the researcher must pay extra attention not only to what the men describe in the interviews, but also to how they say it and how they react to their own sayings (Burt et al., 2005; Yong, 2001).

In the current research process, the understanding of men as a diverse group to females influenced specific choices, when planning and completing the interviews. However, the conscious and active decisions during the research process were primarily grounded on the hermeneutic philosophy. This perspective contributes to seeing human understanding as a way of being, as ontology, which is elaborated earlier in the current section of the thesis. Similar to Scheel, Taylor (2002; 2008) describes how the individuals' identities develop and are recognized in dialogues with other human beings. This perspective contributes to a primary focus on every person as unique. The uniqueness of every individual is furthermore emphasized in relation to the studies with a focus on gender. These studies point to other significant aspects to be aware of, when investigating human experiences, as for example culture, religion, education, ethnicity, and social class (Pateman, 2000; White & Johnson, 1998). Therefore the gender philosophical perspectives which are elaborated above are only one part of seeing the individual as unique during the qualitative interviewing in the present research process.

4.5.3. Computer mediated communication

As the researcher has worked with the possibilities of the Internet technologies in an earlier study (Bjørnes, 2007), as already mentioned, the preconception endures some theoretical perspectives on topics relevant for computer mediated communication as: communication, reflection, and learning. These topics illustrate that the researcher's preconceptions are on the user perspective, meaning what are the Internet users' possibilities and how they use these possibilities. In general, these questions are already explored and discussed in earlier studies and particular according to the Internet technologies evolutions: from paper to computer; from telephone to the Internet; from Web 1.0 to Web 2.0 technologies. Therefore the interpretation of data and the design of a new health informatics tool was influenced by various

perspectives from theoreticians or researchers on learning or E-learning, for example O. Dysthe (2005); E. Wenger (2006; Wenger, 2010); H. Rander (2005); J. Dørup (2005); P.J. Murray (1997); J. Sandars and R. McDonough (2005). One aspect is for example the discussion of the shift from talking to talking via written texts. This aspect is relevant in relation to the generation of data via Internet-based interviews. However, also most important while designing Web 2.0 applications for the patients.

The researcher's preconceptions in this area are therefore discussed in several stages of the research process, which is mainly reported in the Paper II, III, IV, and in the Paper V (the Supplementing Paper).

4.5.4. Disempowerment or insecurity and uncertainty

Throughout the research process the term disempowerment was operationalized to the terms: insecurity, uncertainty, and loss of control, which is summarized in this subsection.

The prior focus for the current research project was men's experiences in relation to their contacts with healthcare professionals. The literature survey, at the start of the research process, substantiates that experiences of uncertainty, insecurity, and loss of control were common feelings for men, when they experienced lack of information and support in their contacts with the healthcare professionals. The survey of the literature also depicts that the terms uncertainty and insecurity are closely related and point to the same: disempowerment, which are feelings of powerlessness or helplessness that reduce the amount of control that someone, has over a situation (Ordbogen.com, 2011).

These early findings are elaborated in Paper I. However, in the current thesis these early findings are also listed as preconceptions, as these terms are an example of how the researcher's preconceptions develop and thereby moved already in the early stages of the research process. This movement was central for the direction and movement in the further processes of gaining new understandings in the project. Thus, the researcher experienced that the operationalizing of the theoretical concept disempowerment to the terms to be insecure and to be uncertain was valuable in diverse dialogues throughout the research process, which is elaborated in the following.

During the qualitative interviewing and the workshops it was relevant to operationalise the terms disempowerment and empowerment, to the words insecurity and uncertainty, and security and certainty. In dialogues with patients, as for example in the interview study, it is not relevant to ask a patient about him being empowered. The questioner primarily needs to use words that describe feelings and experiences, which via the hermeneutic circularity can develop into new understandings for example a concept as disempowerment. One example can

be a patient that describes feeling insecure about blood in the urine and explains that he did not understand why and did not know what to do about it. Such description can depict disempowerment, however via the ongoing dialogue and secondly the analysing of the data (text) the meaning of this description will be understood, based on the whole 'story'.

According to the workshops involving healthcare professionals, the participants and the researcher cooperate by answering the question: What do patients' need to feel secure and certain during their course of treatment and care? Asking this question generated answers that were re-contextualized in the designing of the new health informatics tool. In other words the healthcare professionals answers were transformed to features in the Online Patient Book[©], which is elaborated in the section 7 of the thesis.

Hence, these terms: insecurity; uncertainty; and loss of control were central during the research process.

4.6. Ethical considerations

Throughout, as well as following, the research process the generating, handling, and publication of data are consistent with the guidelines of CVK (The Danish research ethics committees) and reported under Datatilsynet (Danish Data Protection Agency) (2008-03-05). The local CVK was contacted however the research project did not have to be approved.

All respondents gave their oral and written informed consent to interview participation. All respondents in the evaluation gave their written informed consent to participate in the Internet-based interviews.

The participants were guaranteed confidentiality. Respondents remain anonymous in data analysis and in communication of the findings. The quotes provided have been translated from Danish, omitting any corrections in phrasing.

The researcher obtained permission to use pictures and interviews from newspapers or television news flash in communication of the research project.

The new healthcare informatics system the Online Patient Book[©] is established under the standard security approval and procedures at the IT Department, The North Denmark Region. The public section of the Online Patient Book[©] is open for all Internet users via the World Wide Web address. The personal section of the Online Patient Book[©] demands a key code. The healthcare professionals use their personal standard id and key code to the hospital's general IT systems. The patient users log on by their social security number and a personalized key code. The nurses in the clinical practice handled the enrolment of the individual patient via a specified web page in the Online Patient Book[©]. Only the healthcare professional

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users can enter this web page. The enrolment automatically generates an e-mail to the patients private e-mail box containing system generated, secure one way encryption key codes. This encryption is considered compliant with Danish safety and security legislation. Due to the security of the system, the patient users can not change the personal key code.

5. The survey of the literature

This section reports the literature survey, which is categorized as the first phase of the research process. In this phase the dialogical search for knowledge was thereby conducted through dialogue with findings in earlier studies relevant for the research questions.

The literature survey was carried out to summarize the state of knowledge on how men with prostate cancer experience their contact with the healthcare professionals and what these men need and do to feel empowered. According to the researcher's preconceptions, reported in subsection 4.5 of the current thesis, the term empowered was operationalized to feel secure and certain (also cf. the pre-section: Definition of terms). The specific operational questions in the literature survey were:

- * How do men with prostate cancer, treated with prostatectomy surgery, experience their contact with the healthcare professionals in clinical practice based on short stays?
- * What do patients need to feel secure and certain?
- **What is the role of the Internet?**

Secondly, the articles found in the literature survey were analysed to explore how new information and communication tools may be designed to accommodate the needs of men with prostate cancer treated with prostatectomy surgery, in the light of the existing literature on the subject. The questions asked in this process of analysing the data were:

- ➤ How should a new health informatics tool be designed to accommodate the needs of the patients?
- * How do the present information and communication systems oblige the change towards short contacts?
- ★ How do men with prostate cancer treated with prostatectomy surgery utilize the Internet?

Methods, including the search terms, and results in relation to this phase of the research process are reported and discussed in Paper I and Paper II. The following description in this section is therefore restricted to the findings.

5.1. Findings generated in the survey of the literature

The findings are generated from a total of 47 articles having men with prostate cancer as the patient group in focus and with topics related to contact, information, communication, and support. The articles included were published after 1997 according to the focus on short stays

in hospital, in today's healthcare system. The number of articles is retrieved from literature surveys on the PubMed and CINAHL databases in 2007 and, for up-dates, again in February 2011. This is further described in section 9.

Summary of findings:

- Often men with prostate cancer treated with prostatectomy surgery do not receive the individualized support, information, and dialogue they need, which lead to feelings of uncertainty, insecurity, and loss of control
- The importance, in relation to the patients' contact with healthcare professionals, is not the length and amount of time. Instead accessibility of the healthcare professionals and the healthcare professionals' ability to individualise information are significant aspects
- → Providing information and support healthcare professionals may be able to empower the patients, and the empowered patient is also the active patient
- The men use the Internet to stay in control and to engage in their own course of treatment as active and responsible partners
- The men use the Internet to achieve online social support
- → The organisational change towards patients' short stays at hospital challenge the present information and communication systems
- To accommodate the patients' needs for information, supports, and dialogues during their course of treatment, healthcare professionals have to give priority to the development of new information and communication tools.

To depict the coherence between the patients' opportunity to obtain information and support and the patients' empowerment, the Figure 4 and 5 relate the findings in the survey of the literature, by reporting words and phrases, which were found by searching across the articles.

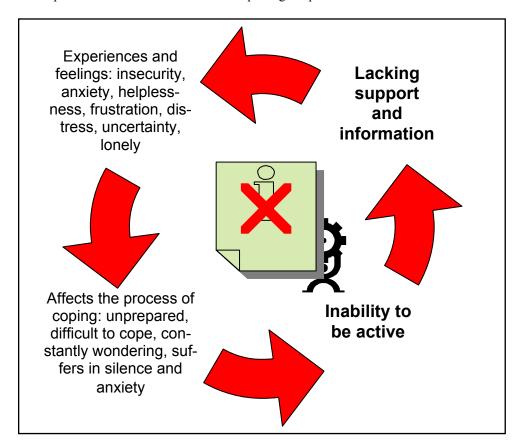


Figure 4: Findings in the survey of the literature: A negative process of disempowerment.

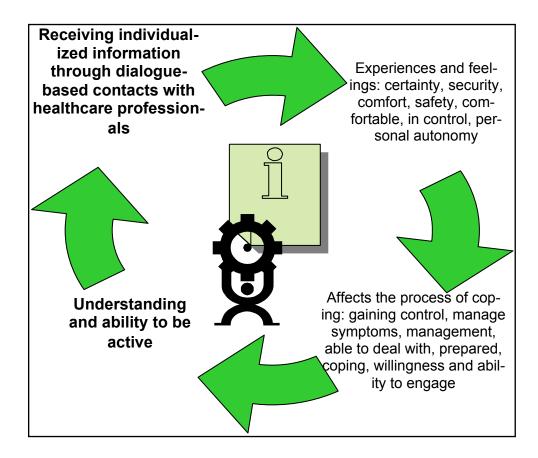


Figure 5: Findings in the survey of the literature: A positive process of empowerment.

As such, the two figures report the findings in the survey of the literature. The figures illustrate how lack of information and support can initiate the men's experiences of uncertainty, insecurity, and secondly continue this process of uncertainty, whereby the individual's ability to cope with the situation are affected. Figure 4 depicts a negative process of disempowerment as a consequence of lack in information and support. In contradiction, obtaining contact, enter dialogues, and receiving individualized information and support are related to experiences and feelings, which support the positive process. Figure 5 depicts a positive process of empowerment. Empowerment is the process of giving somebody power in a particular situation, which means to give somebody more control over their own life or the situation they are in (Ordbogen.com, 2011). This illustrates the importance of receiving information and support during a course of treatment and care. By providing information and support healthcare professionals may be able to empower the patients. The empowered patient is also the active patient.

5.2. The survey of the literature as a phase in the research process

The first connection between practice and theory was to explore the problem experienced in clinical practice, by searching the literature. This early phase of the research process, illustrates what Scheel states: Theory forms practice and practice forms theory. Or the other way round: Practice forms theory and theory forms practice.

The problem experienced in clinical practice by the nurses, as described in section 2 of the thesis; the Background, was the contradiction between: short and limited time for formal and specified face-to-face contacts with the individual patient; a significant and increasing amount of information and guidance in relation to the patient according to the standard care plan; and the different and changing needs for information and support for the individual patients. This problem in clinical practice was substantiated in the survey of the literature, as the nurses' descriptions on how they would like to have more flexibility in their caring for these men are essential. Flexibility in relation to the individual man allows the healthcare professionals to individualize their information and support to this individual patient, which are important to empower the man. Thereby the man can act according to the active patient regime, as active partner in his own course of treatment and care. However, even the literature signifies the importance of flexibility, the healthcare professionals are not allowed more time to be flexible in. Therefore the theory asked the next question: How to establish flexibility in the contact between the men with prostate cancer and the healthcare professionals?

At the same time the theory, by way of the survey of the literature, designed puzzle pieces to what could be a new health informatics tool, especially the relevancies in utilizing the Web 2.0 technologies. This, at that time in 2007, relative new technologies, offer the opportunity to establish a flexible environment for contact between men with prostate cancer and health-care professionals, according to the asynchronous communication. Together with the Web 2.0 technologies the literature survey contributes to a collection of puzzle pieces, as features and functions relevant for future health informatics were found across the literature. These findings are elaborated in depth in Paper II.

In view of that, the dialectics between practice and theory was already present in the current research process. Thus, in a hermeneutic and innovative perspective, the next steps were to continue this dialectic process. The theoretical idea, based on findings in the literature survey, could only become of value if the dialectics between theory and practice continue. Jørgensen et al (2009) explain how a technology is something that is developed, used, and experienced in a practical and social context. A technology needs users to become a technology.

At the same time, there is a mutual influence in the unity of theory and practice. In an innovative perspective, going from idea to value is not a linear process. The theoretical idea of a tool influences the practice, and back-and-forth the practice forms the technology.

In summary, the tool could only become of value, if the practical and social context was explored and understood, too. This generated the next two phases of the research project: The interview study and the intervention study.

6. Interview study

This section reports the interview study, which is categorized as the second phase of the research process. In this phase the dialogical search for knowledge was conducted as qualitative interviewing and supplemented with Internet-based interviewing.

The decisions made in relation to the process of interviewing were inspired by the hermeneutic thinking and operationalized through and reflected upon the book of Kvale and Brinkman (2009), which are illuminated earlier in the thesis, in section 4. The analysis of the data was as well grounded on the description of hermeneutical interpretation of meaning by Kvale and Brinkmann. Additionally, the decisions ahead of and during the interview phase were influenced by the researcher's preconceptions in general, which are elaborated in subsection 4.4 and 4.5. Especially, the theoretical understandings of men as patients and study population were central in this phase. How the theoretical preconceptions influenced the process is illuminated in the current section. The references will not be listed, as they can be found in section 4.

The problem experienced in clinical practice was substantiated in the survey of the literature. However, to substantiate and understand the body of the problem in the specific social and cultural context an interview study was carried out.

In the light of the theoretical idea, from the former phase, the main focus, for this phase, was to develop and implement the new health informatics tool by utilizing the findings in the interview study. Therefore the findings are not presented in full in none of the four papers. Instead the data generated in this interview study were utilized and discussed during the developing phase of the Online Patient Book[©], as an important step to involve patient users in designing the new tool and to contextualize the new technology.

As the interview study is not documented elsewhere, this thesis elaborates on this phase of the research process.

The interview study contextualized the research questions in the specific culture and society; Scandinavia (Denmark). The specific operational questions in the interview study were:

- * How do men with prostate cancer, treated with prostatectomy surgery, experience their contact with the healthcare professionals in clinical practice based on short stays?
- What do patients need to feel secure and certain?

- ★ How do men with prostate cancer treated with prostatectomy surgery utilize the Internet?
- * How should a new health informatics tool be designed to accommodate the needs of the patients?

6.1. Study population

The study population, in this retrospective, descriptive study, was men with prostate cancer treated with prostatectomy surgery, with a length of hospital stay of less than five days. The men were recruited via an open invitation in the magazine of Danish patients association for men with prostate cancer (PROPA).

In all 75 men responded on the invitation. A strategic selection was used to involve men from all areas of Denmark and to interview men with varied length of hospital stays from 1 to 5 days, according to the status of short stays at hospital in 2007, at the beginning of the research process.

In all 15 interviews were carried out from June 2008 until October 2008.

6.2. Qualitative interviewing

The interview study was carried out to generate knowledge on how men with prostate cancer experience their contact with the healthcare professionals and what these men need and do to feel empowered. Descriptions of men with prostate cancer's experiences of contacts with healthcare professionals were generated through the qualitative interviews. An interview guide was made to achieve an insight into how, when, and maybe, why the men had experienced feelings of insecurity, uncertainty, and disempowerment. And what the men had done to overcome those feelings of disempowerment and what they think could have minimized the disempowerment.

Thus, the objective was to conduct semi-structured interviews, according to the researcher's specified focus on the themes: contact, information, communication, support, empowerment, and the Internet. Therefore the interview guide was partly and thematically structured to maximize the focus on the individual man's experiences in relation to these terms. The interview guide, in Danish, can be seen in the Appendix A. The interview guide depict a thematically dimension as well as a dynamically dimension. The questions were contained in this interview guide with a focus on the issues to be covered. One of the main questions was: What makes you, as the patient, feel secure and certain?

The first three interviews were primarily conducted as pilot interviews to test the interview guide. During this phase some minor revision of the interview guide were carried out. Subsequently, these interviews were a part of the data collection, as they contributed to the richness of the data, not to major changes of the interview guide.

Due to the preconceptions about men as a study population, as illuminated earlier in the current thesis, the men were asked in relation to where the interview should take place. Thus, the individual decided, whether the interview should take place at his own home or at a hospital nearby the man's home. One man preferred the hospital; two men suggest their workplace; and the rest of the interviews were carried out at the man's own home.

Ahead of agreement on the interview the men were asked, by phone and by mail, not to invite their partners or relatives. This asking for withdrawing of the men's partners was a conscious decision grounded on the researcher's preconception. According to the theoretical preconception, illuminated in section 4, the presences of the men's female partners could contribute to richness of and details in the data. In the current interview study the de-selection of the partners was therefore an active de-selection. The possible richness the partners could offer was given less priority compared to the opportunity to get a deeper insight in the men's experiences and feelings. Even though the women's presence could be seen as more productive, this production would not identify the concerns of the men themselves.

The men accepted to be interviewed without their partners. In several cases the researcher was introduced to the man's partner before starting, or after, the interview. In one case the man's wife was present during the interview. Ethical considerations in this particular context made the researcher (and interviewer) refrain from asking the wife to leave the interview setting. Instead the researcher, at the start of this interview, explained that she primarily would address the questioning to the man himself. However, during the interview it was clear, that the wife was present to help the man to remember, as he generally suffers mild amnesia. Data from this interview was taken into consideration in the analysis of the data, as the data were found consistent with the data from the other interviews.

The researcher's theoretical preconceptions were also taken into consideration according to the very personal themes. The researcher tried to utilize her professional background to establish a familiar interview context. Ahead of the interview, the men were told, by phone and by mail, that the researcher (interviewer) was a nurse, which included experiences from working in the field of urology. This information was repeated at the start of the interviews, though at that time often in an informal matter.

Due to the personal matters, the men were invited to send supplementing comments using emails both before and after the interview, which a few men actually did.

The interviews started by inviting the men to tell their story in relation to their own course of treatment and care. By that the men were allowed to set the scene and by that sense their control in this unfamiliar situation. The interview guide helped the researcher to conduct the questioning based on the core themes in relation to the individual man's story. During the interviews the men were offered time and space to settle in and to go beyond the topics, to reach to a greater insight of the experiences of the individual men: To go from the normal, initial male statements, on everything being okay, to the individual man's actual experiences and feelings. Partly therefore, the length of the interviews varied from one to two hours, in addition often starting with an informal, not audio recorded, coffee break.

Men's use of tools, for example drawings and personal notes, were recognized and utilized, if relevant, during the interviews.

These structural, relational, and interactional choices were made according to the researcher's preconception of men as the study population. Though, ahead of each meeting the researcher reminded herself to be aware of men as individuals.

The interviews were audio recorded and supported by field notes in a notebook. The field notes were transcribed vertebral to Word files and the audio records were kept as audio files. The researcher experienced the individual interviews, as being partner in a hermeneutic process. The researcher recognized how the dialogues in the interviews generated new understandings for both the individual man, who was interviewed, and the interviewer (researcher) herself. This was supported by the men themselves, as some of them after the interviews denoted new understandings. This experienced hermeneutic circularity was depicted by the researcher, for her own use during the research process, and can be seen in the Appendix B.

The 15 interviews were supplemented by an invitation to 60 men, those who also responded on the open invitation in the magazine of Danish patients association for men with prostate cancer. These men were invited to answer open questions using Internet-based interviewing via e-mail or in few cases text-based interview questions send by mail. 47 men responded and sent their written answers to the researcher either as e-mail or snail mail. These written answers were kept as various documents and are categorized as supplementing answers.

The whole collection of text in this phase of the research process was then completed, and consists of: The audio files, field notes, and written documents.

6.3. Data analysis in the interview study

Guided by hermeneutical interpretation of meaning (Kvale & Brinkmann, 2009), as outlined earlier in the thesis, this collection of diverse data were seen as answers to the operationalized questions which related to this phase of the research process.

The inspiration from hermeneutic philosophy does not contribute to a step by step analysis. Instead the hermeneutic perspective contributes to some principles, as for example the primacy of the question. Another aspect is the back-and-forth process between parts and the whole based on the circularity of the hermeneutic process. In the current research process these hermeneutic principles contributed to a re-contextualisation of the men's primary answers, as illustrated in Figure 6 and 7, which will be explained in the following.

According to the hermeneutic stance of the primacy of the questions, the operationalized questions directed the men's answers. The operationalized questions depict that the men, who participated in the current study, were directed to talk about their experience on contact with healthcare professionals in relation to topics as: short stays, security and certainty, and the Internet. The men's separate answers were recognized as parts in: the individual interview; in the specific phase of the research process; and as parts of the research process as a whole. As such the findings were as well re-contextualised in the light of the design of the health informatics tool.

In relation to the next phase of the research process, the intervention study, the Figures 6 and 7 depict how the data from the interview study were re-contextualized to be utilized in the designing and developing of the new health informatics tool. The men's primary answers were first de-contextualised according to the theoretical preconceptions, for example on concepts as empowerment and disempowerment. Then these de-contextualised answers were recontextualised in the innovative perspective. Kvale and Brinkmann (2009) describe that every hermeneutic interpretation goes beyond the immediately given and enriches the understanding to an understanding-better and to extend its meaning. In the current research process this creative process re-contextualised the men's answers to puzzle pieces of the new health informatics tool. Core themes related to the operational question: How should a new health informatics tool be designed to accommodate the needs of the patients, are thereby outlined in the Figure 6 and 7. Figure 6 relates to the two head sections in the Online Patient Book.

Figure 7 relates to some of the subsections in the Online Patient Book.

The primary "answers"	De- contextualisation: What empowers the men and help them to be active?	Re- contextualisa- tion – further actions: Features in the new tool
Audio files: Man.12: Your nerves are a little on the edge Every thing was run through the healthcare professionals were incredible to inform you both before and after the operation You absorb all (information) that you can.	Information is important	A section with General infor- mation
Audio files: Man.24: I had not dreamed that I would be discharged the day after surgery I did not know anything I was disappointed overwhelmed I had some questions, but I did not get to them The only one, who really explained to me, that was at the first meeting she (doctor) explained what will happen Before the operation I was not nervous, but after the operation, when you are home, I feel, that they (the healthcare professionals) do not care about you. (This man is also one of the patient test users in relation to the preliminary version of the Online Patient Book in the test phase (see Intervention study). In this test phase he describes: I would had like to have this facility to learn so much about prostate cancer, as I can here. I can see everything, read what is going to happen. I can read about everything, it is really good).		
Written notes from the man before the interview: Man.15: About support and information, that is difficult, because there are different phases I think the healthcare professionals should be better in relation to dialogue After the operation. It is only at that time we as men are ready to hear and to take the next step. After the operation there was a gap It was me, as a human being, which should continue to live, not just my scar and bowel movement I think that I am more than that. The next consultations are shortIt went fast at the doctor's office It was a big problem about the lacking dialogue I left without new information. Field notes: Man.15: During the interview the man draws a picture. This illustrates how the healthcare professionals at the local hospital do not see the human behind; the individual needs. He pictures the need for information in different phases of the course by drawing a set of steps.	Individualized information is important	A section with Personal infor- mation
Internet-based interviewing - snail mails: Man.33: There were a lot of questions which I did not get any answers to all the healthcare professionals I meet, were shallow and they did not take their time I experienced two nurses which supported me and talk to me There were many times at home, where I did not feel supported and lacked answers I indeed needed to search for information elsewhere The consequences of the lacking dialogues with the healthcare professionals is an enormous frustration and lots of anxiety and worries.		

Figure 6: Re-contextualized data in relation to the two head sections in the Online Patient Book $^{\!\scriptscriptstyle \odot}\!\!$.

The primary "answers"	De- contextualisa- tion: What empowers the men and help them to be active?	Re- contextualisation – further actions: Features in the new tool
Audio files: Man.21: All along I had their (the healthcare professionals) phone number, and they let me know, that I could always call or come to the hospital then you can not ask for more (to have a good contact) it certainly matters, because you are uncertain, it is a new situation Audio files: Man.24: In the beginning, I experienced some problems, and called the hospital, they say, that I need to call again, using another phone number Then I call, using this other number, to a nurse maybe, or a doctor, I do not know they say the same, that I should not call them either then they are free of you, that is so disappointing (By his own initiative he gets in contact with a district nurse) she tells me that I should just call her again if I experience some problems again It could not be better this security, actually my lifeline and because of that (feelings of security), I only call	Accessibility to healthcare professionals	A subsection for personal contact between the individual patient and the healthcare professionals at the wards
when it is necessary. Audio files: Man.21: For me it matters something I could call X (another patient from the Danish patients association for men with prostate cancer) by phone, and I could call Y by phone and talk to them, and from my point of view it also matters for them to talk with me on, how I had experienced it exchanging experiences. Audio files: Man.30: In relation to a patient survey I was with a group of ten other patients with prostate cancer that was a good experience I could ask some question, which gave me a higher	Sharing with copatients	A subsection for dialogues between groups of patients – online social support.
Written notes from the man before the interview: Man.1: Just from the start I kept a record. Presumably the reason was that I would be in control of the course (the record was structured as doctors' notes in a patient record). Written notes from the man before the interview: Man.15: I used the Internet a lot and many times for us men, I think that, this is a good technique just to sit down and read and hear about the different information. Field notes: During the interview the man draws a picture. Audio files: Man.17:when you feel that you can do something you often avoid feelings of insecurity and the feelings of loosing control. Audio files: Man.30: I had done a lot of research on the Internet I feel that if I acquaint myself, I do, to a certain degree, have my hands on the control stick Another thing I did, from the start I made a Log book. I wrote in it after every blood test, after every meeting with the doctors; what we talked about, what has been put on the table, what did, I get out of it, and what had the doctor been saying about the things I asked about. I needed to do something. I was happy about doing it, it gave me a feeling of being in control at home, writing it down and register it, so I have a long folder.	Tools which supports control	A subsection for the patient's Per- sonal Notes and a personal checklist

Figure 7: Re-contextualized data in relation to some of the subsections in the Online Patient Book $^{\! \circ}\!.$

6.4. Findings generated in the interview study

The findings in the earlier phase of the research process, the literature survey which are analysed in Paper I and Paper II, were as well recognized in the social and cultural context according to the findings in the current phase of the research process. As such the interview study substantiates the findings from the literature survey: For men to be empowered, the accessibility of the healthcare professionals and the healthcare professionals' ability to individualize information and support are important aspects.

Summary of findings:

- Men who described lack in relation to contact, dialogue, information, and support also describes feelings of insecurity, uncertainty, and disempowerment
- In relation to the men's contact with healthcare professionals the important thing is not the length and amount of time, instead it is the quality of the contacts; the healthcare professionals' accessibility and their ability to individualize information and support, based on exchange-ability
- Providing information and support healthcare professionals may be able to empower the patients, and the empowered patient is also the active patient
- The men like to act and to stay in control by being active partners in their own course of treatment and care
- The men use the information to empower themselves and thereby to be active partners in their own course and to continue their normal day of life
- The healthcare professionals' ability to individualize information and support, based on dialogues with the individual man, is essential for the men to experience the contact to the healthcare professionals as good
- For men to feel secure and certain, the healthcare professionals must be easy to get in contact with during the whole course of treatment and care
- ➡ The men often avoid to contact the healthcare professionals, as they do not want to disturb them
- The men experience the information given to be difficult to remember
- The men who use the Internet use it to be well informed, prepared, or even to be at the forefront of the things ahead.

The importance of the healthcare professionals' ability to see the men as individuals, carrying their own experiences, feelings, attitudes, and so on into this, for them as patients, unique and unfamiliar situation, even when it is not obvious at first, is illustrated in a cartoon. The car-

toon is reproduced in Figure 8. This cartoon was handed over from one of the men (Man.42) in one of the interviews. The cartoon shows how the needs of the individual patients may not be obvious at first. The healthcare professionals' ability to recognise the needs of the individual patients are significant and put some demands on the healthcare professionals' qualities and skills. The healthcare professionals may be able to explore the patients' need by way of diverse perspectives (The original cartoon can be retrieved from http://wulffmorgenthaler.dk/strip/2007/06/19).

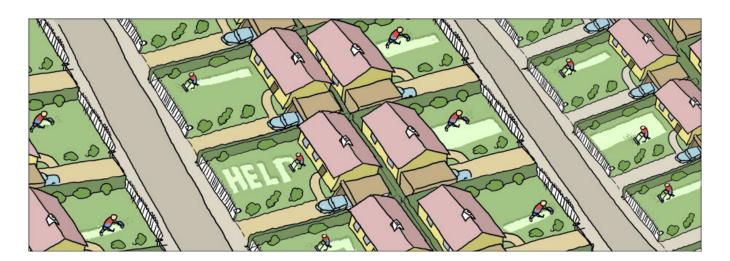


Figure 8: A cartoon from one of the men, who participated in the interview study.

Another man in the interview study (Man.30) describes how he experienced the healthcare professionals' ability to see him as an individual and what it meant to him:

For me, it meant that I felt secure in the course... I felt I was in the hand of professionals... everything is sort of wrapped up by what I will call empathic kindness (Man.30).

As the cartoon seems to summarize some of the core findings in the interview study, it was used as a tool in the next phase of the research process in relation to the involvement of the healthcare professionals. This is described in connection with the intervention study in the section 7.

6.5. The interview study as a phase in the research process

The theoretical idea of a health informatics tool, that was based on findings in the survey of the literature, could only become of value if the future users and their context where recognized, as a technology needs users, and their usage of it in a practical and social context, to become a technology. This is earlier described in the end of section 5.

Therefore in the current phase of the research process it was primarily relevant to substantiate and understand the body of the problem from the patients' perspective. The question was whether, and if, how men with prostate cancer in the specific social and cultural context experience a problem in their contact with the healthcare professionals. In view of that, the dialectics between practice and theory continue, as the researcher in the current phase explored the men's experiences in the practical and social context.

As stated, the findings in the interview study substantiated the findings from the literature survey. It was relevant to develop a new health informatics tool for men with prostate cancer, which they could use in their course of treatment.

Secondary the process of generating and analysing data in the current phase nuanced the theoretical idea of the new health informatics tool, as the findings contributed to clarify and contextualise the puzzle pieces to what a new health informatics system should offer.

These nuanced understandings were important in the next phase of designing and developing the new information and communication technology. By operationalizing the new understandings which the researcher obtained during this phase of the research process, these insights were utilized and further explored, in the following dialogues with the clinical practice, through the intervention study.

At the same time the mutual influence to the unity of theory and practice would continue as the researcher in the next phase of the research process intervene in, and thereby influenced, the clinical practice in which the problem was experienced at first.

7. Intervention study

This section of the thesis reports the intervention study, which is categorized as the third phase of the research process. The section introduces the technology itself and the process of product development, as the intervention study generated the technology. Therefore this section differs from the other sections, which reported the four phases of the research process. The other three phases generated new understandings, which mean knowledge, whereas the current phase results in a product. Thus, in this phase the dialogical search for knowledge was primarily conducted as design workshops.

According to Figure 1 (section 1), which depicts the research process, the intervention study followed a linear process: from problem; to literature survey; to interview study; and then the intervention. However, the research process should be recognised by the hermeneutic spiral. Through documentation of the intervention study, this section illuminates how the separation of the research project in four phases is merely a theoretical distinction. Seen as a practical design process and as a product development the research process consisted of several iterations that created the final product. Though placed separately, the phases were stages in a back-and-forth process, iterations, between progresses in the whole process and progress in the individual phases. The progress in and across the phases depended on and influenced the whole research process. This can for example be illustrated by the significance of the earlier phases of the research process to understand the aim of the tool, which was developed in this particular phase, the intervention study. At the same time, early actions in the intervention phase approved the processes to move on. Seeing the separated phases in the light of the whole research process contributes to understanding the possible relevance of the tool developed in the current phase.

The aim, in this phase of the research process, was to develop the patients' health informatics tool. The theoretical idea of a Web 2.0 application for the patients, which was based on findings in the survey of the literature and in the interview study, could only become of value if the tool was specified. This means that the health informatics tool must be developed and implemented in a practical and social context.

Therefore, the results in this phase do not contribute to answering the research questions directly. Still, the operational questions were utilized during the phase in guiding the design of the tool:

➤ What do patients need to feel secure and certain during their course of treatment and care?

According to the theoretical preconceptions as described earlier in the thesis and elaborated in Paper I, this question, including the terms secure and certain, was in addition operationalized to, and questioned as:

* What do patients need to enhance empowerment during their course of treatment and care?

These operational questions were used to direct the dialogues in the design workshops and in diverse design dialogues with other co-operators throughout the specifying and developing of the new health informatics tool.

In the following the technology itself will be introduced at first, as this is the result of the intervention phase. Next after the process of product development will be illuminated.

7.1. Results in the intervention study: The web application the Online Patient Book[©]

According to the aim the intervention phase led to the development and implementation of the web application the Online Patient Book[©] (www.onlinepatientbog.dk).

From the patient users' perspective the website consists of two sections, both with subsections, as illustrated in Figure 9. A public section, with open access, that provides monologue-based general information generated by clinical experts. The general information is divided into nine subsections. The public section is supplemented with a secure individualized section that requires a login. This personal section provides monologue-based individual personalized information, which can be generated both by healthcare professionals and by the patient himself. Personal information based on nurses notes after the patient's meeting in the outpatient clinic, and the patient's own private personal notes (e.g. Log Book) can for example be entered and accessed in the personal section. Additionally, the uses of Web 2.0 technologies provide the opportunity for personal communication and dialogues within this asynchronous and written environment. In one subsection between the individual patient and well-known clinicians, as the Online Patient Book[©] links to the healthcare professionals the patients met at the hospital. Additionally, in a separated subsection among a group of patients, as the Online Patient Book[©] provides an application for online social support between bounded groups of patients.

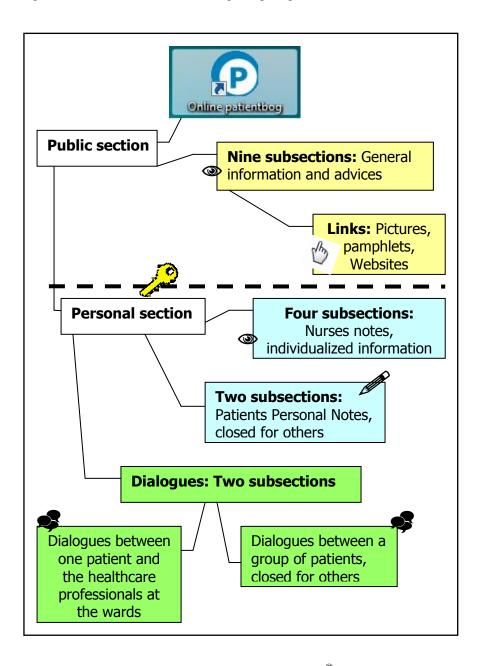


Figure 9: The web application: The Online Patient Book[©] from the patient users' perspective. **⊕**=Reading, **/**=Writing, **♣**= Dialogues.

7.2. Results in the intervention study: Implementation

The usage of the Online Patient Book[©], in clinical practice started in September 2009, at the Department of Urology, Aalborg Hospital, Aarhus University Hospital. It was introduced as a new information and communication tool to men with prostate cancer planning for prostatectomy surgery. The Online Patient Book[©] was implemented in clinical practice as a part of the standard care for this group of patients. Hence, the Online Patient Book[©] was not introduced as a pilot study. Instead, it was introduced as a new information and communication tool

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grounded on the substantiated problems in relation to lack of information experienced by men with prostate cancer planning for surgery.

The patient users can use the tool along their whole course of treatment and care for this condition, as shown in Figure 10. The figure illustrates the individual patient's opportunity to use the Online Patient Book[©] during his course of treatment. The yellow lines demonstrate how the patient can use the tool at home and in different phases. The blue lines document the healthcare professionals' use of the tool in relation to the individual patient.

At the men's second meeting at the hospital, and prior to planning the surgery, the men were informed about the opportunity to use the public section with open access in the Online Patient Book[©]. At the third meeting, at the time the surgery was accepted, the men were enrolled. A personal section was then created, whereby the men had full access both prior and after the surgery. Some patient users had full access up to three months prior their surgery, because of an extraordinary waiting time for surgery.

Information about the Online Patient Book[©] and the enrolment were handled by the nurses, as an element of the standard care for this group of patients. The enrolment automatically generated an e-mail to the patients private e-mail box containing system generated, secure one way encryption key codes. This encryption is considered compliant with Danish safety and security legislation as mentioned in subsection 4.6 in the current thesis. In addition to the key code, the automatically e-mail to the patient users included a user guide specified for patient users. The patient users are able to use the Online Patient Book[©] without limitations in time. However, the ability to contact the healthcare professionals is closed 12 months after their surgery, advising the patients to contact their private doctor instead.

Setting	Care /Treatment	The healthcare professionals' use of the Online Patient Book [©]		
Hospital. First meeting:	Biopsies	-		
Out-patient Clinic				
Home The Online Patient Book® appears as one of the first results in a Google search, if the patient Google "prostatektomi" (Denmark, March 2011)				
Hospital. Second meeting	Diagnosis	Inform about the Online Patient Book®		
Outpatient Clinic	Planning further examinations			
Home				
		inks to pictures, pamphlets, websites - the open access part		
Hospital. Third meeting:	Planning the course of treatment	Enrolment of the patient. Notes on Personal Information including Appointments		
Outpatient Clinic	Surgery accepted	and Summary from meeting		
	Surgery accepted	System-Automatically generation of key code; to patient		
		by e-mail		
Home 🕲 🔊				
The patient are allowed full assess. The patient received the key code by e-mail				
Hospital. 1-3 days: Inpatient Clinic	Surgery Short Stay, discharge within 1-3 days	Notes on Personal Information including Appointments and Summary from stay at the inpatient Clinic + (standard) Written message to the single patient at the day for discharge		
Home ® 9				
The patient are allowed full assess. The patient received an E-Alert in his private e-mail box, e.g. in relation to the written message from the healthcare professionals				
Hospital. Various number of meetings up till 3 months: Outpatient Clinic	Cath. sep. Bio Feed Back	Notes on Personal Information including Appointments and Summary from meetings		
Home ® 9				
The patient are allowed full a Hospital	Control	Notes on Personal Information including Appointments		
3 months Consultations:	Control	Notes on Personal Information including Appointments and Summary from meeting		
Outpatient Clinic		j		
Home 🕲 🦻 🎤				
The patient are allowed full assess				
Home 1 year after discharge The patient are allowed full assess, apart from the patient to healthcare professional contact. The patient will still be able to read earlier dialogues				
The patient is automatically i	The patient is automatically informed that he need to contact his private doctor instead.			

Figure 10: The individual patient's opportunity to use the Online Patient Book during his course of treatment: =Reading, =Writing, =Dialogues.

7.3. The process of product development

As described in section 4 of the thesis an intervention means a process of actions. The processes of actions in this research project were not restricted to the intervention study. However, the actions in the intervention study differ from the actions in the other phases. The aim of the actions in the intervention phase was to produce the new technology. In the other phases the actions aimed to generated knowledge. Combining the four phases, and thereby the aims, the phases covers a process, which can be defined as a course, whereby something happens due to a line of actions, so that something is changed or developed (Ordbogen.com, 2011). The phases depend on and relate to each other, as iterations, which is depicted according to the spiral (Figure 3, section 4.1). The spiral covers the process of developing, creating, or formatting something new, in which the separated phases were utilized to support the spiral, meaning the progress and thereby the continually movement away from the starting point. The movement in the innovative perspective is the developing of a product based on the idea of it. Seeing the whole research process illustrates for example the bottom-up approach and the involvement of participants, which will be elaborated in the following subsections.

Though, the actual developing, meaning the process of product development and cooperation with healthcare professionals and system developers was placed in a limited period of time: From January 2009 to September 2009. The tool was then implemented in clinical practice to be utilized from the 15 September 2009 as depicted in Figure 11.

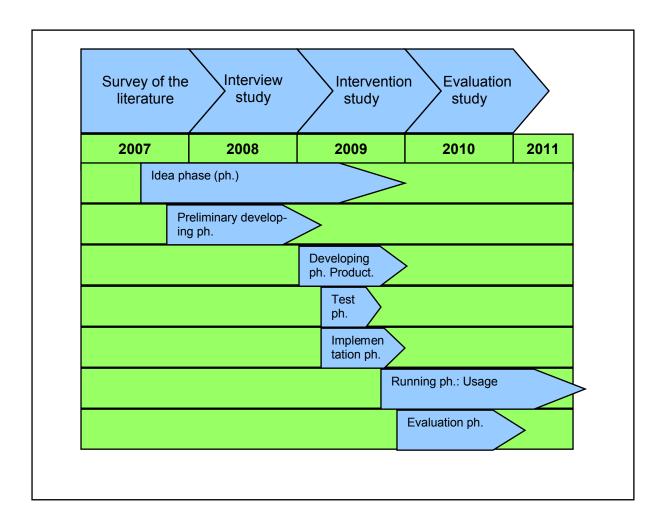


Figure 11: The four phases of the research process, in combination with years, and the different phases of the Online Patient Book[©]. (phase =ph.)

7.4. Participatory methods

As pointed to above, seeing the whole research process illustrates the involvement of users. The importance of needs assessment as a part of the designing, specifying, developing, and implementing the new technology, links the intervention study to the survey of the literature and to the interview study. The phases ahead of the intervention study should therefore be recognized as ways of involving users in the designing of the new health informatics tool. As such patients as well as healthcare professionals were involved throughout the research process, by applying various participatory methods.

Patient users were involved by applying the answers, to the operational questions, which were generated during the survey of the literature and the interview study. In the interview study the men were questioned directly, according to the specific questions about their inter-

est in and ideas to Internet based tools. In addition, the men's experiences of contacts, information, support, and dialogues during their course of treatment, which were generated in the interviews and subsequently analysed, were applied. The re-contextualising of the men's experiences depicts relevant features and functionalities in the future technology, as illuminated in section 6.

Nearly a year after the interview study, six men, who offered their help through the interviews, tested a prototype of the new tool, as a part of the developing phase. Their use of and comments were taken into account before the Online Patient Book[©] was implemented in clinical practice. However, these were only minor changes, for example in relation to the user guide.

After the implementation of the health informatics tool, the patient users were involved in relation to the fourth phase of the research process according to the evaluation study, which the next section, section 8 in the thesis reports.

Healthcare professional users were primarily involved by applying design workshops. The actual design workshops consist of six workdays, where the researcher (also named project manager in relation to the Online Patient Book[©]) worked together with six healthcare professionals. The workshops were all completed within the period of time: March 2009 to September 2009. However, the introductions to the intervention study in the clinical practice already started with a primary meeting in November 2008. This meeting was the first in a line of meetings between the clinical leaders in the relevant departments and the researcher.

According to the workshops the healthcare professional users were represented by six nurses, all end-users as they would ultimately use the health informatics tool in their daily clinical care. At the start of the implementation they should take action as super users. The six workshops, within six months, were the basic in the cooperation between the group of nurses and the researcher. Though, these workdays were followed by ongoing dialogues, primarily based on e-mails and between one or two nurses and the researcher.

From a hermeneutic perspective the dialogues throughout the workshops offered the opportunity to generate knowledge on relevant features to the potentially new health informatics tool. The generating of knowledge was directed by the operational questions, as the ongoing dialogues circled around the answering of what empowers the men treated with prostatectomy surgery in their course of treatment and care. The dialogues, and thereby the generating of knowledge, started with the researcher presenting the puzzle pieces, this means the idea of and the early model to a new health informatics tool, which was grounded on the results from

the involvement of patients in the earlier phases of the research process. To inspire the dialogues with the healthcare professionals during this phase, the researcher presented excerpts from the patients' answers from the earlier phases, for example by introducing the cartoon depicted in Figure 8 in section 6.

The cooperation with the healthcare professional users generated the content to the puzzle pieces:

- ➤ From just being uncreated and unfilled pieces of what could be sections of the new health informatics tool
- To become pieces that were charged and loaded: Filled with for example general information, illustrations, pictures, and headings of textboxes to standard or open remarks on individual information.

The involvement of healthcare professional users, represented by the six nurses, was supplemented by inviting experts on particular topics to complete the feature to the developed tool. Experts as: doctors, surgeons, secretaries, clinical photographer, sexologist, nurses specialised in incontinence, surgical nurses, nurses from intensive care units, nurse specialists, head nurses and head doctors, etc. contributed to complete the content, for example the large amount of general information the Online Patient Book® offers according to the nine subsections of the public section.

The materials to the approaching Online Patient Book[©] were thereby based on answering the operational questions, by means of generating knowledge in cooperation, and in that way dialogues, with clinical experts.

From the perspective of Scheel this development became a process, which shapes not only the health informatics tool, but the practice in general. In particular, as the process generated dialogues among the nurses in the departments. The group of nurses was for example forced to discuss the way they would address their information and communication in the written, asynchronous environment the Web 2.0 technologies offer. It was new for these groups of nurses that the patients would be able to read their nursing documentation. These discussions tend to initiate a general discussion on the subject matter in nursing. Another aspect was initiated at the beginning of the workshop process, as it became clear to the nurses involved that the existing information material to men with prostate cancer was not at all up-dated. Therefore the intervention process produced new paper based information material as well to this specific group of patients, which later on was transferred to other patient groups in the Department of Urology. This paper version was comparable to the one of the subsections, within the public section of the Online Patient Book[©], describing a course of treatment in general.

After the implementation of the Online Patient Book[©], patients, who did not use the Online Patient Book[©], were offered a paper version of the general information. Though, this paper version did not contain pictures, links, personal information, and pamphlets (instead these were handed out on separate paper sheets). The communication elements available through the Online Patient Book[©] were obviously not available to this group of patients. Even so, this paper based information material was up-dated due to the possibilities the intervention study generated.

Thus, patients and healthcare professionals participated in both the designing and developing phase, by means of utilizing the data collected from the literature survey, the qualitative interviews, and the workshops in the current phase, the intervention study.

7.5. Bottom-up design

As pointed to above, the progress in the innovative perspective is the developing of a product based on the idea of it. In the current research project, this idea, was born in the clinical practice, and shaped in the unity of nursing practice and theory.

Seeing the whole research process illustrates the bottom-up approach, as:

- ➤ The tool was grounded in the clinical practice, by which the project manager (the researcher) was placed in clinical practice
- * The tool was designed using participatory methods, by which the primary focus was on the future or potential users: the patients and the healthcare professionals.

Through co-working with both experts from clinical practice and system developers, the researcher (project manager) linked the clinical practice to the IT Department.

As the project manager was the researcher, with a professional background as nurse, the project manager did not carry any professional IT background into the cooperation with the system developers. Thus, the development process, in this case the process of product development, bridges the boundary between the contexts and work practices of two very different professions: the clinical practice and the practice of system development.

The clinical practice was organized under The North Denmark Region, which is one of five regions in Denmark. The healthcare sector is the main task for the regions, and The North Denmark Region includes four hospitals with approximately 8.700 employees.

The region also includes an IT Department, which is physical and organisational separated from the hospitals. The IT Department is a part of the Regional Administration with approximately 800 employees.

To establish a possible cooperation the researcher contacted this IT Department the first time in November 2007. To set up the cooperation two initial meetings were completed in the preliminary phase (see Figure 11). Four design meetings were completed within five months during the eight months developing phase, this means the process of product development, from January 2009 to September 2009. The total amount of meeting hours were around 10 hours. The cooperation was therefore primarily based on e-mail contacts.

The user generated design, which was produced through the involvement of patients and healthcare professionals, was communicated from the researcher (the project manager) in clinical practice to two system developers, at the IT Department by e-mails. From the initial design of the Online Patient Book[©] in January 2009, to the implementation September the 15, 2009, more than 500 e-mails were sent from the researcher to the system developers. Attached to the e-mails were a numerous numbers of: text files; pictures; and visualization by commented screenshots using colour codes as illustrated in Appendix C.

This co-working contributed to the results: The implementation of the Online Patient Book[©] in clinical practice, which is illuminated earlier in the current section.

Still, bridging the boundary between these contexts and work practices do challenge the partners, who were involved. To get an insight in this process, the researcher analysed and discussed the process with researchers within the field of health informatics. These dialogues contribute for example to the Paper V, the Supplementing Paper.

Additionally, section 9 of the current thesis elaborate some perspectives to the bottom-up approach, as this way of facilitating new health informatics system is discussed.

7.6. The intervention study as a phase in the research process

The current section aims to depict the non-linear process of the research process and thereby illustrate the iterations. These iterations were significant for the progress of the process and thus for the progress of the technology itself.

The intervention study should neither be seen as identical to the usage of the new tool in clinical practice, nor as the implementation of the tool. The intervention study included these sub phases as well. However, the intervention study was also the practical process of designing and developing the new product, in which the design workshops and cooperation with the system developer were central.

Contradictory to the linear process depicted in the Figure 11 the practical process of designing and developing the new product consisted of several iterations that created the final product. This is for example illustrated by:

- The project manager's (the researcher's) first contact to the IT Department was completed already in November 2007 and then followed by various contacts during the research process as depicted above
- ➤ The first meeting with the clinical leaders in the departments was completed already in November 2008 and then followed by diverse contacts and meetings during the research process as depicted above
- The Online Patient Book[©] do not differ much from the first draft of the idea, according to the number of sections and subsections, which were based on findings in the literature survey and the interview study. However, the implemented tool was much more nuanced and larger than the researcher could imagine at first, and therefore, as the IT Department estimated from the start. This made it necessary to raises more funding during the process.

In summary, the intervention study depends on the spiral, meaning the iterative processes. The hermeneutic spiral contributes to a picture of how the four phases were closely related, in which one phase depends on the former phases and at the same time relates to the next phase. The four phases:

- Were not strictly separated in periods of time
- Interacted with each other
- * Affected each other
- **X** Could only be recognized as phases of a whole process
- ➤ Were influenced by the ongoing and continuously developing of the clinical practice in which the research process was contextualised
- * Made an impact on the clinical practice in which the research process was placed in
- ➤ Should all be seen as important stages of the designing, specifying, developing, and implementing of a new health informatics tool.

The intervention study moved the conceptualisation of the patients' health informatics tool to the specified tool: The Web 2.0 application, the Online Patient Book[©], www.onlinepatientbog.dk.

To understand the effects of patients' health informatics tools, as the Online Patient Book[©], the use of the tool in clinical practice must be evaluated. Thereby the next natural phase was the evaluation study.

8. Evaluation study

This section reports the evaluation study, which is categorized as the fourth phase of the research process. In this phase the dialogical search for knowledge was conducted as Internet-based interviewing. The decisions made in relation to the process of evaluation by way of Internet-based interviews were inspired by the hermeneutic thinking and operationalized through and reflected upon the book of Kvale and Brinkman (2009), which is illuminated earlier in the thesis, in section 4. The analysing of the data was also grounded on the description of hermeneutical interpretation of meaning by Kvale and Brinkmann (2009). Additionally, the decisions ahead of the evaluation study were influenced by the researcher's preconceptions in general, which are elaborate in section 4 as well. Especially the theoretical understanding of men as patients and study population was central in this phase.

To understand the qualitative effects of patients' health informatics tools such as the Online Patient Book[©] an evaluation study was completed. The focus was on the patient users' perspective. The operational questions were:

- How can an online contact contribute in the contact between men with prostate cancer and healthcare professionals?
- * How can an Online Patient Book, as an example of the patients' health informatics tool, enhance the patients' continuity of care?
- ★ How can dialogue based web applications, as part of an Online Patient Book[©], improve quality in the contact between male cancer patients and healthcare professionals?
- ➤ How can dialogue based web applications facilitate contacts between male cancer patients?

Patients' experiences, as users of the resource tool, were generated by Internet-based interviews via a web page in the Online Patient Book[©]. The evaluation web page consisted of six textboxes, each related directly to an open question. These six concrete interview questions were all generated from the above mentioned operationalized research questions, for example: Describe how you use the Online Patient Book[©] in your course; Describe the meaning the Online Patient Book[©] has in relation to your course; and Describe the meaning it has for you, that you could enter a dialogue with other patients. The patient users describe their use of and what they consider about the tool, by filling in the six textboxes. The patient users themselves could decide how many of the textboxes they would fill in and the length of each

reply, as there was no word limit imposed. User identity was automatically collected, which made it possible to count and separate the unique evaluation.

Methods and results in relation to this phase of the research project are elaborated and discussed in Paper III and Paper IV. The following description in this section is therefore restricted to the findings. Though, the analysis of data will be explained first, as will the reason for choosing Internet-based interviews.

8.1. Internet-based interviews

In the current phase of the research process, which means the evaluation study, the men's experiences in relation to contact with healthcare professionals, specified to their experiences of online information and communication according to their use of the Online Patient Book[©], were generated using Internet-based interviews. While earlier in the research process the men's experiences were conducted using face-to-face interviews.

According to the researcher's theoretical preconceptions of men as the study population (see subsection 4.5) and the researcher's experiences of men as the study population in the interview study earlier in the research process (see section 6), it was determined that it was relevant to use the Internet-based interviewing as the method in the current phase.

The supplementing use of Internet-based interviewing during the earlier interview study establish that the group of men are potential participants in Internet-based interviews, as 47 out of 60 men responded on the invitation to answer open questions using Internet-based interviewing (see section 6). In the interview study the men responded on the text-based interview questions, primarily send out per e-mail, either by e-mail or by mail.

According to the theoretical preconceptions Internet-based interviews may have some advantages as well as limitations, which are listed below. In Internet-based interviews it is possible to utilise the asynchronous environment as in e-mail based interviewing or utilise the synchronous environment that the chat interviews offer. In the current study the asynchronous environment the actual health informatics tool offers was utilized, as the patient users' evaluations were conducted via a web page in the Online Patient Book[©]. Therefore the lists of advantages and limitations are produced in the light of an asynchronous environment.

Advantages of Internet-based interviews, according to the theoretical preconceptions (Doerup, 2005; Dysthe, 2005; Georgsen, 2003; Rander, 2005; Sandars & McDonough, 2005; Walston & Lissitz, 2000; Kvale & Brinkmann, 2009):

Flexibility; the patient users can contribute to the evaluation in a time and place most convenient for them

- Familiarity; the patient users are, as users of the health informatics tool during their course of treatment and care, familiar with the use of it
- Reflections; the patient users' written answers can contribute to new understandings when writing, as the process of writing can generate reflections, which again generates new knowledge
- Resource saving; the patient users as well as the researcher may save time in comparison with face-to-face interviews
- ➤ Various perspectives; the number of patient users, who can contribute in the evaluation can be enhanced, which could broaden the input
- ✗ Ongoing evaluation; the patient users can reopen the evaluation and thereby supplement his earlier evaluations
- ➤ Self-transcribing; the patient users' written answers generate a text, which is basically ready for analysis.

Limitations of Internet-based interviews, according to the theoretical preconceptions (Doerup, 2005; Dysthe, 2005; Georgsen, 2003; Kvale & Brinkmann, 2009; Rander, 2005; Sandars & McDonough, 2005; Walston & Lissitz, 2000):

- ➤ Short answers; the writing process can be a more cognitive demanding task than talking, which can shorten the patient users' written sayings
- Merely a monologue; the written answers cannot be questioned and thereby explored, as in face-to-face dialogues or as in chat interviews. The written answers are only directed according to the interview questions
- Less in-depth; the combination of a more cognitive demanding task, the monologue-based answering, and the higher number of responders, reduce the opportunity for indepth answering and, or analysis. Kvale and Brinkman (2009) describe how it can be difficult to generate rich and detailed descriptions
- * Lack of facial expression; as there are no bodily presences.

The lists of advantages and limitations may not be complete, though it provides evidence that Internet-based interviews are suitable for some purpose and not for others, which Kvale and Brinkman conclude as well.

In summary, using face-to-face interviews in the evaluation could have been relevant and would potentially contribute to a more in-depth insight as what can be depicted in written Internet-based evaluations. Therefore face-to-face interviews are relevant in the future evaluation of health informatics systems as the Online Patient Book[©]. However, for the purpose in this phase of the research process in combination with a population who already were

familiar with this particular web environment, the Internet-based interviewing was relevant and therefore the evaluation was carried out by way of Internet-based interviews.

8.2. Data analysis in the evaluation study

To explore the patients' experiences and what it means to them to have this health informatics tool in their course of treatment and care, the analysis of the data was based on hermeneutical interpretation of meaning (Kvale & Brinkmann, 2009), as outlined earlier in the thesis. The hermeneutic approach was used to explore the patients' answers by entering into a dialogue with the evaluation-text, as the hermeneutic philosophy does not contribute to a step by step analysis. The patient users' evaluations were handled as separated answers; as parts, and as one whole text. What the text itself stated about the use of and the effects of the Online Patient Book[©], were identified and understood by a continuous back-and-forth process in and across: the individual interview; the specific phase of the research process; and the research process as a whole. The evaluation text was recognized and analysed as the individual patient user's whole story on him being user of the health informatics tool. Additionally, a search across the individual evaluations divided the answers according to the interview questions. This back-and-forth process generated core themes, which are elaborate in Paper III and Paper IV. The core themes were as follows:

Two themes explaining the effects (Paper III):

- * The patients stay in control
- **➤** The patients stay free.

Two themes relate to the use (Paper III):

- * Patient users depend on healthcare professional users
- **X** Comments on the user interface and the design.

Seven core themes regarding usage of Web 2.0 technologies (Paper IV):

- * The patients become partner in a dialogue
- * A flexible environment for dialogues
- **Emphasizing** is not always the same as using
- * A calm environment, which generates dialogues
- ➤ Potential problems are taken care of
- **✗** Online social support as an opportunity
- **✗** Different levels of participation. **✗**

These themes reflect the findings, which are illuminated in the next subsection. Though, the illumination is restricted to a summary of the findings as these are elaborated in Paper III and IV.

8.3. Findings generated in the evaluation

As depicted at Figure 11, in section 7, the evaluation study was carried out within the first year of production of the Online Patient Book[©]. In the current research process the term production is named as the running phase and relates to the usage of the tool in clinical practice. The Figure 11 (section 7) also depicts that the usage of the Online Patient Book[©] continues after the first year of production and is still running today, in May 2011. However, seen from the perspective of the current research process a line was sat after the first year of production, as only the first year was a part of the funding and the agreements on collaboration between the IT Department, the Department of Urology, and the researcher. After this first year the role as project manager was succeed by the Department of Urology.

The evaluation study in the current research process therefore relates to the first year of production from September 2009 to September 2010.

The usage of the tool in clinical practice was not influenced by the evaluation, as the patient users could use the tool before, during, and after the evaluation study. The patient users' usage of the tool was independently of them participating or not in the evaluation study. This was according to the organisation of the tool as a part of the standard care plan in the clinical departments. The healthcare professionals were not involved in the evaluation, as the researcher handled the invitation to the patient users' and following administrated their participation in the Internet-based interviews. Therefore the healthcare professionals did not know, who or how many of the patient users that participated in the evaluation.

In the specified urology department, approximately 120 men with prostate cancer started their course of treatment from September 2009 to September 2010. Of these patients 90 accepted the invitation to use the Online Patient Book[©]. The exact number of actual rejections is not recorded, as in some cases the introduction to this new tool could have been forgotten and information about rejections was not specifically gathered by the nurses. This resulted approximately in:

→ 75 percent of the men in this group of patients in the Department of Urology were users

Patient users were invited to the evaluation from two to seven months after their surgery. The evaluation stopped September 2010. Therefore patient users, who had their surgery after July 1st 2010 were excluded from the evaluation study. This left 58 potential evaluators, of whom 34 completed and sent the written responses. This resulted in:

◆ 59 percent of the men who were invited to evaluate responded

Summary of findings:

Combining Web 1.0 and Web 2.0 technologies, the health informatics tool:

- Was recognised as the men's own health informatics tool, which they used throughout their course of treatment and care
- Assisted the patients in being active participants in their care with the freedom to use it as and when needed
- ▶ Empowered the men, which made them able to stay in control and feel secure
- Support accessibility of the healthcare professionals
- Represents the key to continuity:
 - As the flexibility establish feelings of an always open electronic door through which the men at any time during the course of treatment can obtain contact, enter a dialogue, and thereby gain individualized information and support
 - ➡ This increase the patients' ability to stay in control, which reduce the patients' dependence on the healthcare professionals and thereby enhance the continuity of care
- Demands active partners including the healthcare professionals to be of value
- Generates reflections and new understandings for the individual patient, as he can read other patients' experiences in the online social support groups
- Facilitate valuable contacts between male cancer patients. Though when designing applications for patient to patient dialogues, it is necessary to oblige different types of users, as the men's need for support from co-patients and their capability to help others changed along their course.

Figure 12 illustrates how using health informatics tools such as the Online Patient Book[©] can be the key to enhanced continuity of care:

- ▶ Individualized information and dialogue helps the men to take action;
- ▶ the patients' health informatics tool support the men in their actions;
- ▶ and usage of the health informatics tool generate individualized information.

At the start of the course of treatment and care, the individual man experience to be in a new and unfamiliar situation. As such, there is a risk for disempowerment because of uncertainty and insecurity. Due to the general and individualized information via the Online Patient Book® the man knows what to do. He understands and has insights in the course of treatment and care, which he is in and thereby is able to act in. Thus, health informatics tools as the Online Patient Book® enhance continuity of care, by means of the individual patient's reduced dependency on the healthcare professionals. At the same time, the patient experiences a freedom to continue his normal day of life.

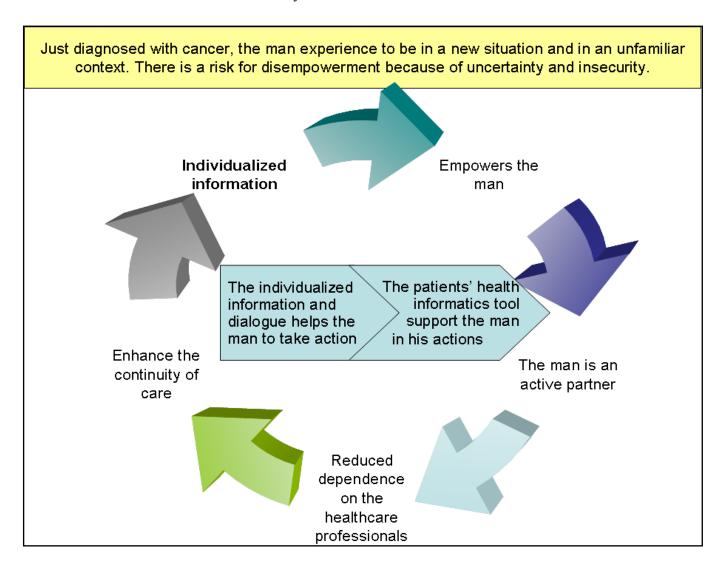


Figure 12: The patients' health informatics tools can be the key to enhanced continuity of care, by way of the individual patient's reduced dependency on the healthcare professionals.

8.4. The evaluation as a phase in the research process

The evaluation phase contributed to an important fourth phase in the hermeneutic spiral of the whole research process.

First of all, the findings must be recognized in the light of the problem experienced and substantiated at the start of the research project. The nurses in the particular urology department describe how they would like to have more flexibility in their caring for these men. During the literature survey the importance of flexibility were substantiated. Flexibility in relation to the individual man allows the healthcare professionals to individualize their information and support to the individual patient. Thereby the men are allowed the support to be active partners in their own course of treatment and care. The relevancies in and potential of utilizing the Web 2.0 technologies to establish flexibility in the contacts between men with prostate cancer and healthcare professionals are substantiated in the current phase.

Secondly, the evaluation points to the relevancy in future redesign phases. This at the same time demands an ongoing involvement of the users, to accommodate their needs continuously and in a constantly changing practical and social context. It is for example relevant to redesign the application for online social support. The literature survey, the intervention study, and the evaluation substantiated the value of patient-to-patient dialogue. Though, the patient users, who evaluated the Online Patient Book® were not frequently active users of this application. Instead the men were often passive users, as elaborated in Paper IV. A few of the patient users, who contributed in the evaluation of the Online Patient Book®, suggested that they themselves could act as "older" patient users, as a sort of moderator to support the ongoing dialogues among patients in the establishing of new patient groups within the Online Patient Book®. This example stresses the importance in using participatory methods in the future processes as well.

Thirdly, future evaluations are significant for the technology itself to coordinate with the present and the future practical and social context, as the context itself continuously develops. The current research process depicts how the back-and-forth-process in an innovative intervention study shapes not only the health informatics tool, but the practice in general. The technology itself generates developing processes in the clinical practice. To coordinate with these continuous progresses the health informatics tool also need the future iterative processes, which a spiral depicts, whereby every new stage provides the researcher and the participants involved with new knowledge.

Core aspects outlined above, for example future evaluations and redesign phases, are discussed in the following section 9 as well as in section 11.

9. Discussion

The results are reported in each of the four sections 5-8, which describe the four phases of the research process. This section works across the four phases of the research process to discuss the methods used, limitations, and the findings. Finally, the new technology itself will be put into perspective.

9.1. Perspectives regarding the participatory processes

The approach in the current research process combined the hermeneutic philosophy with the innovative thinking. Recognized as a process of designing and developing a product, various participatory methods were applied throughout the research process. Recognized by the hermeneutic spiral, the results of every iterations, stages, and phases in the research process, were used as a source for the next movements.

Thus, the research process is characterized by core aspects in the hermeneutic philosophy:

- The usage of different types of dialogues during the phases generated new understandings and knowledge, for example on how to design the patients' health informatics tool
- ➤ The phases of the research process could not be separated: one phase depends on the other phases, as such there were an ongoing back-and-forth process between seeing and working with the whole perspective and seeing and being in one phase
- The research process was recognised by the researcher as being in a hermeneutic spiral, as an iterative process whereby each stage provided the researcher with knowledge. Thus, the researcher's understanding, and thereby preconceptions, develop in and ahead of each new phase
- ➤ The individual dialog was recognised as a hermeneutic process, as for example the interview dialogues generated new knowledge for both partners. At the same time the individual dialogue was a part of the whole research process
- ➤ The researcher's preconceptions were naturally implicated during the phases and affected as well. The generation of new knowledge inspired, formed, and thereby changed the preconceptions continuously
- * The work was completed because of and in the dialectical connection between theory and practice
- The researcher felt as being in the art of questioning and testing, as sometimes there were several more new questions than answers
- Understandings were actions.

The hermeneutic perspective contributes to a method on the philosophical level, which however supported: the innovative process; the synergy between theory and practice; and the involvement of participants, as understandings and actions were generated in a back-and-forth process between theory and practice by means of diverse dialogues.

The involvement of users was significant in trying to design the patients' health informatics tool. The hermeneutic perspective guided this involvement by emphasizing that questions need to take precedence over knowledge. The need to gain new knowledge and to learn generates the art of questioning and testing. Being a questioner; always know that you do not know, is a prerequisite if the researcher wants to involve users. The hermeneutic philosophy contributes to seeing the involvement of users as ontology, which means a way of being.

Corneliussen (2009) criticises how the previous IT architecture has contributed to an understanding of the user as one standard. The general IT architecture reduces the complexity into one standard, for example: The patient user. This standard patient user is seen and understood outside the context. From a hermeneutic perspective the patient user is always situated in a practical, social, and cultural context. The individual influences and are influenced by the context, and can only be defined by including the context (Taylor, 2008). The hermeneutic perspective supports the contextualisation of the health informatics, as the patient users are defined and contextualized via the hermeneutic circularity of the dialogues.

Diverse challenges in the current innovative intervention study made it relevant to discuss whether the research project could have benefited from action research or participatory design on the method level. The challenges were for example financial and how to facilitate coworking across diverse organisational levels and diverse working cultures and practices.

Action research in nursing science seems to be the counterpart to participatory design within the field of health informatics. In nursing science the action research method has gained popularity. This seems natural, as the method offers a way of developing practice-based knowledge. Nielsen and Svensson (2006) illustrate the closeness of action research to the basic concepts of hermeneutic philosophy, for example the dialectics between practice and theory. They describe action research as a child of hermeneutic philosophy due to conceptualisation of cultural and social phenomena through dialogues. They emphasise how hermeneutic dialogues create knowledge and meaning, by changing the preconceptions of the dialogue partners, as through dialogues the partners educate and cultivate themselves. Nielsen and Svensson (2006) explain, how the dialogues cannot be separated from the actions, the dialogue is an action in itself based on the unity between interpretation and action.

The current research process gave priority to these dialogues, however another core aspect in action research was not strictly followed; the democracy.

The phases of the research process supported the dialectic between theory and practice by means of the back-and-forth process. Thereby theory forms practice and practice forms theory, which for example can be illustrated by the substantiation of the problem experience in clinical practice, in the literature survey. However, it was only the researcher who walked through the whole process. The patients and the healthcare professionals that were involved in the process were involved in separated and limited phases. To take advantages of the spiral between the phases conflicted with the democracy, as the ongoing developing of new knowledge sat the scene for every succeeding phase in the light of the former, future, or even ongoing other phases. The lack of democracy is for example illustrated by starting the design workshops presenting a potential new health informatics tool to the nurses. This preliminary picture of the tool was presented as an answer to the problems in clinical practice. A partly theoretical answer, but the developing and realization of the theoretical tool demands the healthcare professionals' involvement.

A democratic process in relation to the group of nurses, as one of the important group of contributors and users, seems to be most relevant, at least along the separated and limited phase of the design workshops. On the other hand, already placed in the clinical practice, the researcher knew the organisational limitations, when planning the healthcare professionals' involvement in workshops for example: working across different and diverse timetable; working in 24 hours shifts; and working in an often unpredictable environment in relation to workload and acute demands (Sandars & McDonough, 2005). These aspects conflicted with an equal involvement in the design process. This is illustrated by the fact that the first workshop was carried out two months later than it was planned to be. Also by the fact that particularly one nurse was missing during the workshop's process, as she was not present in three out of six workshops. This nurse was primarily on evening duty. Therefore the risk of prioritizing the democracy is that the innovative intervention process will slow down and maybe even decline. If this specified phase of the research process slows down, it will not support the spiral, meaning the progress of the research process. The risk is that the potential new tool will not be developed at all. Another scenario is that a slow phase just delays the development of the potential new tool. If so, there is a risk that the tool, at the time when it is finally ready for implementation in clinical practice, do not match the practical and social context, as the context itself continuously develops. The risk is that the movements inside the spiral do not reflect the continuously movement of the context.

Thus in the current research process, dialogues were prioritized to democracy, as the dialogues were essential to generate new knowledge and by that develop a new tool.

Collaboration, and by that sharing a community, is also an important stance in action research. The action researcher's role is to intervene normally in the social and cultural processes (Nielsen & Svensson, 2006; Rodgers, 2005). Even though the collaboration, in the current project, was central in the design phase and the researcher was placed in clinical practice, the researcher did not intervene naturally. The researcher did not share the same community of practice as the healthcare professionals. Instead the researcher walked in and out of, or along, the communities, which means: the community of the healthcare professionals; the community of system developers; and in combination communities of different research networks. The researcher had to navigate through these different practices and perspectives, as this was central to take advantages of the spiral and thereby generate new knowledge and the new health informatics tool.

In summary, the specifying, designing, and developing of the Online Patient Book[©] was based on the knowledge that the hermeneutic spiral, the iterative processes, generated. If, instead, the research process had been organized as action research, the answer would not be the Online Patient Book[©] – maybe something similar, but not the same, and most likely not at the same time and place.

9.2. Perspectives regarding the bottom-up design

The Online Patient Book[©] was developed using a bottom-up design. Grounded in clinical practice the users were categorized as patients and healthcare professionals. These groups were therefore seen as core participants in the designing of the new health informatics tool.

Participation means involvement, all though there seems to be various levels of involvement for example: to take part; have interest in; or be concerned with the thing possessed (Ordbogen.com, 2011). Kushniruk and Turner (2011) describe a change of behaviour that goes from participation and into engagement. Fundamentally, participation often generates relationship or ownership.

In the current research process, the patients' and the healthcare professionals' engagement in the interviews, workshops, and finally their usage of the Online Patient Book[©], presented a picture of their interest in developing and using the Online Patient Book[©]. This interest may be classified as relationship, as it is a user-ship, however not an ownership. Therefore a relevant question is: Who owns the Online Patient Book[©]?

Even though the administrators within the Department of Urology, in which the Online Patient Book[©] was developed and implemented, agreed on being owners, there was a need to support this ownership. According to the characteristics of the new technology, as a health informatics system, it was relevant to have co-owners from the IT Department as well as on the level of head administrators within the hospital setting.

Participatory design is an approach which focuses on processes and attempts to actively involve all stakeholders. In the participatory design perspective, the socio-technical approach helps in recognizing the interaction between people and technology (Nøhr & Kanstrup, 2009; Jensen et al., 2007; Nøhr, 2010). Berg et al (2003) describe how technological innovation is a social process, in which organizations are deeply affected.

A socio-technical analysis in the beginning of the current research project could have stressed the importance in thinking the bottom-up design "to the top". Stakeholders within the overall management groups should also be seen as participants, as they are needed to contribute to the environment, especially the economic environment. If these stakeholders do not see themselves as stakeholders they cannot contribute adequately. The stakeholders' involvement, which means ownership, is almost as important as the involvement of patients and healthcare professionals.

However, in relation to the development of the Online Patient Book[©] some attention was given to stakeholders in the IT Department as well as on the level of head administrators' within the hospital settings. This attention, from the researcher, was accepted by the partners, as both partners contributed to financial support already from the beginning of the process. Though the stakeholders were identified, there seems to be a need to know more about them during the process, to continually sustain their engagement too.

Kushniruk and Turner (2011) appear to set a framework on how to go beyond the attention of participators to take actions and recognise them as diverse users. They point at the importance of differentiating between types of users for example according to; which roles the different users expect themselves to have; which roles the other partners in the process expect them to have; which roles the researchers or project managers expect the different users to have in the project and in the shifting phases of the project. The framework by Kushniruk and Turner set five questions to analyse and thereby generate understandings of the different users. This means that the questions could help recognising the users:

- **Who** is the user?
- What expectations are there in relation to users?
- When do we engage the user?

- **Where do we engage users?**
- **Why engage users?**

Utilizing these questions appears to be very relevant in the current research process, for example to support the stakeholders' engagement in an ongoing financial support. Answers to these questions could move the attention of different users, as when recognising the diverse users it is possible to take actions in relation to them, and thereby facilitate the process from the participants' involvement and into engagement.

Developing health informatics often includes participation across very different working practice. Answering the questions could support crossing these lines or bridges, and even take advantages of the different working cultures, theoretical backgrounds, organisational levels, and so on. In addition, to facilitate the understandings of for example the qualitative effects of new health informatics tool in all organisational levels.

9.3. Perspectives regarding the literature survey

The findings from the literature survey were utilized in the design of the new health informatics tool. The usage is based on 41 articles retrieved from a literature survey on the PubMed and CINAHL databases in 2007. Paper II substantiates how the findings generated the preliminary picture of the tool.

To understand the effects of the Online Patient Book[©] in an up-dated perspective, the literature survey from 2007 was accomplished with an up-dated literature survey in 2011. Paper I documents the findings from the total amount of papers, which were 47 articles.

The number of articles represents the findings from a survey of the literature with the aim of understanding, how men with prostate cancer experience their contact with the healthcare professionals. This defined population and research questions generated a relatively limited number of articles. Therefore, the number of articles does not necessarily cover the area completely. The questions asked are for example based on nursing practice, expanding the search terms to other professions as doctors or health informatics would potentially give various perspectives. Furthermore, several papers were excluded, because their focus was mainly incontinence. Some of these papers could have been relevant in relation to the specific population. However, the overall themes were contacts, dialogues, information, and support, in the light of short stay surgery, and not long term complications after surgery.

The field of health informatics expands quickly. In relation to men with prostate cancer the number of decision support systems increase rapidly. The purpose of such websites is to guide men choosing the right treatment. Articles related to various decision support systems

were mostly excluded, as the group of patients in focus is men with prostate cancer already in a course of treatment with prostatectomy surgery.

The updated survey of the literature, in 2011, supported the evidence of the earlier findings according to the men's need for individualized support, information, and dialogue. A study from 2008 (Sinfield et al., 2008) described the importance of healthcare professionals' need to identify and respond to the information needs of the individual man. Another study from 2009 (Iyigun et al., 2009) documents the effects of obtaining information, as the men felt more secure and comfortable afterwards.

The men's active use of the Internet, even prior their first meeting with the healthcare professionals, has increased over the few years from 2007 to 2011. This can be seen by the supplementing papers from the survey of the literature in 2011. Dickerson et al (2010) describe how men with cancer incorporate Internet use into their cancer journey and become problem solvers. The men use the Internet to enhance their sense of control. The men seek to be proactive, prepared, and responsible trying to change the provider-patient relationships towards collaboration and open communication. Ramsey et al (2009) document that a little more than half the men in their sample accessed the Internet to obtain information about prostate cancer. Considering the findings from the evaluation of the Online Patient Book[©] in these perspectives supports the relevance and importance of healthcare professionals active involvement in and use of the patients' health informatics tools.

9.4. Perspectives regarding the interview study

In the interview study many men responded to the open invitation to contribute, via the Danish patients association for men with prostate cancer: PROPA. During the interviews the men were often very willing to share their experiences. Several men explained how they liked the idea that their contribution might help other men in the future. Though, it is important to take into consideration that the men involved, in this part of the research process, were restricted to members of the national patient organisation or to readers of the magazines from this organisation. This could be a possible bias, as the recruited men were more likely to be men with an interest in and motivation to discuss their experiences. They may therefore not be typical of all men with prostate cancer, as men who act more invisible may have different stories to tell.

The researcher's preconceptions, both prior to the current research project and arising from the knowledge generated during the survey of the literature, were dealt with in the individual interview setting by starting the interview by inviting the men to tell their story in relation to their own course of treatment and care. By that the men were allowed to set the scene and the researcher had to build the questioning on their individual stories, though guided by the interview guide. The relevance of the core themes of the interview guide were supported in relation to every interview, as every man had a story to tell in relation to the themes in focus, either in a positive matter, in a negative matter, or a combination.

During the individual interview the researcher validated her experience of the meanings. The ongoing dialogue and questioning were not only generated on the interview guide, but also on the ongoing dialogue itself. The answers were integrated in the following questioning to test the understanding of the information obtained. At the end of each interview the researcher identified and summarized core aspects of her understandings to be confirmed, or not, by the man himself. This circularity was supported by the interview guide, as the guide depicts a circle.

During the process of the 15 interviews the researcher experienced a saturation of data, as no new information to the core terms were generated in the latter interviews. Though every patient story was individual and brought nuances to various topics, the validity of the findings was supported by the saturation of data.

The data from the interviews were utilized in the design phase to contextualize the new technology. Therefore the researcher's focus in the process of analysing the data was influenced by that perspective. This limited focus could hinder the richness of the data to be unfolded. A more open focus to the patients' stories would potentially have generated valuable supplementary knowledge in relation to this large and increasing group of patients, and to the knowledge on men as patients and men as the study population in more general perspective. However, it was not possible within the current study's framework to explore these perspectives in depth.

The interviews were kept as audio files. This allowed the researcher, in analysing the data (see Figure 6 and Figure 7, section 6), to step back from the re-contextualising to the primary answers from time to time during the design phase. By re-listen to the individual interviews the researcher re-experienced the interview, which was valuable to still remember and understand the men's needs during the design and developing phase. By recalling the men's sayings these were part of the ongoing dialogues in the processes, as described earlier in the thesis (subsection 6.4 and 7.4). In the design and developing phases the men's expressed needs were for example discussed with healthcare professionals via the design workshops, as well as with the system developers.

9.5. Perspectives regarding the evaluation study

The findings generated in the evaluation study, and substantiated in Paper III and Paper IV, are based on a response rate of 59 percent. The analysis of the results reveals that the majority of the patients could benefit from the use of health informatics tools as the Online Patient Book[©]. 32 out of the 34 patient users who evaluated their use of the Online Patient Book[©] stated that the tool contributed positively to their feelings of security and certainty, which means it could support their empowerment during their course of treatment and care. The two patient users, who describe no affects to their feelings of security or certainty, still valued the freedom to use the tool, when needed, and explained how the tool helped them to maintain their overview during their course of treatment. This points to how the tool in general empowered the patient users.

Possibly the patients who valued the Online Patient Book[©] were higher in the group of responders. However, none of the patient users stated that the tool had a negative effect on their contact to the healthcare professionals.

From a qualitative perspective patients indicated that the Online Patient Book[©] was important. As the Online Patient Book[©] is still a part of the standard care in clinical practice, it is both possible and relevant to supplement the evaluation for example with face-to-face interviews, content analysis of the dialogues generated, and quantitative methods to document reduced resource consumption. In addition, with other groups of responders, for example the healthcare professional users or the men's relatives. This will be discussed further in the following subsections.

9.6. Perspectives regarding the evidence of qualitative effects

The qualitative effects of the health informatics tool, primarily substantiated in Paper III and Paper IV, are based on analytical generalisation. This is also the case in relation to the findings in the literature survey and in the interview study.

The analytical generalisation emerges by means of the dialectic between practice and theory. The empirical generated data were brought into dialogues with the theoretical preconceptions and relevant studies or theory explored during the research process, as documented in the list of references.

Analytical generalisation presupposes a detailed description of the research process. The current thesis, in combination with the attached research papers, aimed to do so by describing details of and the links between the dialogical and iterative processes and the four phases of the research, and thereby make the whole research process transparent.

The dialectic research process generates an interplay between discover, define, and identify, for example what lies behind the individual patient's description of insecurity. This methodological reflection provided insight and nuances in the understandings of the effects of the health informatics tool. Findings based on analytical generalisation can not be seen as decontextualized. Therefore, when utilizing findings elsewhere attention must be paid to differences in relation to contexts.

The findings generated in this research project must be seen as one of the first steps in documenting the effects of patients' health informatics tools. The aim was to generate understandings, explore nuances, and gain insight in how men experience different forms of contacts: short contacts; contacts during a course of treatment; online contacts. Combining the results from all phases of the research process provided a solid insight in the value of health informatics tools as the Online Patient Book. Still, the effects are qualitative, substantiating the patients' experiences. However, as the intention in the current study was to develop the patients' health informatics tool, a tool which aimed to meet the needs of the patients, and thereby empower the patients, it is of great value that the patients, in their evaluation emphasize these qualitative effects.

As a part of their evaluations some of the men spontaneously explained how they experienced quantitative effects as; reduction in their use of the healthcare professionals' time due to reduction in telephone calls, and prevention of acute or extraordinary meetings at the hospital. These quantitative effects were, however, not investigated in the current study. Therefore it is relevant that future study survey these quantitative effects.

9.7. Perspectives regarding the new health informatics tool

The perspectives regarding the technology itself must be seen in the light of the researcher's professional background, as a nurse, and not having a professional IT background.

The Online Patient Book[©] was implemented in clinical practice as a part of the standard care for this group of patients. Hence, the Online Patient Book[©] was not introduced as a pilot study or research project. Instead, it was introduced as a new information and communication tool grounded on the substantiated problems in relation to lack of information, experienced by men with prostate cancer planning for surgery.

Even though the first year of implementation in some ways is identical to a pilot study, it was the researcher's conscious choice not to implement the tool as a pilot testing. Placed in clinical practice, the researcher knew how the ongoing introduction of new research projects can be experienced as a heavy burden for the healthcare professionals in combination with the often high workload.

This conscious articulation around this new health informatics system may have been a part of the qualitative effects. Or et al (2009) explain how healthcare professionals felt uncomfortable using a health informatics system if they perceived the use of it as a burden to their patients, for example due to increased time consumption. Therefore, to be an active and positive healthcare professional user it is important that the particular health informatics system improves the quality care and treatment. Looking at the Online Patient Book[©] it is therefore relevant to comment on how the healthcare professional users actually recognized the importance of this tool. When the Online Patient Book[©] was implemented and utilized in a period of time in the clinical practice the healthcare professionals expressed how they experienced the Online Patient Book[©] as of great value for the patients, as it empowers them. In addition, the healthcare professionals experienced flexibility in their caring for these men. Thus, the Online Patient Book[©] becomes a tool for the healthcare professionals, which can contribute to quality in the care and treatment of their patients, and especially in relation to accommodate the needs of the individual patient. Even though these experiences are only expressed by the healthcare professionals in informal meetings, and therefore not a part of the data gathering in the evaluation, such experiences are very important for establishing a positive environment around the every day use of the tool in the clinical practice. However, further evaluations are needed to explore these experiences.

Furthermore, Or et al (2009) point to the importance of the organisational levels to promote and encourage the use of health informatics tools. The Online Patient Book[©] project supports these findings. Guidelines and action plans were a central part of the introduction of the tool (See Appendix D and E). These were based on agreements in the group of clinical leaders and followed up by ongoing meetings with super users in the clinical departments.

In addition, the running phase (Figure 11, section 7) of the Online Patient Book[©] denotes the importance of a project manager. To be a useful and valued tool in general, the actual patients' health informatics tool has to be reliable and valid. Meaning it has to reflect the complexity and the ongoing and constant development of the clinical practice, in which it is situated. This demands the healthcare professional users' daily use of the tool, the use of the tool in relation to every patient, and the overall administration from a project manager. A project manager placed in clinical practice has the opportunity to continuously keep the health informatics tool updated according to the ongoing development expressed in both formal and informal meetings. Maybe most important, the ongoing dialogue with the healthcare profes-

sional users sustains the healthcare professional users in relation to their daily use of the system.

This illustrates how health informatics tools benefit from contextualisation in all phases; from idea, design, and use, to redesign. The contextualisation supports a focus not only on the technology itself, but also the way the technology is used and in which relations and contexts it is used. Therefore it is also important that future patients' health informatics tools incorporate both the patients' and the healthcare professionals' usage of the tool, during the design and redesign phases.

In some earlier research project which encompassed pilot tests on diverse computer based tools (Clemensen, 2006; Dinesen, 2007), it is described how such studies often face major problems, because the new technologies are not robust and safe enough. According to the usage of the Online Patient Book[©] there was no localized breakdowns the first year. However, in relation to general breakdowns of IT system in the hospital's e-mail system the Online Patient Book[©] was involved as well, due to the automatic E-Alert to the patient's private e-mail box. These breakdowns were documented two times. Minor technical problems were experienced a few times, most often due to misunderstanding in the usage of the technology.

In the evaluation of the Online Patient Book[©] only a few of the patient users commented on the user interface or the design. One user described that he once lost the outline of the website and had to start from the beginning again. Another user suggest both top and side menu, which actually was deselected in the design to make the website simple in relation to the general users aged over 50. One user felt it could have been good to separate the Web 1.0 pages from the Web 2.0 pages. These applications were linked so the user could jump directly from the personal section to the public section with general information that was relevant to the pertinent topic (See screenshots in Appendix F). Due to the security of the system, the patient users could not change the personal secure key code, which one user criticized. Two users rank the Online Patient Book[©] as a part of their evaluations. One scored the static pages with general information to 7 on a scale from 1 to 10. Another scored the overall Online Patient Book[©] with top marks.

The usage of the Online Patient Book[©] at the project manager level is however complicated, as the software is not build upon a content management system (CMS). Therefore the project manager is not able to edit and up-date the content in the Online Patient Book[©]. Instead the project manager has to request for content changes which are then carried out by the system developer. Including a CMS was a part of the preliminary picture of the tool according to the

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researcher. However, it was excluded in the process of product development due to financial reasoning.

The Online Patient Book[©] represents an example of the patients' health informatics tool, however only as a design which means a model to inspire future patients' health informatics tools.

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10. Conclusion

In this section conclusions on the research questions are drawn.

The research questions were:

- ★ How do men with prostate cancer, treated with prostatectomy surgery, experience their contact with the healthcare professionals in clinical practice based on short stays?
- ➤ How can an online contact contribute in the contact between men with prostate cancer and the healthcare professionals?

It appears that men with prostate cancer, treated with prostatectomy surgery, often experience a lack of individualized information and support. However, the importance, in relation to the patients' contacts with healthcare professionals is not the length and amount of time. Rather it is the accessibility and exchange-ability that are significant aspects. For men to feel secure and certain the healthcare professionals must be easy to get in contact with during the whole course of treatment and care. Concurrently, the healthcare professionals' ability to individualize information and support, based on dialogues with the particular man, is essential. Providing information and support, the healthcare professionals may be able to empower the patients, and the empowered patient is also the active patient.

The organisational change towards patients' short stays at hospital challenge the present information and communication systems. To accommodate the patients' needs for information, supports, and dialogues during their course of treatment, healthcare professionals have to give priority to the development of new information and communication tools. To offer Internet applications to men with prostate cancer appears relevant as these men are already Internet users.

To accommodate the need for accessibility of the healthcare professionals, the patients must be able to get in contact with healthcare professionals at the hospital at any time during their course of treatment. The asynchronous environments, via the Internet, are open for flexible contacts where the users can get in contact without having the feelings of disturbing, and in a convenient time for them as patients.

To accommodate the needs for individualized information and support the users must be able to exchange and understand each others information. As such a dialogue is essential. Web 2.0

technologies open for flexible and dialogue-based contacts between the patients and the healthcare professionals.

It appears that an online contact can contribute in the contact between men with prostate cancer and healthcare professionals by enhancing the patients' continuity of care, as the patients' ability to stay in control and stay free reduces the dependency on the healthcare professionals. At the start of the course of treatment and care, the individual man often experience to be in a new and unfamiliar situation. As such, there is a risk for disempowerment because of uncertainty and insecurity. Due to the general and individualized information via the health informatics tool the men know what to do. They understand and gain insights in their course of treatment and care. Thereby the health informatics tool assists the patients in being active participants in their care with the freedom to use the tool as and when needed, and by that continue their normal day of life. The individualized information and dialogues help the men to take action and the patients' health informatics tool support the men in their actions. Thus, the patients experience themselves as respected and active partners in their own course of treatment and care.

It is substantiated that Web 2.0 applications can contribute to the accessibility of the health-care professionals. The way the men describe their use of the tool, illustrates how the health informatics tool provides an unlocked electronic door, which the patients can open and close in their own pace, time, and place. The patients experience the healthcare professionals as easy to contact and at the same time experience a freedom to continue their normal days of life. Via the online care potential problems and insecurity are addressed. Web 2.0 technologies open for flexible and dialogue-based contacts, which underpin a collaborative approach and an open and respectful dialogue. The Web 2.0 applications support the men in being active partners in their own course of treatment and care.

The evaluation of the Online Patient Book[©] substantiates the importance in extending the Web 1.0 technologies with the Web 2.0 technologies. The findings in the current research project support earlier findings that patients are satisfied with short stays at the hospitals. Though, the patients need individualized information including accessibility of the healthcare professionals to learn to cope in this new and unknown situation. The nurses' descriptions of how they would like to have more flexibility in their caring for these men to target their information, counselling, and guidance to the individual patient, are recognized in the men's

descriptions. The asynchronous environments, which the Web 2.0 technologies provide, are a significant way to expand the time for contacts besides the restricted formal face-to-face contacts at hospital. Utilizing this expansion in flexible time healthcare professionals have the opportunity to comply with the contradiction between the patients need for contact and the intensifying of patients' short stays at hospital. The course of care can go beyond the formal face-to-face contacts between the patients and the healthcare professionals, so that the patients have the opportunity to feel informed and supported, and thereby empowered, even at home. As such the online asynchronous health informatics tools can be one of the components to accommodate these organisational changes.

The findings confirm the relevance of the healthcare professionals' active involvement in facilitating online contact between men with prostate cancer. The men's need for support from co-patients and their capability to help others changed during their course. Some users do not engage or do not have the capacity to go beyond the role as a reader. However, just by reading other patients experiences in the online social support groups can generate reflections and new understandings for the individual patient.

When designing applications for patient to patient dialogues, it is significant to establish an environment which can host and accommodate the needs of different types of users and even benefit from it, for example by providing diverse applications for patient to patient dialogues, as well as establish a construction that is well-functioning even though several users are passive users.

Based on the results in this study, it seems relevant to continue the development and implementation of health informatics systems designed to accommodate the needs of the patients: The patients' health informatics tool. The future use of the patients' health informatics tools, both in relation to men with prostate cancer and other groups of patients, is underpinned by stated recommendations from patient users in the current study.

The results of this research are important to learn from and subsequently, to develop and transfer the patients' health informatics tool to other groups of patients.

The next section of the thesis seeks to follow these next possible phases into the future of health informatics tools.

11. Implications

This research process contributed to new insight on how health informatics tools can be of value seen from the patient users' perspective, when the health informatics tools are developed to accommodate the patients' needs.

Additionally, the research process produced a new technology that is still used as a part of the standard care in the specific department and for the specific group of patients. This specific health informatics tool is valued among the patients and the healthcare professionals, which is also described in a general hospital patient satisfaction survey conducted by Ruby and Poulsen (2010) (Paper III). Though, the technology itself is not of value outside this specific context. From a system developer perspective it is a prototype and at the level of the clinical project manager the tool is not flexibly enough to work with in the long run.

Still, the hermeneutic spiral by which this research process was driven continues beyond the current study, as the research process initiated new dialogues and phases. These implications will be elaborated in the following.

According to the specific tool, for this specific group of patients, and in this specific context, meaning the usage of the Online Patient Book[©] in the Department of Urology, at the Aalborg Hospital, Aarhus University Hospital, it was relevant to redesign the subsection for patient to patient dialogues. As elaborated in Paper IV, when designing web applications for online social support, it is necessary to oblige different types of users. In correlation to this subsection of the Web 2.0 application, the findings substantiated a tendency that the patient users act as passive users, either throughout their course of treatment or in various periods of time during their course. However, just being passive users by reading other patients' experiences can generate reflections and new understandings for the individual patient. In Paper IV it is also described how some of the patient users spontaneously or in relation to the evaluation offered their help, as they would like to participate in the newer establish groups. These offers were all from men, who had used the Online Patient Book[©] during their course of treatment and now were "older" patients in the light of this tool, as well as according to a course of treatment for prostate cancer. These men would like to act as the opening writer (see Paper IV and subsection 8.4) in the establishment of new patient groups within the Online Patient Book[©]. To accommodate and build up these valuable patient resources, according to the Online Patient Book[©] in this specified context, the application for patient to patient dialogue in small, demarcate groups, was supplemented with a secondary subsection for patient to patient dialogues. This section opens for dialogues across all the patient users enrolled in the Online Patient Book[©] at the Department of Urology. In this subsection the patient users can participate as readers or as readers and writers. When writing only the men's first name is assigned automatically, as in this subsection the automatic generation of user identity is restricted to the patient users' first name.

This redesign was carried out after the evaluation and after the first year of production, therefore an evaluation of this subsection is relevant in the future evaluations.

Secondly, the research process initiated collaboration between the Department of Urology and the Department of Oncology at the Aalborg Hospital, Aarhus University Hospital. The aim of this process is to transfer the Online Patient Book[©] to other groups of patients with cancer. However, this process seems to face problems, due to the fact that the software is not built upon a content management system (CMS). It is possible to establish the CMS in the technology, but at this time the collaborators have not been able to raise the funding sources for this upgrade of the specified tool.

According to the limitation of the technology itself, as illuminated in subsection 9.7, and in line with the aim of the research process, it is however more relevant to recognize the specific tool, the Online Patient Book[©], as a model that can inspire future design processes. The results of this research process can be relevant to learn from, if trying to develop health informatics that primarily aims to accommodate the patients' needs. In this perspective the current research process by now has initiated new dialogues at the national level.

The national organisation Danish Patients, which represents approximately 800.000 patients from 71 different patient organisations, published a written statement about telemedicine in 2010. This report from Danish Patients (2010) supports the relevance of future usage of telemedicine including health informatics systems and telehomecare technologies. The potential of patients' health informatics tools as the Online Patient Book[©] is explicit pointed at in this report (page 5 in the report). It is recognised that these health informatics tools may enable the patients to capture valuable information, because the information are tailored to the individuals' needs and resources, whereby the patient can stay in control and be an active partner in his own course. In other words, it is from the patients' perspective recognised that these health informatics tools may empower the patients.

In 2011 the Online Patient Book[©] is mentioned among other health informatics systems in a journal for Danish healthcare systems, primarily for the healthcare professionals and administrators in the healthcare system (Mollerup, 2011). In addition, the nurses, who participated in

the development of the Online Patient Book[©] and were super users, as well as the researcher, have been invited to conferences for healthcare professionals in Denmark, to give a presentation of the tool (FSUIS National course, 2010; UTF Nordic Conference., 2011). A demonstration model is developed to support the nurses in their presentations on how they use the tool in clinical practice. Thus, at the national level the Online Patient Book[©] has gained some awareness, both among patients and among healthcare professionals.

Due to this national awareness the researcher has been invited to meetings with diverse working groups, who all aim to develop new health informatics tools to empower the patients. These groups are established throughout the national healthcare system, independently from each other, and in primary care settings as well as in different hospital settings. The workgroups differ at the professional level and illustrates how health informatics systems involve an interdisciplinary field. Across the workgroups the members of the groups are healthcare professionals, administrators, or system developers. The combination of members in the individual workgroups differs to a great extent. The patient group or groups in focus for the different workgroups also vary. The patient groups in focus are for example: patients with allergy; patients with lung or heart conditions; patients with cancer in general; and patients suffering from chronic diseases. However, the working groups all aim to develop new health informatics tools to empower the patients.

Thus, these meetings with diverse groups generated new dialogues with healthcare professionals as nurses, doctors, administrators, project leaders, communicators, and so on, as well as system developers. These dialogues depicted how there already has been a shift in focus from health informatics systems, that primarily serves the healthcare system, towards patients' informatics systems, which aim to inform, teach, and empower patients to participate meaningfully in their healthcare. This shift seems to relate to the active patient regime, with the aim of empower the patients by utilizing health informatics tools.

However, the dialogues also depicted how this shift not naturally initiated the involvement of patients and clinical experts in the design and development phases. According to the findings in the current research process, this shift therefore still needs a movement to a primary focus on the patients' needs. When developing new health informatics systems that aim to empower the patients, the specific group of patients must be involved, as only they know what is meaningful in their healthcare. Therefore, if designing and developing health informatics systems that enable to empower the patients, the patients' needs must be an important first step to learn from. This demands the involvement of the patients, as well as the clinical experts who

meet these patients in their course of treatment, already when starting to design the future health informatics system.

In this perspective, the knowledge generated in the current research process is of value to initiate the next shift from a primary focus of the active patient regime to a primary focus of accommodating the patients' needs. Therefore, at the meetings with these diverse working groups the researcher seeks to question and discuss how the patient users and the healthcare professional users can be significant participants in developing health informatics systems that aim to empower the patients.

There would probably be overlaps according to features and functions in the health informatics systems that primarily aim to empower the patients from the perspective of the active patient regime and the health informatics systems that primarily aim to accommodate the needs of the patients, as the patients most often would like to participate as active partners. Though, a primary focus on the patients' needs will support a health informatics system that encompasses the patients' needs and thereby enable the patients to continue their normal day of life. In addition, this could support the patients' familiarity with the new technologies, as they are in line with their experiences as patients. Instead of health informatics systems that serve the complexity of the patients diagnoses or the complexity of the healthcare system, and thereby represents the unfamiliar context of the health care system or the none-recognisable medical language, which are problematized in Paper II.

Looking at the upcoming generations and a changed perspective towards seeing the individual as responsible for his own health, the future patient will see himself as a partner in his own course of treatment and care. The future patient will therefore: expect to be seen as a respected partner in a provider-patient relationship build on collaboration and open communication; will be more active and use diverse health informatics systems to educate and cultivate and by that empower himself; expect the freedom to continue his personal day of life (Clemensen, 2006; Dickerson et al., 2010; Rasmussen et al., 2009; Rasmussen & Clemensen, 2009; van de Poll-Franse & van Eenbergen, 2008).

In this perspective it is essential that future health informatics systems incorporate the needs of the patients in the design process. A primary focus on the patients' needs will support a health informatics system that encompasses these future patients' needs.

In summary, health informatics applications that primarily aim to meet the needs of the patients, such as the Online Patient Book[©], need to be a central part of future health informatics

systems to serve the patients instead of serving the healthcare system or the diagnoses of the patients.

The Internet allows the patients to act. However, this will only be the case if healthcare professionals are aware and accept the new roles that exist between a patient who is empowered by the use of the Internet and the healthcare professionals. The healthcare professionals must provide encouragement, guidance, and support to patients in relation to their Internet usage to achieve the maximum benefit from future patients' informatics systems (Broom, 2005). Additionally, in relation to Web 2.0 tools, such as the Online Patient Book[©], the healthcare professionals also have to take an active role in the usage.

To sustain the healthcare professionals' active roles, their participation in future designing and development of health informatics systems are significant. However not documented in the current research process, the researcher still experienced how the nurses, who participated in the developing of the Online Patient Book[©], gain new understandings. During the process of intervention their preconceptions develop, for a few of them from scepticism, to now where the nurses advocate for the future use of patients' health informatics tools.

At the international level, the Department of Urology has been invited and has accepted an invitation to be a partner in a European project, which involves collaborators from hospitals and universities from five European countries. The aim is to define, design, and develop health informatics systems, which motivate patients to participate actively in their health management. During the current research project, the Department of Urology gain experiences with and interest in future use of such health informatics systems, which includes the participation of the healthcare professionals and the patients when designing and developing these health informatics systems. The Department of Urology has interest in further development of patients' health informatics tools to this specified group of patients, as in the current research process, as well as to other group of patients in the department.

The area of health informatics systems, telemedicine, and telehomecare technologies is characterised by a high degree of optimism in the present society (Danish Patients, 2010; Dinesen, 2007). Among politicians (Haarder, 2010) this optimism is often articulated in the light of the expected future demands to the healthcare system. Telemedicine including health informatics systems are seen as a core solution to these future demands.

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The current study can be seen as a contribution to this optimism. However, it is essential to be aware of the thinking behind the development of new healthcare systems.

Through this study, the researcher's professional and ethical stance is that the patients' experiences of high quality care and treatment and quality of life during their course of treatment need to be prioritized. Potential reduction in time and use of resources may always be the second parameter, however of value if the qualitative effects are obtained. Therefore, documentation of health informatics tools qualitative effects should always be prioritized and documented, too.

Though, there is a need for future large scale research studies to document the findings of qualitative effects of patients' health informatics systems in the current study. Secondly, there is a need for future research to document the patients' descriptions on quantitative effects as reduction in the use of healthcare professionals' time, reduction in telephone calls, and prevention of acute or extraordinary meetings at the hospital, by usage of the patients' health informatics tools.

12. References

The following references complete the list of references according to references only referred to in Paper I-IV: (Andersen & Ruland, 2009; Berglund et al., 2003; Billund & Zimmer, 2005; Boberg et al., 2003; Brennan, 1996; Buntrock et al., 2007; Butler et al., 2001; Cathala et al., 2003; Coreil & Behal, 1999; Cummings, 2010; Davison et al., 2003; Davison et al., 2004b; Davison et al., 2004a; DeHart, 1996; Dickerson & Feitshans, 2003; Dickerson et al., 2005; Gooden & Winefield, 2007; Gotved, 2001; Gray et al., 1999; Hack et al., 2007; Harden et al., 2002; Hedestig et al., 2005; Hedestig, 2006; Huber et al., 2010; Jakobsson et al., 1997; Jakobsson, 2002; Jensen et al., 2010; Johnston et al., 2000; Kearney et al., 2004; Kehlet & Wilmore, 2008; Kirsh et al., 2000; Klein et al., 1996; Klemm et al., 1999; LaCoursiere, 2001; Larsen & Plenge, 2003; Lindgren et al., 2005; Magnusson et al., 2002; Maliski et al., 2001; Mccormick et al., 2007; Milne et al., 2007; Moore & Estey, 1999; Moore & Sherwin, 2004; Nagler et al., 2010; Nesse, 2001; Nilsson et al., 2006; Norlyk, 2008; Owen et al., 2004; Pai & Lau, 2005; Pautler et al., 2001; Phillips et al., 2000) (Pinnock & Jones, 2003; Poulsen, 2010; Powel & Clark, 2005; Rondorf-Klym & Colling, 2003; Roos, 2003; Rozmovits & Ziebland, 2004; Ruland et al., 2007; Schultz et al., 2003; Seale et al., 2006; Shaha et al., 2008; Smith et al., 2007; Sullivan, 2003; Taylor, 1998; Thaxton et al., 2005; Valaitis & Sword, 2005; Willener & Hantikainen, 2005; Wong et al., 2000; Ziebland, 2004).

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- Wong, F., Stewart, D. E., Dancey, J., Meana, M., McAndrews, M. P., Bunston, T. et al. (2000). Men with prostate cancer: influence of psychological factors on informational needs and decision making. *Journal of psychosomatic research*, 49, 13-19.
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- Ziebland, S. (2004). The importance of being expert: the quest for cancer information on the Internet. *Social Science & Medicine*, *59*, 1783-1793.

Paper I-V

Paper I:

Men with prostate cancer and the accessibility to information – a literature survey.

Bjørnes, C.D., Nøhr, C., Delmar, C., Laursen, B.S.

Accepted for publication Open Journal of Nursing, 2011, August.

Paper II:

Designing health informatics tools to accommodate the needs of men with prostate cancer.

Bjørnes, C.D., Nøhr, C., Delmar, C., Laursen, B.S.

Submitted to Research and Theory for Nursing Practice, 2011. March 20.

Paper III:

A Health 2.0 application designed and implemented to meet patients' individual needs: The impact on continuity of care.

Bjørnes, C.D., Laursen, B.S., Delmar, C., Cummings, E., Nøhr, C.

Submitted to International Journal of Telemedicine and Applications. 2011, May 26.

Paper IV:

Web 2.0 applications enhance personalized access to healthcare professionals.

Bjørnes, C.D., Laursen, B.S., Delmar, C., Cummings, E., Nøhr, C.

Accepted if revised BMC Medical Informatics and Decision Making. 2011, April 21.

Paper V: Supplementing Paper: Second author

Communication Challenges in System Development: Involvement of System Developers in small-scale IT Projects.

Petersen, L.S., Bjørnes, C.D., Bertelsen, P.

Information Technology in Health Care: Socio-Technical Approaches. 2010

Appendix A

Interview guide utilized in the interview study. Danish version.

Interviewguide

Spørgsmål jf. projektets temaer:

Med afsæt i mændenes indledningsvise fortælling spørges ind til mændenes oplevelser jf. projektets temaer:

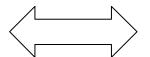
- Korte kontakter
- Individualiseret kontakt; dialog, information og støtte
- Tryghed, sikkerhed, Utryghed, usikkerhed, manglende kontrol

afdækning af mulige sammenhænge

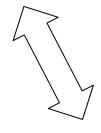
og til sidst efterlyses konkrete ideer fra mændene til II redskab

Konteksten - Fortællinger - Spørgemåder

Hvordan oplever mændene de korte og afgrænsede kontakter?



Hvordan oplever mændene den information og støtte de har fået, og dialog de har haft?



Oplever mændene, at kontakten har betydning for deres oplevelse af tryghed/sikkerhed og kontrol?

Hvis du havde haft en mulighed for kontakt via Internettet, hvad kunne du så tænke dig, at den indeholdt?

Hvad bidrager til tryghed og sikkerhed? Oplever mændene utryghed og usikkerhed.

Indledning:

Kan du fortælle om... Du snakkede om... (henviser til uformel indledning) Kan du huske, det første møde...

Kan du fortælle om situationer eller perioder...

Uddybning:

Du fortalte, at... kan du fortælle lidt mere om det...
Hvordan oplevede du...
Hvad betød det for dig...
Hvordan synes du...
Havde du mulighed for...
Hvad tænkte du om...
Hvad gjorde du...

Validering:

Du har beskrevet, at du...
Tror du,...
Er din erfaring...
Du har fortalte om...

Appendix B

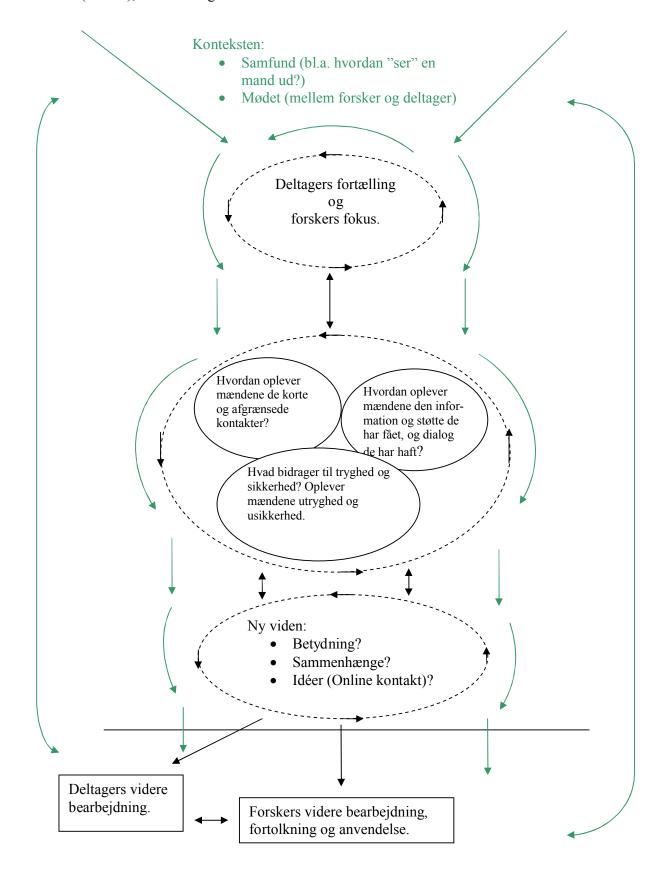
A sketch from the interview study

which the researcher draws during the process of interviews, for the researcher's use only to recall the study later on.

The researcher experienced how the dialogues in the interview study generated new understandings for both the individual man, who was interviewed, and the interviewer (researcher) herself. Danish version only.

Figur interview. Billede af, at interviewet opleves at være:

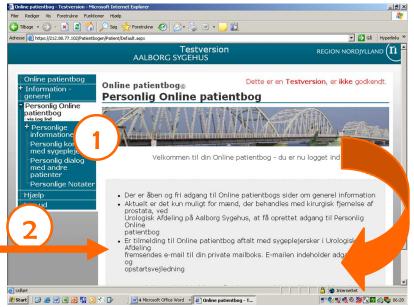
- Dialog.
- (Et sted), hvor viden genereres.

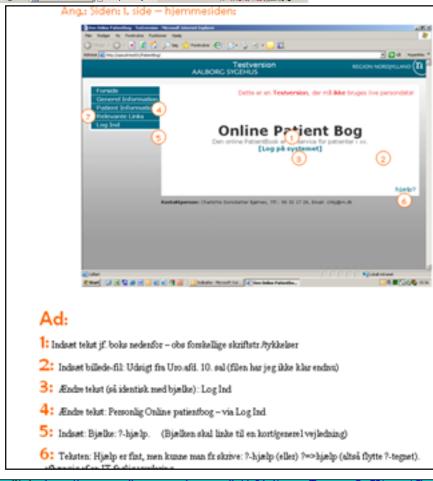


Appendix C

Examples on visualising the design in the developing phase of the Online Patient Book $^{\circ}$.

Commented screenshots, colour codes, and so on were used to communicate the design between the system developers and the project manager (the researcher).







Appendix D

User guide for the Online Patient Book® to healthcare professionals.

A paper version was placed in the specific departments, who used the Online Patient Book[©]. The user guide in full length was attach at the first web page for healthcare professionals and related parts of the user guide were attach at each web pages to be opened with a click on the Help Icon.

Vejledning: Online patientbog © www.onlinepatientbog.dk

Ved spørgsmål, fejlmelding el. andet kontaktes: projektansvarlig Charlotte D. Bjørnes Tlf.: 50 92 55 75 – E-mail: chbj@rn.dk





Vejledning: Online patientbog ©

1. side efter log ind

1. side efter log ind

Brugervejledninger
Skabeloner til tekst

Skabeloner til tekst

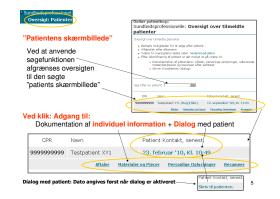
Faner for sundhedsprofessionelle efter log ind
Primære faner:

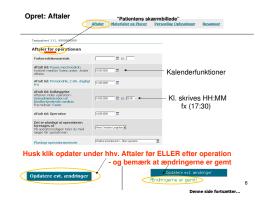
Oversigt over patienter

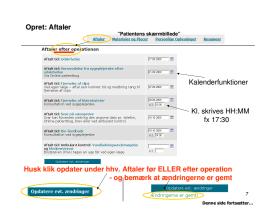
Tilmeld ny pt.bruger

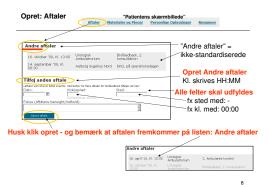
Under faner: Dialog med patienter
angives henvendelser fra patienter
angives henvendelser fra patienter,
der skal bekræftes inden for 24 timer









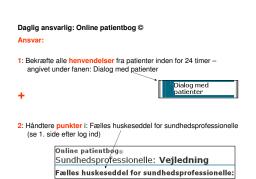


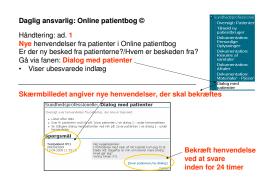


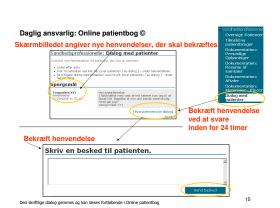


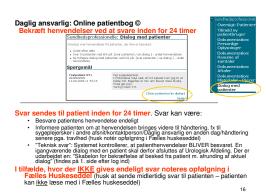




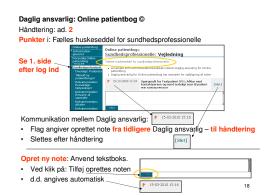












Daglig ansvarlig: Online patientbog ©

Ansvar:

- Bekræfte alle henvendelser fra patienter inden for 24 timer angivet under fanen: Dialog med patienter Håndtere punkter i: Fælles huskeseddel for sundhedsprof.

- Svar sendes til patient inden for 24 timer.
 Svar sendes til patient inden for 24 timer.
 Svar sendes til patient inden for 24 timer.
 Besvare patientens hervendelse endeligt
 Informere patienten om at hervendelsen bringes videre til håndtering, bx til
 sygeplejersker i andre afsnit/kontaktperson/Daglig ansvarlig en anden
 dag/händtering sener pga. traivhet (husk noter opplaginig i Fælles
 huskeseddel)
 Teknisk svar: Systemet kontrollerer, at patienthenvendelser BLIVER
 besvaret. En igangværende dialog med en patient skal derfor afsluttes af
 Urologisk Addeling. Der er udarbejdet en: "Skabelon for bekræftelse af al
 besked fra patient in. afrunding af aktuel dialog' (findes på 1. side efter log
 Ittifælde, hvor der IKKE gives endeligt svar noteres opfølgning i
 Fælles Huskeseddel (husk at sende midlertidig svar til patienten –
 patienten kan ikke læse med i Fælles huskeseddel)

Appendix E

Action plan for healthcare professionals.

The action plan was placed at write boards in the healthcare professionals working area. The write boards listed the actual patients in the department and the plan for the particular days work practice.

.

Tjekliste Online patientbog



	Oversigt:	Håndtering af:	
1	Patienten oprettes i Online patientbog	Tilmelding ved Urologisk Ambulatorium (ønske om tilmelding senere i forløbet kan ske i Afsnit 9/10 – husk label på VIPS og journal forside)	
		Online patientbog:	
2	Forberedelsessamtale i Afsnit 9	- Ajourføring af datoer og data (under Personlige oplysninger og Aftaler)	
		- Skrive resume	
		Skiive resume	
		- Afkrydsning af udleveret materiale	
	Udskrivelse i Afsnit	Online patientbog:	
3	10	- Ajourføring af datoer og data (under Personlige oplysninger og Aftaler)	
		- Skrive resume af indlæggelsen og samtaler	
		- Afkrydsning af udleveret materiale	
		- Sende 1. dags kontakt via Online patientbog (se skabelon)	

Daglig ansvarlig Online patientbog: Håndtering af: - Mandag, tirsdag, onsdag: Urologisk Amb. - Torsdag, fredag, lørdag, søndag og alle helligdage: Afsnit 9/10

Ansvar	Tjek under: - Fælles huskeseddel for sundhedsprofessionelle - Dialog med patienter Henvendelser fra patienter skal bekræftes indenfor 24 timer	
Udpeget Daglig ansvarlig	Dato:	Initialer:

Appendix F

Screenshots from the Online Patient Book[©] which illustrate features and functions within the health informatics system. Patients' ID numbers and names on the screenshots are fictitious.

The Online Patient Book $^{\hbox{\tiny o}}\!/\!$ Online patientbog $^{\hbox{\tiny o}}\!:$ Screenshot presentation: $\underline{www.online patientbog.dk}$



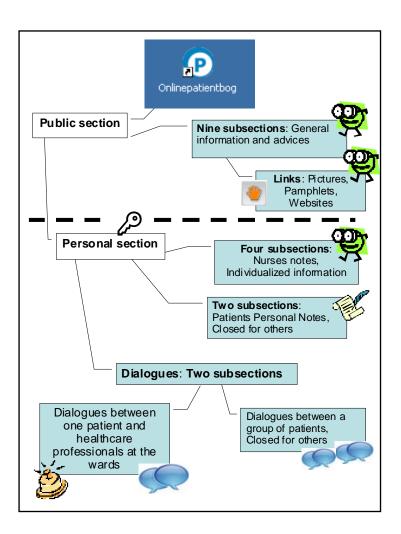
The website consists of two sections, both with subsections:

- * A public section, with open access. Provide:
 - o Monologue-based general information generated by clinical experts
 - o Divided in Nine subsections
 - o Include pamphlets, pictures, and links to other websites
- * A personal section. Requires a login. Provide:
 - Monologue-based individual personalized information generated by healthcare professionals
 - o Patient's personal notes: Log book and memory notes
 - o Personal communication between the individual patient and healthcare professionals at the particular hospital wards the patients consult during this course of treatment
 - An application for patient to patient dialogue. Every patient user is connected to a group of patient users. The patient users are divided into groups with six patient users in each.

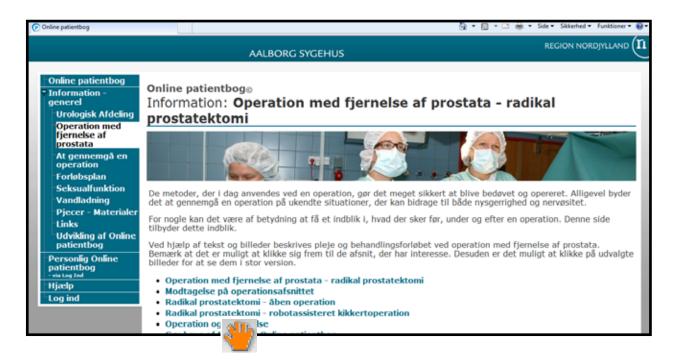
Information about the Online Patient Book[®] and the enrolments are handled by the nurses, as a part of the standard care plan:

- ★ The enrolment automatically generates an E-mail to the patients private E-mail box containing system generated, secure (one way encryption) key codes and a user guide
- **✗** The patients have full access both prior and after their surgery
- The patient users are able to use the Online Patient Book[©] without limitations in time.

 Though, the facility to contact the healthcare professionals is closed 12 months after their surgery, advising the patients to contact their private doctor instead
- Updates on the individual patient's personal web pages generate automatic E-Alerts to the patient's private E-mail box.



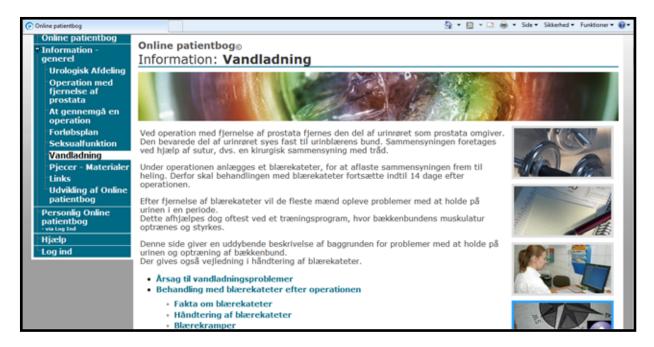
Illustrate one, out of nine, subsection, in the public section. Menu bar links to the other subsections. The features in this subsection are related to the topic surgery. The blue marked text is shortcuts to features on this web page.

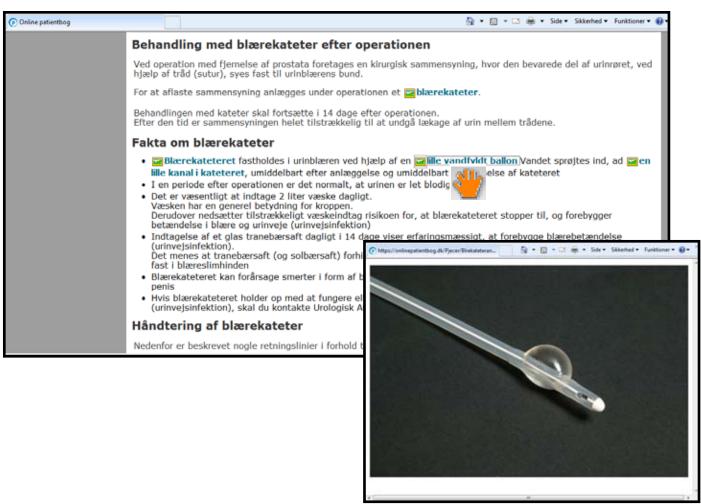


Illustrate same subsection, in the public section, with general information supplemented with pictures and blue marked text for shortcuts to other websites and pamphlets.

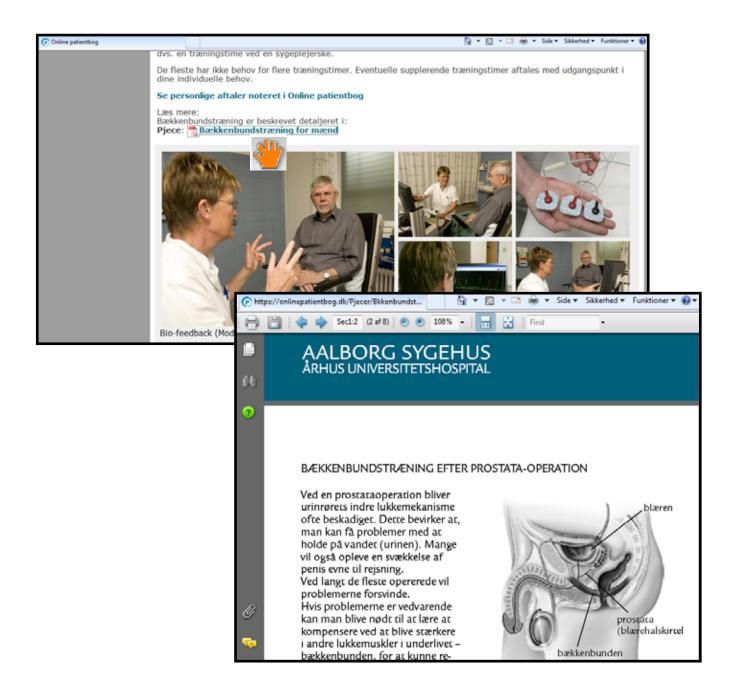


Illustrate a subsection in the public section with general information and shortcuts to pictures when reading the text, marked with blue text and icons. This subsection is about urination and catheter.

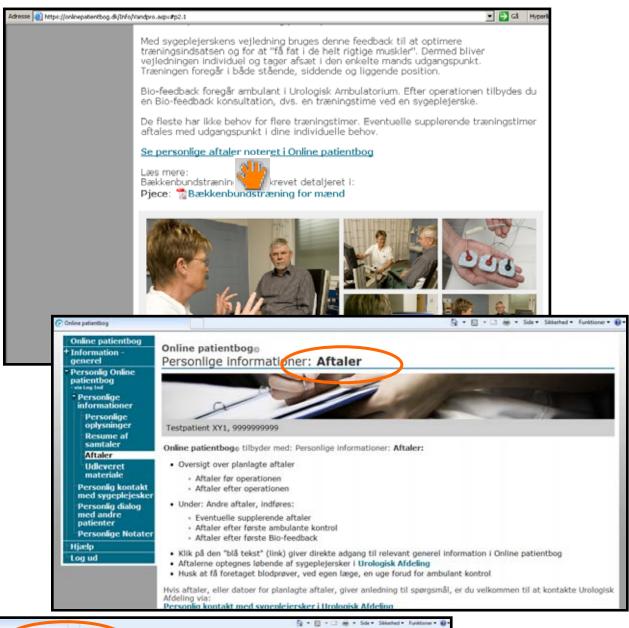




Illustrate the same subsection, in the public section, with general information and shortcuts to pamphlets, when reading the text, marked with blue text and icon.

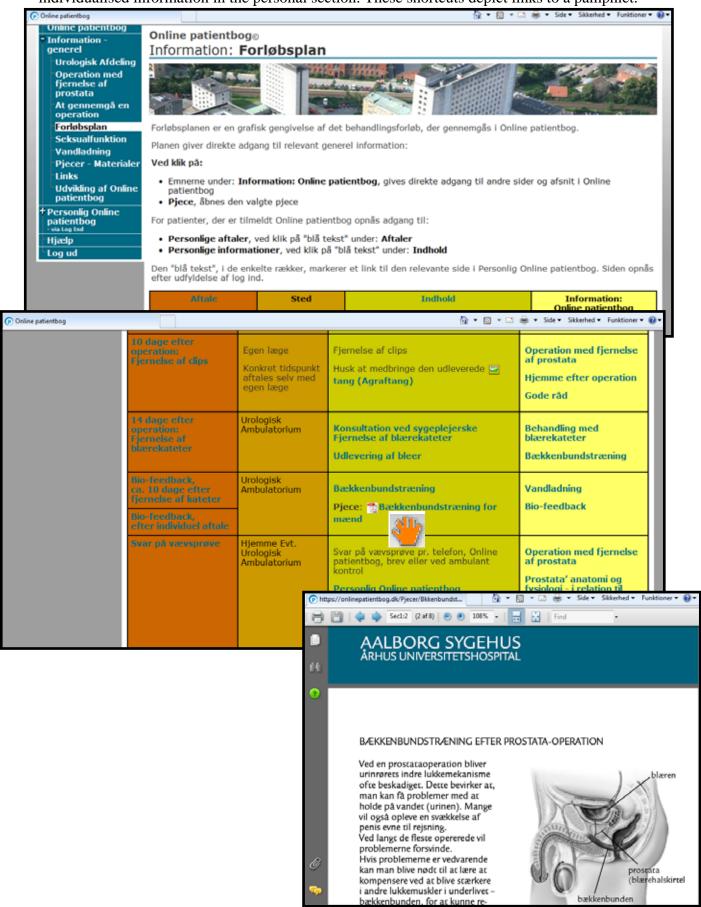


Illustrate public section with general information and shortcuts, marked with blue text, to personal sections, when reading the text. The shortcuts link to related individualised information according to the topic in the general information, at these screenshots to the patient user's future appointments. If not log on, the shortcuts demand the key code for further linking.

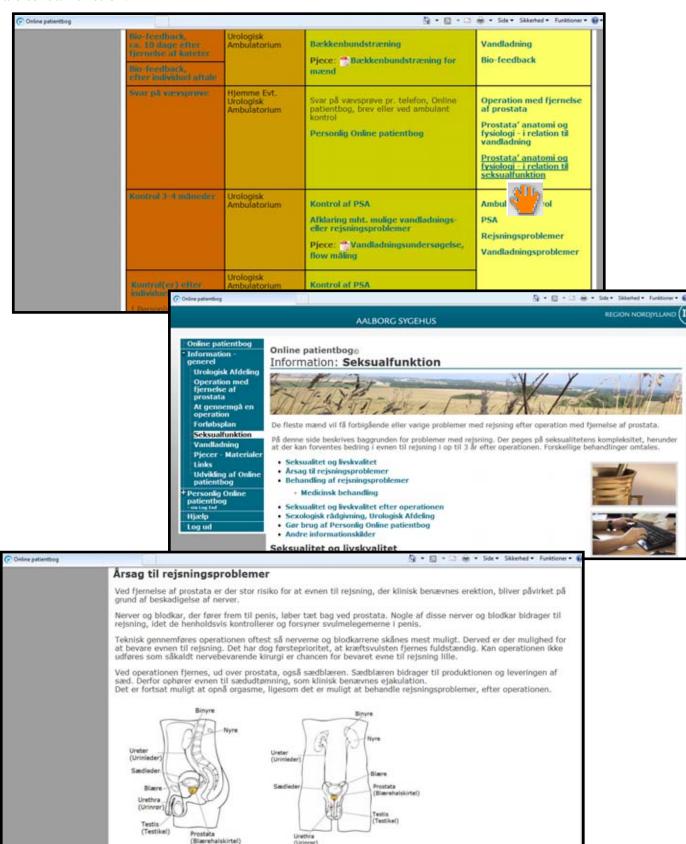




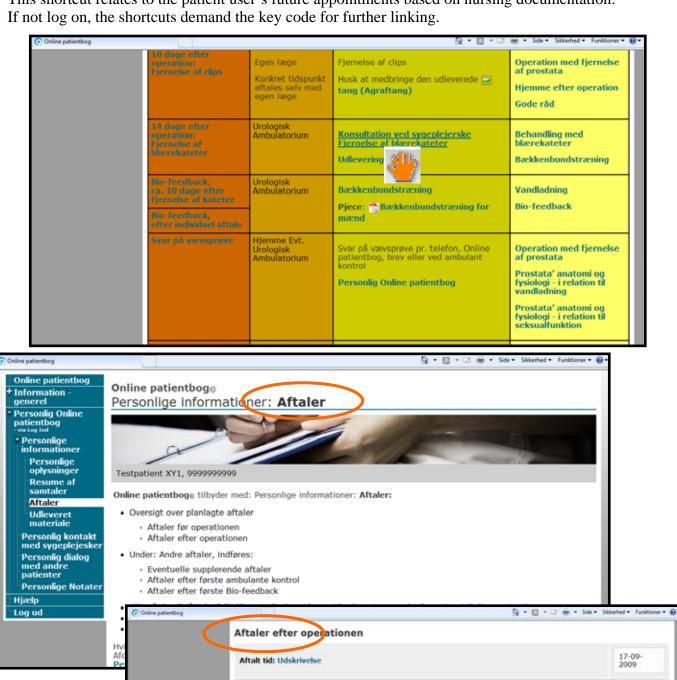
One of the subsections in the public section with general information features a standard plan. The plan depicts all stages in a normal course of treatment and care. Shortcuts at every stage allows the user to move between the standard plan; related general information; pamphlets; and to related individualised information in the personal section. These shortcuts depict links to a pamphlet.



Illustrate shortcut, marked with blue text, from standard plan to related general information. This shortcut relates to general information in the subsection that features general information about male sexual function.



Illustrate shortcut, marked with blue text, from standard plan to related personal information. This shortcut relates to the patient user's future appointments based on nursing documentation.



Aftalt tid: Fjernelse af clips Ved egen læge – aftal selv konkret tid og medbring tang til fjernelse af clips

Aftalt tid: Ambulant kontrol: Vandladningsundersøgelse og blodprøvesvar Blodprøven (PSA) tages en uge før ved egen læge

Aftat tid: Fjernelse af bierekateser
Konsultation ved

I forbindelse m

on er udtaget vævsprøve. Prøven er sendt til analyse. Svar på
vævsprøve vil timps om digge efter
Periode for analyse af vævsprøve varierer meget. Når svaret foreligger, vil du blive kontaktet og
informeret herom pr. telefon, via Online patientbog, pr. brev eller ved ambulant kontrol

Aftalt tid: Fjernelse af blærekateter

Aftalt tid: Bio-feedback Konsultation ved sygeplejerske

02-03-2010 10:00

16-10-2009 14:00

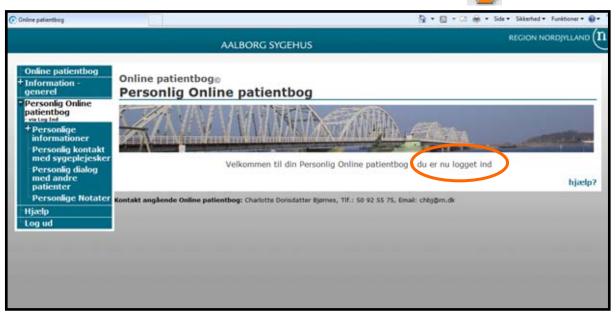
25-11-2009 10:00

4 uger

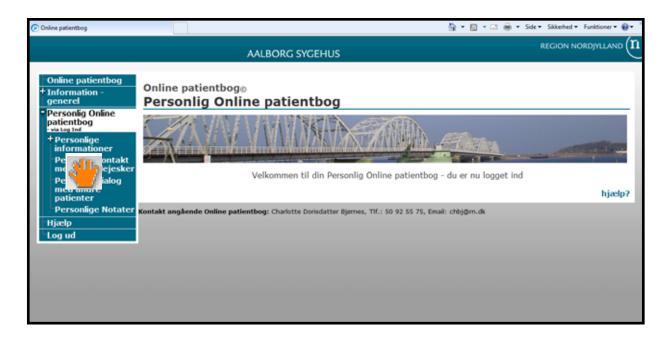
Illustrate log on. Patient users as well as healthcare professionals use the same public section for log on. Patient users log on by their social security number and the personalized key code. Healthcare professionals use their personal standard id and key code to the hospitals general IT systems. The third screenshots illustrate a patient user's personal web pages listed at the menu bar.

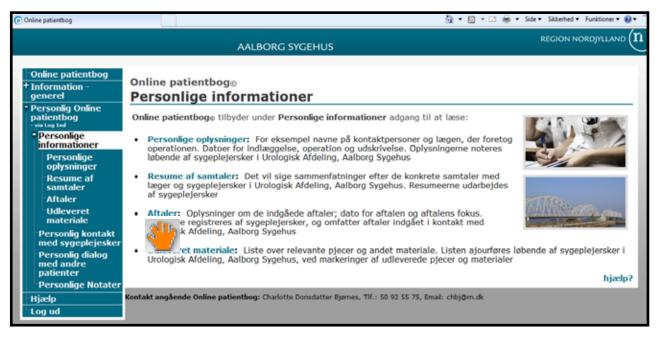




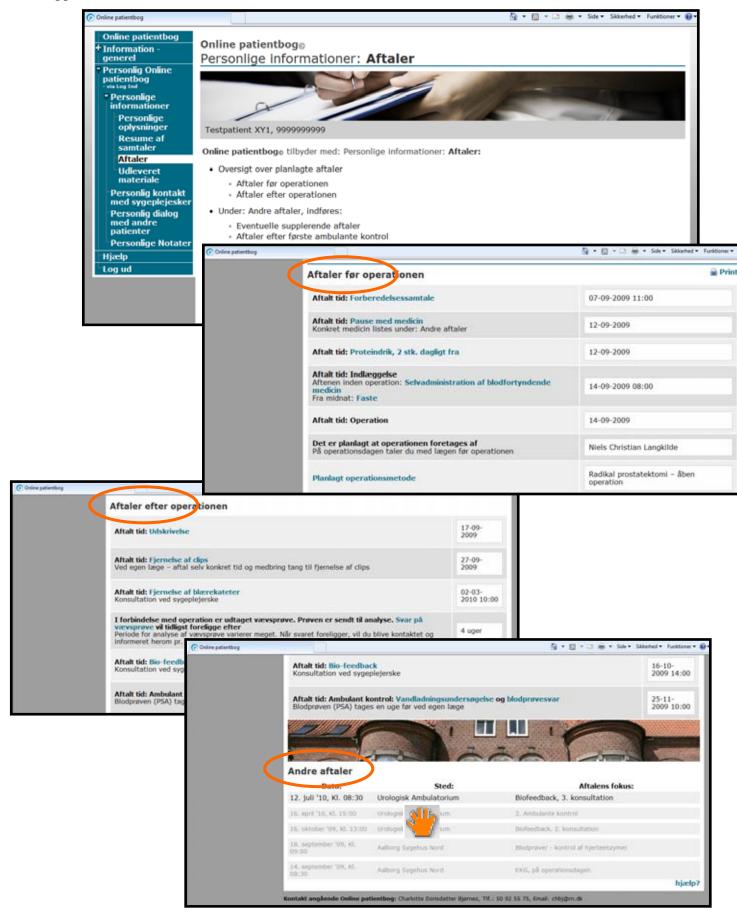


Illustrate personal section. The four subsections for monologue-based individual, personalized information generated by healthcare professionals listed as shortcuts at the menu bar and via the blue marked text. The text gives a short introduction to the type of individualized information.





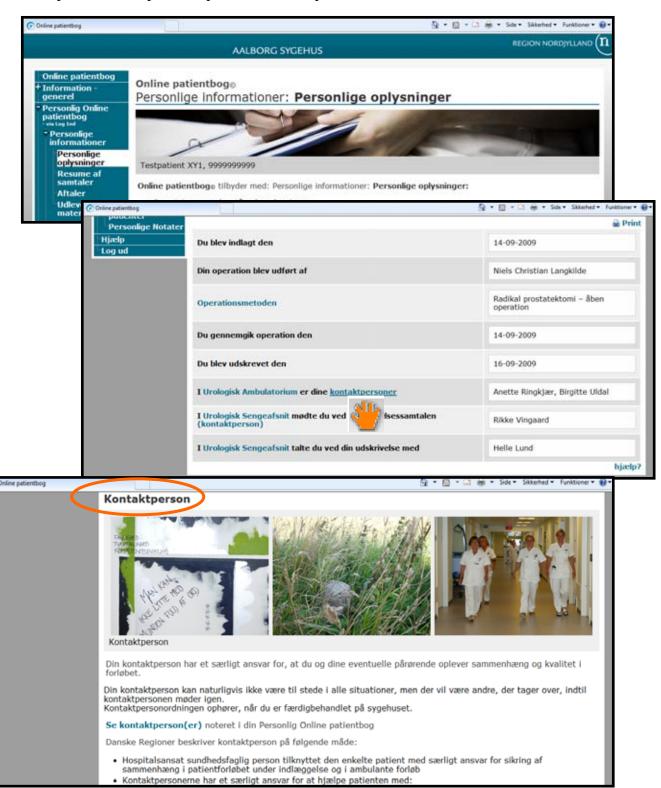
Illustrate monologue-based individual information generated by healthcare professionals. These screenshots depict the subsection for personal future appointments, featured in standard text boxes to be user-friendly for the healthcare professionals' in their documentation. The standard boxes are divided in: appointments ahead of the surgery; appointments after the surgery; and other appointments, without standard remarks.



Illustrate monologue-based individual information generated by healthcare professionals.

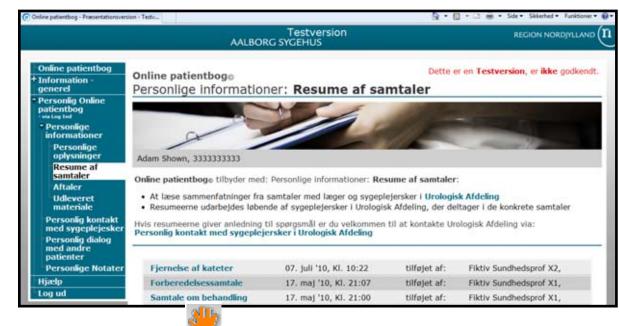
These screenshots depict the subsection for personal details for example; contact persons; surgical procedure; surgeon. The web page features individualised details via standard text boxes to be user-friendly for the healthcare professionals' in their documentation.

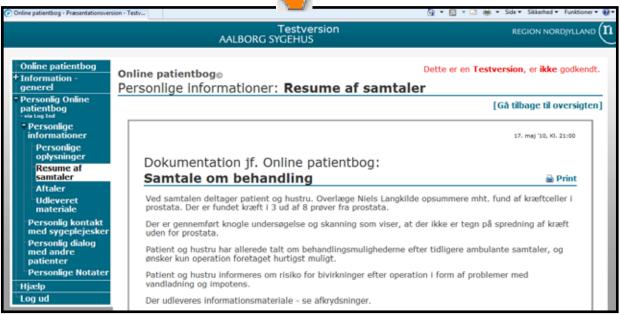
Illustrate shortcuts, marked with blue text, from personal information to related general information, for example what to expect of a personal contact person.



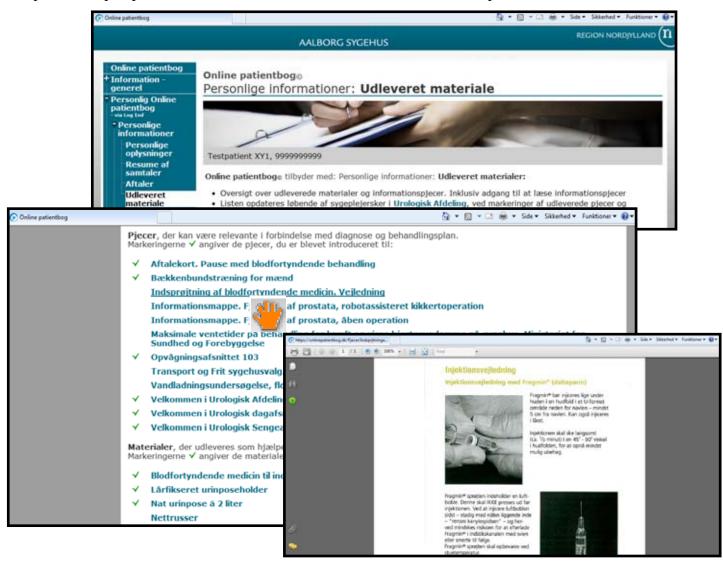
Illustrate monologue-based individual information generated by healthcare professionals. These screenshots depict the subsection for summary after meetings with the healthcare professionals. The summaries are listed after dates, with shortcuts to the written summary. According to the automatically generation on user identity, name and profession on the specified healthcare professionals are automatically formatted.

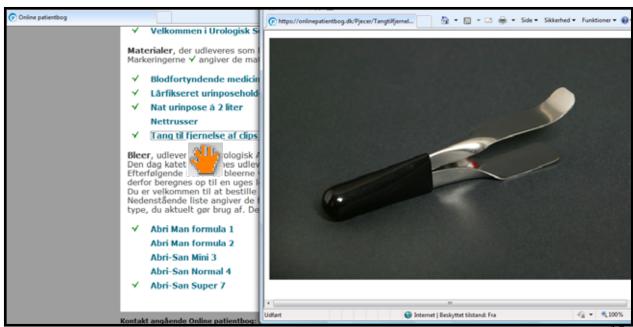




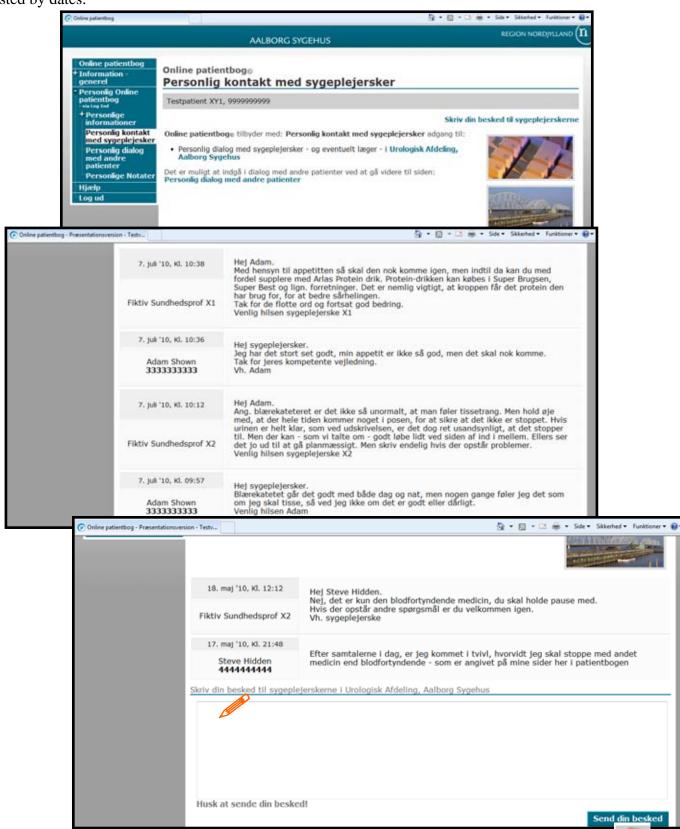


Illustrate monologue-based individual information generated by healthcare professionals. These screenshots depict the subsection for pamphlets and material. The pamphlets are listed with shortcuts, blue marked text, to separated read- and printable files. The materials are listed with shortcuts, blue marked text, to pictures of the specified material for example diverse incontinence pants. The pamphlets relevant and materials hand out to the individual patient are marked with:





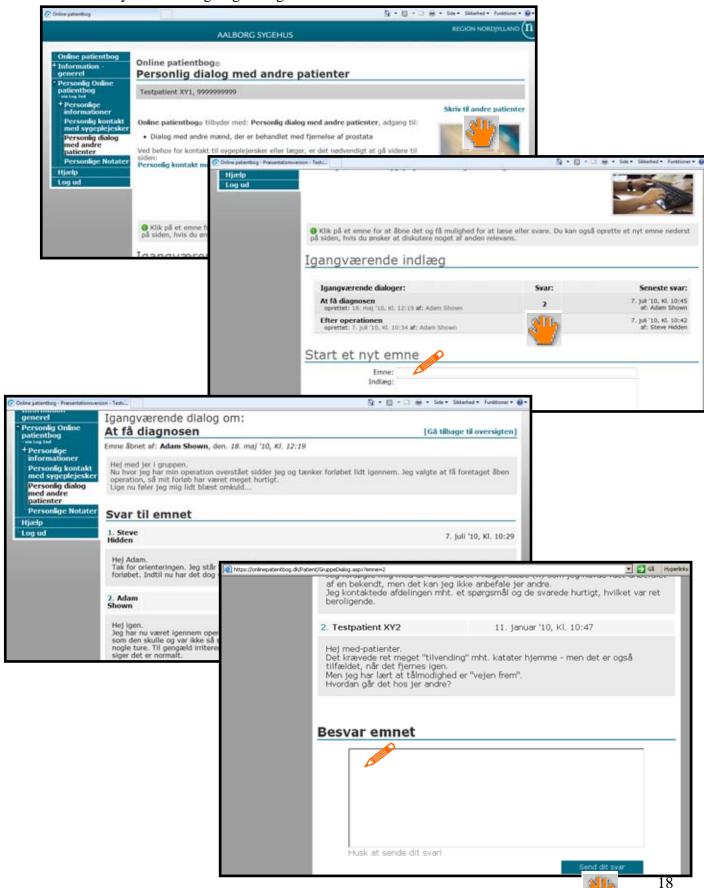
Illustrate personal communication between the individual patient and the healthcare professionals at the particular hospital wards the patients consult during this course of treatment. According to the automatically generation on user identity, name and profession on the specified healthcare professionals, who answer the request, are automatically formatted. Earlier requests and answers are listed by dates.



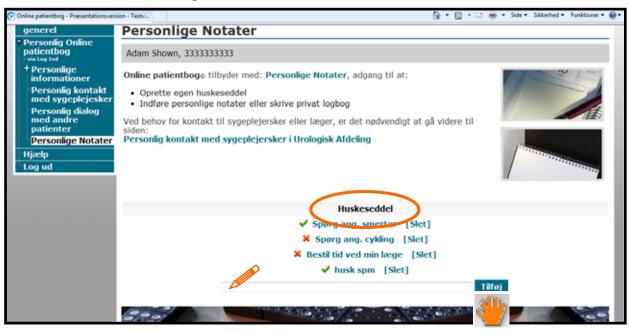
Illustrate a dialogue between the individual patient and the healthcare professionals. The screenshots switch from the patient users web page to the healthcare professionals' web page.

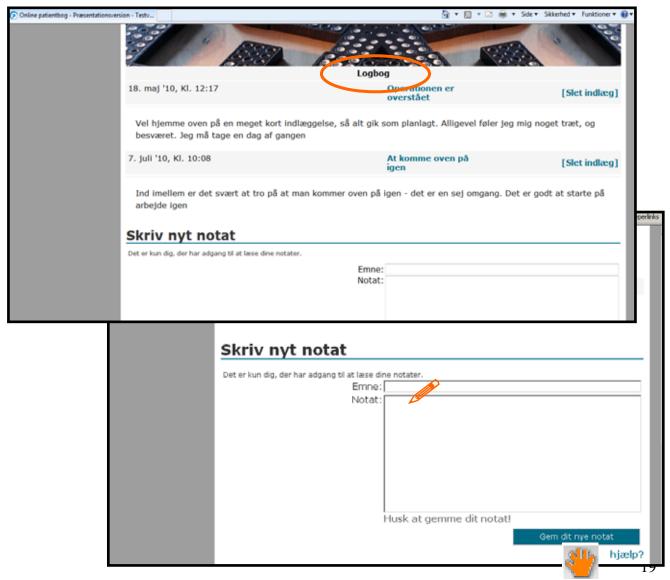


Illustrate the application for patient to patient dialogue. The patient users are divided into groups with six patient users in each. The patient user will be able to send his answers according to ongoing dialogues listed under a specified topic. In addition, the patient user can start a new dialogue under a new topic. The patient users name will be assigned automatically, according to the automatically formatted user identity. The patient user's identity will not show up for the other users if he only read the ongoing dialogues.

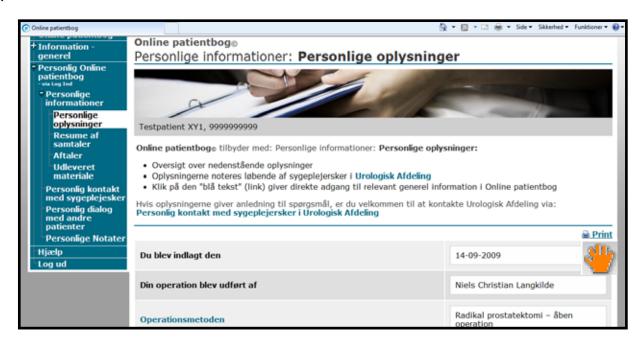


Illustrate the patients' personal notes: Log book and memory notes. Notes in the log book are formatted according to dates. Notes in the memory notes can be listed as: to do; mark off; or delete. The healthcare professionals are not allowed to enter this web page. Though, the patient user can invite the healthcare professionals to read the patient's private notes if relevant for example during a face-to-face consultation at the hospital.

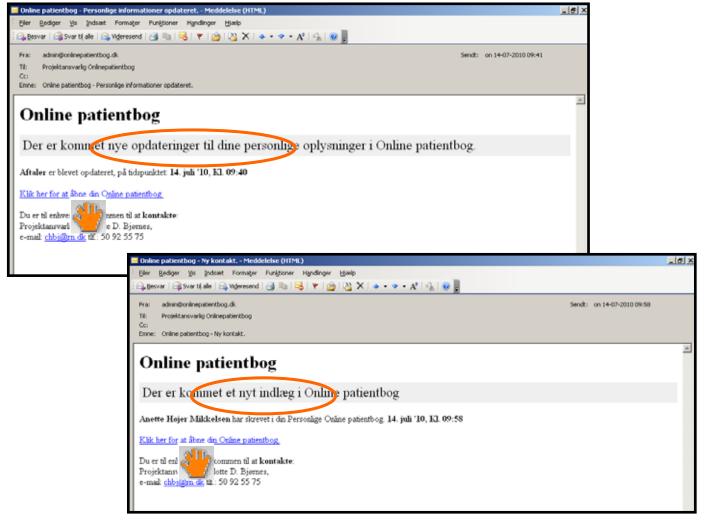




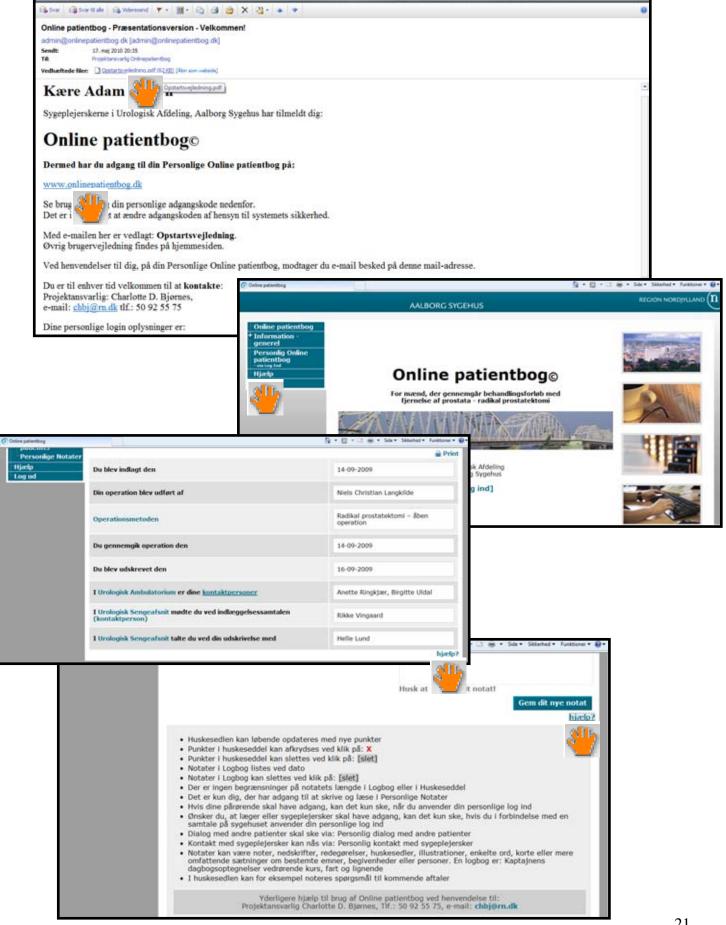
Illustrate that each web pages are printable. The attach pamphlets can as well be printed as PDF files.



Example E-Alert: System generated E-Alert will automatically be sent to the patient's private E-mail box explaining about and in which web page news are uploaded by the healthcare professionals. The E-mail features a shortcut to the Online Patient Book[©].



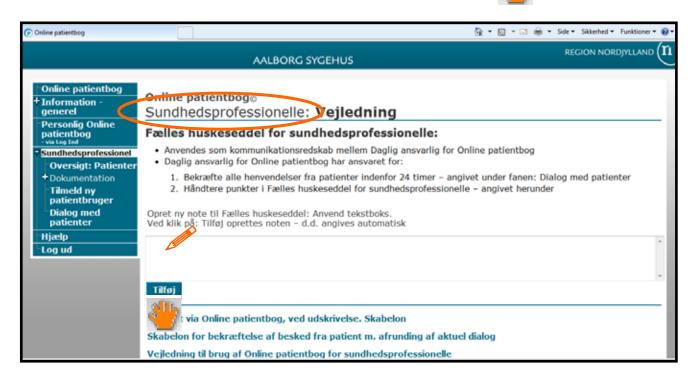
Illustrate various user guides for the patient users: one is attached to the automatic E-mail to the patient's private E-mail box at enrolment; one can be link to via the menu bar; and shortcuts at the bottom of every web page links to partial, related user guides.



Illustrate log on. Patient users as well as healthcare professionals use the same public section for log on. Patient users log on by their social security number and personalized key code. Healthcare professionals use their personal standard id and key code to the hospitals general IT systems. The third screenshots illustrate the web page the group of healthcare professionals share after log on. The patient users are not able to see this web page.

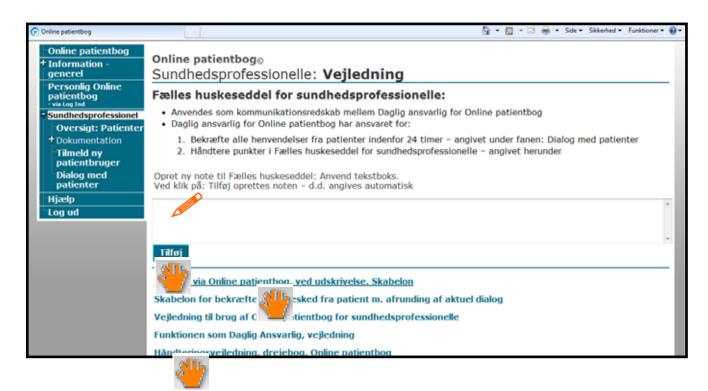






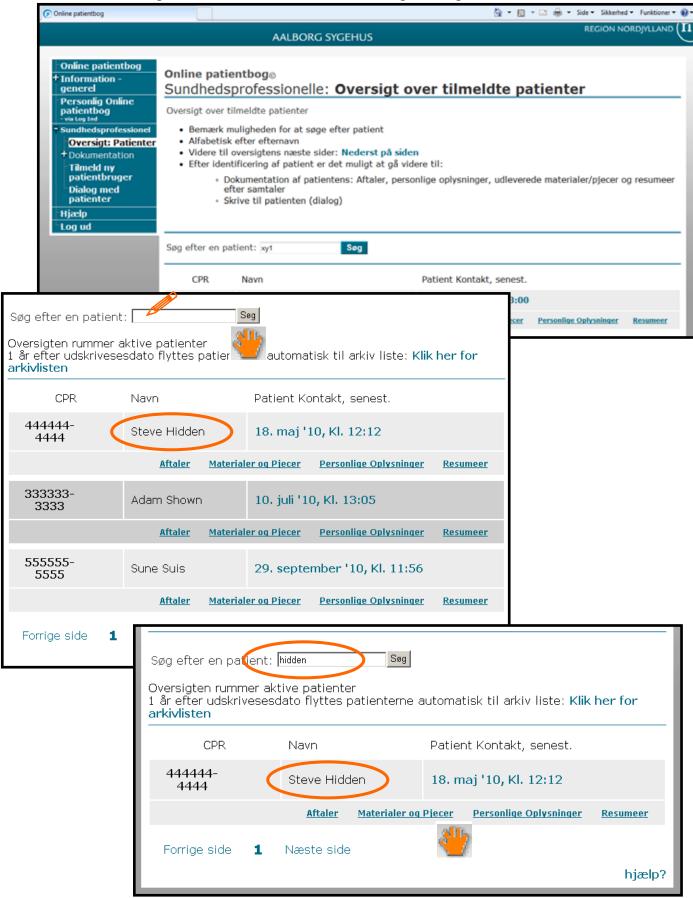
Healthcare professional users: Illustrate the web page the group of healthcare professionals share after log on. The patient users are not allowed to see this web page.

This web page features shortcuts, marked with blue text, to: user guides; roadmaps; guidelines; and standards for written messages to the individual patient for example at the day of discharge after surgery. The web page also features shared notes for communication among the healthcare professionals for example notes on further actions in relation to a specified patient.

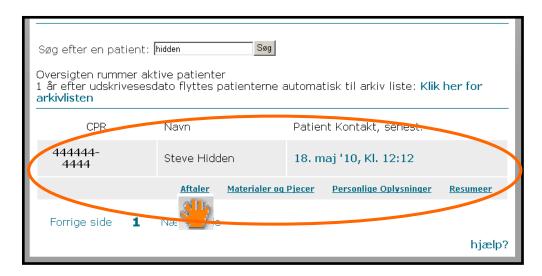




Healthcare professional users: Illustrate the menu bar for the healthcare professionals with shortcuts to the list of enrolled patients. The patients are listed alphabetic after surname. By way of the search feature the healthcare professionals can track and enter the specified patient's record.



Healthcare professional users: Illustrate the specified patient record, which have been tracked by way of the search features. The record lists shortcuts to the specified patient's web pages. Using shortcuts from the record and on the various web pages the healthcare professionals are able to move between the specified patient's web pages and the main record.

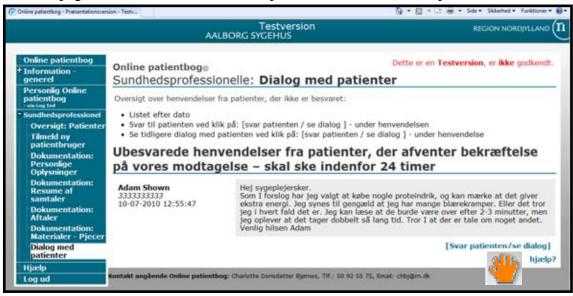




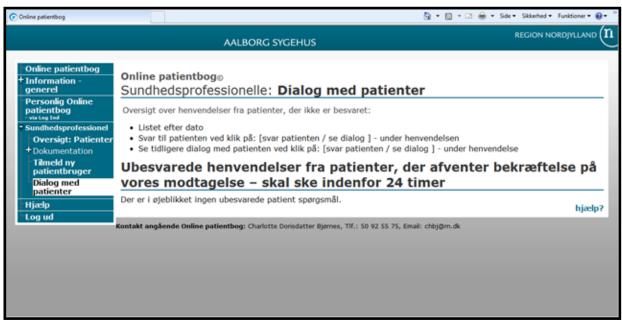


Healthcare professional users: These screenshots illustrate the web page which list not yet answered requests from the patient users. All requests must be answered within 24 hours. As a part of the day-to-day standard care plan one nurse are responsible for checking today's requests from patients via the Online Patient Book[©]. The patient users are not able to see this specified web page.

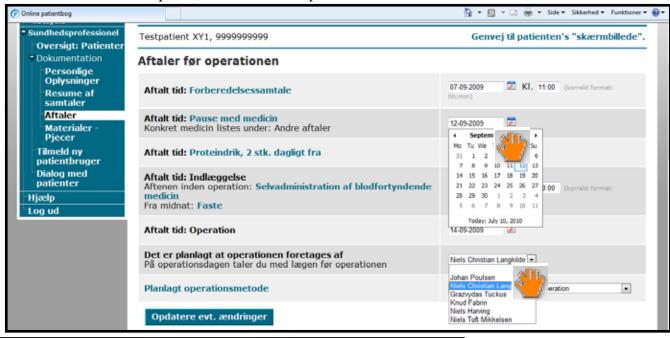
After responding via this web page, the request is automatically moved to be listed only on the patient's web page for contact between him as patient and the healthcare professionals.

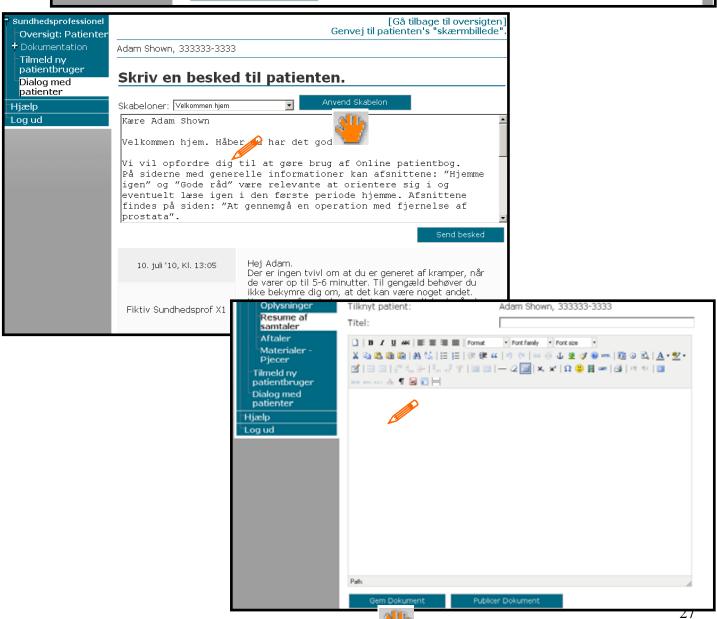






Healthcare professional users: These screenshots illustrate various user friendly features for the healthcare professionals in their documentation to the individual patient: drop down menus; calendars; standard templates; and save before publish.





Healthcare professional users: Illustrate user guides for the healthcare professionals. The first web page for healthcare professionals after log on features shortcuts, blue marked text, to the complete user guides. At the bottom of every web page, shortcuts link to partial related user guides.

